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The Representations of Social Support from External Resources
by Families Raising Children with Severe Disability
in Connection with Dolphin Assisted Therapy

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Abstract

This thesis is focused on the analysis of the representations of social support by families raising children with severe disabilities. The family situation is perceived as uncertain with problems occurring when dealing with them requiring social support from external resources.

The understanding of social support is conceptualized by House (1981, cited in Peterson *et al.*, 2009) and Tardy (1985, cited in Malecki and Demaray 2002, 1) who divide its content into emotional concern, instrumental aid, information, and appraisal. The concept of social support is used as unified in the defining of support from external resources. The main external resources are held to be the medical, social and educational systems, as defined in the Law of Social Integration of Disabled People (2005) of the Republic of Lithuania. Dolphin Assisted Therapy was engaged as a system taking a window place for analysing social support on a legitimized social support basis.

The thesis focuses on investigations into representations by families of social support during stressful periods of their lives, when social support acts as a stress-buffer. Therefore, external resources are seen as reducing the negative effects of the causes of stress. Fisek *et al.* (1991, cited in Bonito, 2007) puts forward the idea that the evaluation of social support is based on the personal perception of conceived competence. This approach gives the meaning of representations as subjective perceptions by families in the analysis of their belief that social support will be available during stressful periods of their lives and when stress did occur how it was handled by external resources.

Representations of social support by ten families raising children with severe cerebral palsy were analysed. Research was focused in particular on gathering data on the historical approach to families. Interviews encompassed representations by families of social support from registering their child for Dolphin Assisted Therapy to the coming of their perceived projection of the future.

Social work is perceived as mediating in external resources. Applied Scandinavian activity theory allowed the reconstructing of Engerström's (2007) schema for revealing the position of the social worker in a Lithuanian context due to the representations by families.

Key words: social support, family, severe disability, dolphin assisted therapy

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1 Background and Focus of the Study

This introductory chapter to the study contains four subchapters overviewing the main problems of families experiencing situations of severe disability, forming the aim of the study, observing the interactions of the main theoretical commitments, and viewing the structure of the study.

The first subchapter is dedicated to the general observation what issues arise for families in severe disability situations. Problems arise in conceptualizing severe disability, because terms *severe*, and *cerebral palsy* have connections to rather diagnostic paradigms than being merely interpretative. Faced with the ethical dilemma of keeping a social constructivistic approach I could not avoid using as well as the diagnostic paradigm perception of the term *severe disability*, therefore I see this situation as a *constructed meaning* (term used by Bruner, cited in Swartz, 2009) for a concrete situation. Diagnostic *severe disability* understanding is used only as a situational construct when it must be perceived as a *passport* for the benefits. Such understanding relates to Vygotskian (1984, cited in Alifanovienė and Kepalaitė, 2008, 30) the analysis of disability via primary and secondary deficit exploration. I also draw discourse on the understanding of disability in Lithuania. Gedvilaitė (2006) analysing the transformation of welfare systems in post-soviet countries concludes that shifts in paradigms are directly related to the support provided for families. Discourses have the power to organize social life because they are frameworks of knowledge that create and sustain normative practices of social support within society (Howarth, 2000, 49).

The second subchapter contains the main research questions, the concepts used in the thesis are presented, also the aim of the research. In this subchapter I present Lazarus & Folkman's (1984) schema which was developed from Hartley *et al.* (2005, 169) and Snell and Brown (2006, 40–41) in my own interpretation. Figure 1 illustrates this schema with the influencing factors of social support (internal and external), however, the thesis is focused only on the analysis of support from external factors. Such determination is tightly related to the term *representation on social support* which is defined in a qualitative way, seeing *the perception of the value of social interactions* (Lazarus & Folkman, 1984, cited in Martz, *et*

al., 2010, 334). In this way social support is perceived as a qualitative paradigm described as a *resource available in the social environmen*t (ibid, 334).

The third subchapter analyses the interaction of the main theories used in the thesis. The thesis is based on three main theories: social constructivism, systems theory and Scandinavian activity theory. Therefore, this subchapter reveals the interconnections in the application of these theories. The revealing of representations on social support requires the engagement of a few different theoretical angles. Social work as a profession possesses a brief historical approach in Lithuania. Varažinskienė (2009, 125) writes that the first legal document defining social work and its competence – the concept of social support was released in 1994. Because of clear social work and social support relations this subchapter was constructed to reveal the thesis's methodological relationship with the context of social work.

The last subchapter contains the main ideas of the study and an overview of all chapters of the thesis.

1.1 Families Raising Children with Severe Disabilities in Lithuania

After Lithuania regained its independence in 1990 transformations affected all areas of everyday life (Bučinskas, 2009). The situation of families raising children with severe disabilities was impacted via the paradigm shift from diagnostic to interpretative and changes to the understanding of family support.

Gedvilaitė (2006, 24) analysing governmental family support systems, writes that the Lithuanian welfare system till 1994 can be called *compulsory* and after 1994 – *liberal bureaucratic*. Such change directly affected the relationship between social workers and families seeking social support. Gedvilaitė (2006, 30) in presenting research results writes that the shifts in post-socialist countries affected the psychological and social positions of welfare recipients. Procedures became more bureaucratized, regulative and the practices of social work became more humiliating. Striving towards a greater efficiency of the welfare system in Lithuania created

an unsupportive social space. Contrary to Gedvilaitė's (2006) research, Rutkauskienė (2005) sees positive changes in the governmental support system after Lithuania enrolled in the EU in 2004. Rutkauskienė (2005) points out the idea that the system is in a formative stage having features yet to learn from the best EU examples. Analysing the EU context, she writes (ibid, 31) that governmental support systems in the future will seek a closer divergence in the social system because serving the needs of its citizens requires implementation of the same equal rights.

Together with political changes, transformations were influences on paradigm shifts in Lithuania. Till Lithuania gained its independence it was a *normal practice* to have many *hidden*[1] institutions established for disabled people. Children were taken from families and brought long distances from their homes to such institutions. The governmental policy orientated towards the implementation of a strict diagnostic model. Viluckienė (2008) analysing the discourse of disability states that in these years physical deviation was equated to social deviation. Vygotski (1984, cited in Alifanovienė and Kepalaitė, 2008, 30) analysed social deviation as a perception of *social deficit* by society that is constructed because of a child's physical deviation. Perceiving the ideas of an interpretative paradigm, Vygotski (ibid, 30) highlights substantiality as moderating or overcoming secondary deficits.

Parson's (1951, cited in Viluckienė, 2008) functionalistic view towards the perception of illness and health impacted disability as a social deviation impacted by physiological, psychological and anatomical disorders.

Usually medics were specialists in Lithuania who convinced parents of a better life for disabled children apart from the family. The given information that a child will not understand the world, not recognize parents, sisters, brothers and other relatives, and he/she would need better care, means *curing* seemed to be more a matter of convincing. Medics were appearing in social support as a substitute for parents, as such functions were delegated.

The understanding of interpretative disability was influenced by the ideas of social constructivism about the interests of solitary individuals or groups creating and reproducing social reality. Interpreting this social reality gives a basis for creating social phenomena and their

1 Hidden institutions are an act of social segregation that Dewey (cited in Danforth, 2008, 60) described as a system based on classification elements.

institutionalization, which transformed into a tradition (Viluckienė, 2008).

The situations of families raising children with disabilities can be described as being under change in Lithuania, because both paradigms can be met in everyday practice[2]. Bernotas and Guogis (2004, 12) state that such traditions have an influence upon the stereotypes of the Soviet period, which are difficult to *shake off*, like all systems they were understood as *social provision*, guaranteed by the state and not as an individual's perceived condition. Therefore, quite often people with disabilities or people that represent their interests are taught to represent themselves more often as beggars than inclusors as well as society tending rather to give than include disabled people.

Viluckienė (2008, 51) writes that the main problem with the shift of paradigms lies in contradistinguishing biological and social spheres. Therefore, there is a need to search for ways of speaking of the nature of disability beyond the interpretative paradigm and integrating different aspects of this phenomenon.

Statistical data from the Ministry of Social Security and Labour[3] shows that each year the number of children diagnosed with disabilities is growing in Lithuania. If in 2002 the number of children with disabilities was 13 824, in seven years this number increased by about 2000 children and in 2009 there were 16 002 disabled children in Lithuania. Research by Guscia *et al.* (2006, 154) showed that there is greater need for social support by those people that suffer from multiple disabilities or more severe levels of disability. Therefore, before conceptualizing social support, I will develop an understanding of severe disability which will be applied in the thesis.

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2 For example, Ališauskienė's research (2007, 26) carried out in Early Intervention Services of Lithuania in 2003–2005 showed that early support is provided for each child from birth when needed, specialists work in teams, understand the meaningfulness of collaboration. However, there must be improved coordination among the educational, social and medical services, the quality of support in remote districts must be checked, work on individual plans for a child should be implemented. Kuginytė-Arlauskienė's research (2010, 130) on the integration of children with special needs in the Marijampolė region (Lithuania) showed that educators do not have negative representations of children with special needs and try to involve them in class activities. However because of the lack of specialists and shortage of financial resources it is still not possible to organize special education for a child nearest to his place of living.

3 www.socmin.lt

While writing this thesis I faced problems and ethical dilemmas in conceptualizing *severe disability*. It is impossible to neglect existing biological factors while focusing only on disability as a social construct further removes from understanding the essentiality of social support.

The term severe disability is used differently by the different authors (e.g., Heimlich, 2001; Breitenbach *et al.*, 2009) in their researches. Due to international classification of illness severe disability can be subsumed as severe cerebral palsy in the same way as autism.

I focus on severe disability in my thesis to be understood as severe cerebral palsy. Not neglecting the biological factors and perceiving disability as a social construct I apply both understandings. The answer to the question why it is not possible to use only a constructivistic approach for developing of a conceptualization of severe disability lies in the empirical part of the thesis. The need for homogeneity of research respondents presupposed the situation where both angles must be presented.

The diagnostic paradigm allows me to reveal the seriousness of severe biological disability factors that face each family member raising a child with severe cerebral palsy. Morrow *et al.* (2006, 529) describes that severe disability may cause associated problems, such as uncoordinated swallowing, gastro-esophageal reflux, malnutrition, aspiration and chronic lung disease which may lead to a significant morbidity and mortality. Eating problems usually occur early before other signs of a serious permanent movement disorder. Sleigh (2005, 373–374) writes that children usually experience problems in talking or other neurological problems may occur, such as epilepsy.

Ruškus (2001) describes the interpretative understanding of the disability paradigm not only as a physical, intellectual and psychological indication but also the result of stereotypes, social constructs and social interaction. Disability is perceived and evaluated as an interaction between a disabled person and the environment. Howarth (2000) writes that influential concepts gain power and circulate as discourses that are tactical elements or blocks operating the relationship forces.

The perception of disability as pathology served for many years in Lithuania as practice to exclude people with disabilities from society and led to the legislation of practices for segregated care, education, and treatment.

Therefore, highlightened aspects of severe disability being related to diagnostic paradigm is used as a *constructed meaning* (term used by Bruner, cited in Swartz, 2009) for concrete situations. Meaning is constructed to reveal the interaction between the biological condition of the child and the social aspects created by society via the interaction process between child and family. Constructed meaning gives the possibility of taking into account that the severe physical disability of the child may influence family change in: everyday life, career plans, shared roles within the family, and other elements of social life. Therefore, a family dealing with issues interacts with external resources for social support.

1.2 The Aim of the Study

The diagnostic perception of the issues of a family raising a child with severe cerebral palsy allows the substantiating of the essentiality of social support. Brajtman (2003, 454) writes that families in severe disability situations are caused by many issues, like restlessness, Margalit *et al.* (1992, 202) analyses issues as avoidant coping, lower sense of coherence, less emphasis on family members' interrelations and personal growth, Carpenter (2007, 176) writes that families in severe disability situations require support during their life cycle.

Carpenter (ibid, 176) writes that the need for support comes not only from *primary deficiencies* (term used by Vygoski 1984, cited in Alifanovienė and Kepalaitė, 2008, 30) but also because of changes in family patterns. Carpenter (ibid, 176) shares the view that with the rise of issues of more uncertainties, risks, more single parents, and absence of supportive family networks, outward social life is full of fields of tension, such as economical unstableness, power conflicts, and oppressive responsibilities.

Such understanding allows me to shift from the diagnostic to the interpretative paradigm and see the family not only from the perspective of the child's deficiencies, but as a system dealing in social environment via an interaction process. Margalit *et al.* (1992, 202) writes that a family raising child with a severe disability during its lifetime will experience longitudinal stress.

The findings of Lee *et al.* (2009, 425) show that social support for families under the prevalence of stress perform as a defence mechanism. A high level of social support ensures the stress relieving functions that influence positive psychological, social, and physical outcomes of family members. An interesting point mentioned in the research of Lee *et al.* (ibid, 418) is that social support does not relate to the quantity of members[4] in the social networks of families. This point of view is held in my analysis of social support from the external resources analysis. Therefore, a term *representation* is engaged additionally. *Representations on social support* allow the analysis of subjective families' understandings on gained social support from external resources.

The concept of the understanding of social support is taken from Lazarus & Folkman (1984, cited in Martz *et al.*, 2010, 334) and seen as *the perception of the value of social interactions*. This way social support is perceived as a qualitative paradigm described as a *resource available in the social environment* (ibid, 334).

The ideas of conceptual social support taken from Lazarus & Folkman (1984, cited in Hartley *et al.*, 2005, 169; Snell, Brown, 2006, 40–41) were developed into a schema (see Figure 1). Figure 1 shows that a child with a severe disability increases the stress experience in a family. Tobin and Tippins (1993, cited in Jones & Brader-Araje, 2002) write that *the reality in which a family interacts is known in their personal and subjective way*, therefore, the stress experience is understood as an individual family process. Sarason & Sarason (1985, cited in Heiman, 2006, 463) state that the social support concept refers to an individual's perception that he or she can be helped. Bernard (2004) and Haber *et al.* (2007, both cited in Saylor and Leach, 2009, 71) define social support as the individual perception of being cared for, valued. An important note that these personal perceptions are not measured as a quantity of social network members, but as the quality of relationship within a concrete social support provider.

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4 Belsky (Belsky, 1984; Belsky & Vondra, 1989, cited in Lee, 2009, 425) suggested a conceptual model of direct relations between social network support and positive parenting, though, I substantiate my understanding of social support on the subjective qualitative representations given by families on social support in external resources. Therefore, social support is used in Lazarus & Folkman (1984, cited in Hartley *et al.*, 2005) as a conceptual understanding.

The schema of Figure 1 shows that a family in a stressful situation deals with it individually, depending on the social support gained from internal and external resources. This schema should not be perceived as a static act of stress relieving. Stress prevalence and the need of social support is perceived as an integral aspect of the family's life. Cohen *et al.* (2000, cited in Malinauskas, 2010, 743) holds the same position as is shown in Figure 1 that social support is seen as a social resource that persons perceive to be available from both non-professionals and formal support groups.

Social support providers according to Lazarus & Folkman (1984, cited in Hartley *et al.*, 2005) and Cohen *et al.* (2000, cited in Malinauskas, 2010) are divided into internal resources (seen as personal resources) and external (seen as support from Dolphin Assisted Therapy, Medical, Social, and Educational systems).

Families adjust to coping with the behaviour of stressors due to social support received from internal and external resources. Adjusting ways of coping with behaviour has a direct relationship to the final stage of this process – the families' further social, psychological and physical functioning.

Social support for families is a very broad topic. Therefore, the thesis is focused only on one constituent part of social support – external resources. Having many years of consultations with families I used to face complaints about existing problems in the support provided by the medical, social and educational systems. Families were sharing individual representations on the perceived understanding of *subjective social support.*
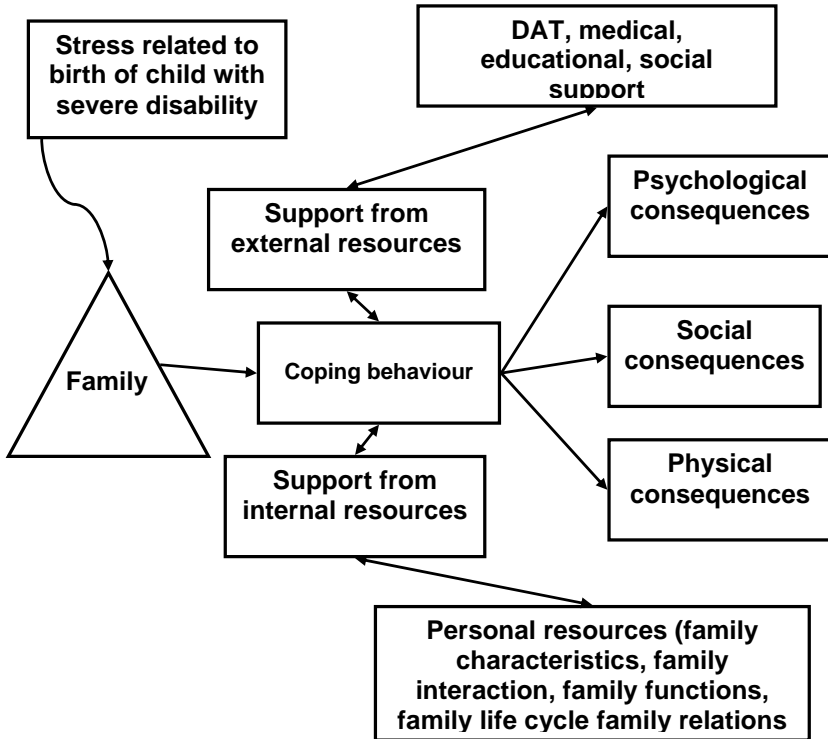
Developed on Lazarus & Folkman, 1984 Hartley *et al.*, 2005, 169; Snell, Brown, 2006, 40–41.

Figure 1.   Family coping behaviour schema.

The subjectivity factor allowed me to engage the term *representation* in the analysis of social support. Representation of the understanding of social support gives a personal character to the aim of analysis. The main point in the empirical part was focusing on the subjective representations' analysis of perceived social support as a social reality in the *sense of family* (term used by Gabb, 2009, 37).

Souza-Filho and Beldarrain-Durendagui (2009, 772) writes that the analysis of representations is used in achieving particular goals. Representations on social support are seen as *mediums of exchange and instruments of exchange* (terms used by Moscovici, 2008, 121, cited in Gillespie, 2008, 377) in dealing with external resources. In such a way

I took the role of *voice giver* to the families revealing their subjective representations.

The genuine concept of *representation* used by Durkheim (1898, cited in Gillespie, 2008, 375), later expanded as the tradition of *social representation* by Moskovici (ibid, 375). Notwithstanding, knowledge of Moscovici's theory of social representations, this thesis is orientated on the analysis of social support as key concept. Therefore Moscovici's term *social representation* and the term *representation* I use in this thesis can be seen as semantic divergence. The phrase *representations of social support* is seen as a non-dividable construct for analysis in the subjective sense of the social support for families. Representation on social support allows the strengthening of my empirical position in revealing the subjectivity of families.

The concept of representation is closer to Gillespie's (2008) term *alternative representations* which he developed while analysing Moscovici's concept of social representations and addressed the feature of subjectivity in understanding. Gillespie (2008) notes that the alternative representations' understanding belongs to social representations. Therefore, subjective representations on social support are understood not as representations but as ideas that families attribute to professionals in external resources.

However, my understanding of representations by families on social support is seen not only by attributing the opinions of professionals, but also representing the plurality of other contexts that are related to the social support content. I perceive representation of family as subjective representing the attributing opinions of professionals (in categorization *they all, they are* etc.) and the plurality of contexts as related to the social support content. Families speaking in their social support contexts invoke representations of professionals' personal qualities, models of work, perception of the child and other qualitative aspects attributing to the subjective evaluation and conceptualization. In other words, representation re-shapes social support from the stable theoretical assumption given in the theoretical part of my thesis to an explanatory one presented by families in the empirical part.

The external resources in my thesis consist of medical, educational and social net. The uniqueness of my study is the up-springing of the additional

theme to the social support schema – Dolphin Assisted Therapy (DAT). This uniqueness is based not on adding an additional system, but on the research organization. I use DAT as a *window* to reveal the subjective representations of social support for families in the medical, social and educational systems. Ideas that families attributed to the medical, social and educational systems looking through the DAT window created a beneficial position for me as researcher – families created a diversity of perceived attributes on social support showing interconnections of all the analysed systems. Therefore, the aim of the research is focused on the subjective representations on social support.

The aim of the research is to analyse representations of social support for families raising children with severe cerebral palsy within the medical, educational and social systems in connection with dolphin assisted therapy.

The aim raises the research questions:

> What are families' subjective representations on social support from external resources?

This research question is decided as a core question of the thesis. This research question is answered in the empirical part where an analysis of the attributing ideas of social support providers (professionals) is given. The third part gives a broader discourse understanding on the social support for families raising children with disabilities in Lithuania. The theoretical analysis of the supporting systems: medical, educational, social and DAT is viewed rather as an addition than in connection, however interconnection between the systems is seen via the social support provided, in particular disability discourse of Lithuania. The empirical part of thesis answers this question from the personal position of families. Representations on social support are analysed in a particular way: representations of attributed ideas towards professionals and the plurality of contexts related to the social support content have been analysed. As a tool for resolving subjective representations on social support holistically I engaged the Eco-map method. Eco-map helped to display schematically the variety of the *pluralistic field of representations* (term used by Gillespie, 2008, 376) and their interconnections.

The following research questions are closely connected with the main research question and have the role of specialization revealing the main research question.

> How families perceive the social support of social workers in the context of other professionals?

The social worker is seen in this thesis as a professional who is directly connected with providing social support for families raising children with severe disability. The thesis is orientated towards the analysis of social support from an external system; therefore, mediation is held to be the core action of the social work arena. This question is specified in the methodological part conceptualizing the idea of social work mediation and is answered in the empirical part.

> What elements of perceived social support content in families receiving Dolphin Assisted Therapy interconnect with the representations of social support from the medical, social and educational systems?

The purpose of this question is based on the empirical idea of shaping cognition of the subjective representations by families of social support from external resources via the DAT window. Practical consultations inspired me to develop a particular logic for research. Families were giving their representations in the manner of perceived attribution of medics, social workers and educators as social support providers with projection to the future attribution of DAT professionals they had never met. Families giving their subjective representations on social support as attributing opinions opened the possibility for me not only to investigate the subjective representations on the social support given, but also to reveal the interconnection among these social support understandings with future projection.

1.3 Theoretical Integration within the Perspective of Social Work

Social work is one of the newest professions in Lithuania (Kavaliauskienė, 2005, 213). Varažinskienė (2009, 125) writes that the first legal

document to define social work and its competence is the conception of social support in 1994. It states that social workers perform social support. Bitinas *et al.* (2010, 19) analysing the Lithuanian social security system writes that it consists of two parts: support by payments and non-monetary – by social services. Social services are provided by social workers in Lithuania. Providing social services, social workers act within various levels of society. Varažinskienė (2009, 125) points out the implementation of social work practice in micro, mezzo and macro levels of society. She writes (ibid, 125) that social workers not only work with groups, but also act as formers of social policy.

This context of social work in Lithuania requires an understanding of the general systemic functionings. The main theoretical ideas of systems theory are taken from Bronfenbrenner, (1979, 1997, cited in Bowes *et al.*, 2001) and Weiß (2001). They reveal the broader perspective of levels where social workers may act providing social support, also showing connectiveness of one system with another.

Division into micro, mezzo, macro systems gives a general understanding of existing systems that are both: as functioning separate organisms and open organisms bounded and dependant upon each other. As Vass (2005, 21) states the application of systems theory is beneficial for social work in encompassing the perspective of the family and social environment. Therefore, the analysis of representations on social support from a systems theory application gives me the possibility to distinguish internal resources from external in a network perspective. It does not mean that the quantitative aspects of a family network are analysed. Keeping the basic Lazarus & Folkman (1984, cited in Hartley *et al.*, 2005) idea of the understanding of social support in a subjective and qualitative way, I use systems theory as a way of understanding families' possibilities to deal with, interact and communicate. Systems theory helps us to see social support as Sarason & Sarason (1985, cited in Heiman, 2006, 463) conceptualize perception of being helped by close or significant persons.

The macro level is understood as values, culture, politics, economy and social policy, and has a clear connection with the social constructivism approach used in the thesis. The family, being the smallest cell of society, receives social support as a construct. Ruškus and Mažeikis (2007) write that the social policy for the disabled is interrelated with practical

support. Having roots in works of Vygotsky, Piaget and Bruner the social constructivism approach gives focus to meaning and knowledge of construction of the analysed phenomena (Lowenthal & Muth, 2008). Analysing social support for families raising children with severe disability Berger's and Luckmann's (1999, 73) approach is invoked that systems within society act only as creations of human beings. The constructivistic approach gives us the possibility for constructing a broader social support concept. Social support for families in disability situations is seen as an *institutionalized act perceived as being epitomized as a two way process* (used in Berger & Luckmann, 1999, 77). Systems theory shows the general functions of systems, where a constructivisitic approach gives determinations of institutionalized social support for families in a disability situation.

A shift of paradigms from diagnostic to interpretative for the last thirty years has opened discussions on the provision of social support for families raising children with severe disability. Application of the social constructivism approach reveals the understanding of disability discourse in Lithuania.

Another aspect must be clarified on the relationship between representations of social support and social constructivism. Social constructivism analysis of reality *par excellence* gives the understanding of disability discourse as a constructed reality, in other words it explains why social support was provided in the way it was. Jesuino (2008, 95) states that representations are the object of social psychology *par excellence*.

Therefore, constructivism meets families' representations *par excellence*. In this way the analysis of subjective representations on social support is seen as the construction of a social reality via families' attributing ideas to professionals that were perceived through interaction and evaluation of other pluralistic contexts related to the social support content. Foucault (1999) notes that for ages nobody wanted to listen to or hear of people with disabilities, as they were considered meaningless. Therefore, an investigation of the representations of social support identifies the social work position as *voice giving* (term used by Gudliauskaitė-Godvadė *et al.*, 2008, 73). A representation of research results in an Eco-map perspective sets generalizations on subjective representations by families[5], where

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5 In a similar way Moscovici conceptualized *objectivization* (term used in Orfali, 2002).

subjective representations are reproduced as the realities of families in disability situations.

Scandinavian activity theory applied in this thesis strengthens the social work position. Firstly, this theory clarifies systems' theoretical division into micro, mezzo, macro levels showing focused interest in the defined mezzo level's external resource. Social work understanding via the mediation process adapts the understanding of generalized social support[6] and analyses the meeting of the social worker and other professionals in a particular arena of play, where peculiar tools, rules and division of labour are applied. The social worker interacts with other professionals for deserved result – social support for the family that gives positive social, psychological and physical outcomes.

Secondly, Engeström's Scandinavian activity theory in relation to the macro context opens the possibility to integrate the constructivistic approach into the mediation process and see it not only as belonging to the inter-personal interaction, but also as a construct depending on the sociocultural context. Paavola *et al.* (2004, 560) notes that such understanding analyses human beings and behaviours embedded in the sociocultural context.

In summary, theoretical application is perceived in a systemic view of functional systems focusing on an external resource level where social support seen via a mediation process and a social constructivistic approach is engaged to reveal the context.

1.4 The Structure of the Study

My study is divided into ten chapters that are essential for analysing the representations of social support from the medical, social, educational and DAT systems – so-called external resources.

The next chapter mainly focuses on the theoretical – methodological background of the analysed aim. The significance of systems theory is based on the writings of Bronfenbrenner, (1979, 1997, cited in Bowes *et al.*, 2001), Weiß (2001). These ideas give the perspective of a socially supportive network as well as revealing how severe disability of one family

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6 That can be commonly used by medics, social workers, educators and DAT professionals.

member is associated with family stress. Unresolved stressful situations may have negative results on a family's psychological, physical and social outcomes as seen in Figure 1.

In the same chapter the term social support is constructed. The main ideas take their reasoning from the works of Butler *et al.* (2007), Marlow and Rooyen (2001), Berger & Luckmann (1999), and Urek (2005). The concept of the social worker providing social support via a mediation process and dealing with other professionals was viewed through the Scandinavian activity theory. This theory was meaningful in drawing research insights in the Lithuanian context. The main ideas of the theory were based on the writings by Engeström (1987, 1999, 2007) and Cole and Engeström (1993) and the schema for analysis was taken from the Engeström's (1987) work.

In Chapter 3 analysis and viewing are drawn in order to reveal a disability discourse in external resources in Lithuania. The main social support systems are overviewed: medical, social, educational, and DAT. There I also overview the majority of acts that directly impact the situation of families in Lithuania nowadays.

In Chapter 4 I present the methodology and methods of the thesis. The research was based on the main law of Lithuania concerning and regulating situation – Law of Social Integration of Disabled People (2005). The social support concept was based on the many authors' ideas and analysis that I used as a synthesis for constructing a professionally generalized understanding: Carlson and Perrewe (1999), Parasuraman *et al.* (1992), Groungaard and Skov (2006), Rogers (2007), Wong and Heriot (2008), Burgess and Gutstein, (2007), King *et al.* (2006).

It is presented as social support provision for families in a disability situation via a social worker's mediation process; therefore the related laws of the Ministry of Social Security and Labour of the Republic of Lithuania[7] were invoked in the construction of the research. This chapter presents the inductive logic of my research design. Cañadas and Castro (2007, 68) indicate that inductive reasoning is a method of discovering properties from phenomena and of finding regularities in a logical way.

While working with families in DAT I held my practical family consultations. These consultations revealed understandings of some of the

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7 Valstybės žinios, 2006–07–20, Nr. 79–3123; Valstybės žinios, 2006–08–05, Nr. 86–3375, Valstybės žinios, 2006–08–26, Nr. 91–3586; Valstybės žinios, 2006–04–20, Nr. 43–1569.

problems existing within the social support system. Therefore, I was faced with many questions such as what overall representations families have of social support. And how they define supportive and non-supportive systems, what qualities they construct in the meaning, and how dolphin assisted therapy is related to other sources of social support. Therefore, finding regularities in applying for the DAT programme I decided to develop these ideas in a logical way.

The qualitative interviews were conducted with 10 families and content analysis was applied. The research material was analysed in the context of the emerged themes that naturally distributed the material into medical, social, educational and DAT fields.

Chapters 5–8 contain the research results split into the spheres: medical, social, educational. I draw analysis in each sphere that was derived from the families' experiences on the specialists they met in the mentioned spheres, representations reflected on the child, applied models of help, and the results of intervention (or social support provider). The summaries are made after each overview of joint social support. Additionally the Dolphin Assisted Therapy connection with the main three social net participants is analysed in the same way as the expectations of families for DAT. These chapters answer the main research question raised in the introductory part. The following research questions in relation to the theoretical part of the thesis also find answers in these chapters.

In Chapter 9 I draw my conclusions of the thesis based on the research findings. The main ideas of the research results are presented there. A schema based on the theory of Engeström is applied in the Lithuanian context and an Eco-map is formed in order to show the connections of subjective representations on social support in an objectivised way. The Eco-map was formed in order to picture the main research results and the answers to all research questions.

Chapter 10 contains the final evaluation of the research process. The methodological and empirical commitments are given. Also the practical implications of the research results are displayed.

2 Social Support Reasoning: Methodological Background

The methodological background is formed on the basis of the systems and Scandinavian activity theories. These theoretical ideas are fulfilled by the social constructivism approach to the phenomena. Systems theory presents the possible levels of implementation of social work in different intervention levels, and also includes interaction with other social net agents. Scandinavian activity theory allows the application of theoretical ideas for revealing the social support process via the social worker's mediation process in dealing with other professionals. The social constructivism approach gives a broader understanding of the context of the analysed phenomenon. This approach gives us possibility to present a discourse on disability in Lithuania.

2.1 Significance of the Systems Theory

The question of the analysis of systems theory on representations of social support gives a clear perspective of functioning systems in society. In the introductory part I presented social support as being divided into internal and external resources. Application of systems theory clarifies the levels in which I operate.

Patton and McMahon (2006, 153) write that systems theory can be applicable to many spheres because the contributors to systems theory have come from many diverse fields (e.g., physics, Capra, 1982; biology, anthropology and psychology Bateson, 1979; the work on living systems Ford, 1982).

Pearson (1984, cited in Davidson and Demaray, 2007, 384) writes that social support can be described both quantitatively and qualitatively. Focusing on the quantitative aspects of social networks relates to social support analysis in stable networks, where the qualitative aspects relate to the understanding of social support as a stress-buffer.

The conceptualization of both models belongs to Cohen and Wills (1985, cited in Davidson and Demaray, 2007, 385). They note (ibid, 385) that stable social support networks may provide ongoing feelings

of security, positive action, self-efficacy, and safety. When stressors arise, a stable and effective social support network can provide the help that is needed. The main effect of such a model is that everyone can benefit from receiving social support. However analysis of representations of social support is projected on a second understanding the so-called stress-buffering model.

Cohen, Underwood and Gottlieb (2000, cited in Davidson and Demaray, 2007, 385) describe the stress-buffering model as where support is related to well-being only (or primarily) for persons under stress.

This stress-buffering model focuses on individually perceived qualitative support factors. Cohen *et al.* (2000, cited in Davidson and Demaray, 2007, 385) notes that the buffering effect can materialize in two ways. First, if a person believes that support will be available in times of crisis, this belief improves that person's ability to cope with and handle such a crisis. Second, if a major stressor does occur, social support can reduce the harmful consequences of such a stressor, including the effects on the person's health and/or behaviour.

Figure 1 can be applicable for analysis of either the qualitative or the quantitative aspects of a family's internal resources by virtue of the first, stable social support network perspective. It reveals the representations of social support and the research construction required to distinguish between internal and external resources. From the perspective of systems theory, the family being a small system is seen as dealing with the social environment. A family raising child with severe disability in particular periods of life experiences crises requiring support in the form of stress-buffering. The issues eliciting crisis for a family with a child in a severe disability situation is directly related to the need for professional support. Professional support is seen as medical, social, educational and DAT. Therefore, in my thesis I focus on external resources that are related to family's well-being and that have effects on family members' health and behaviour.

A family in crisis tends to seek the required support from the medical, social, educational or DAT systems. Weiß writes (2001, 5325) that even when dealing with family problems at a professional level, specialists have to see the systemic approach. Because of existing interaction, a family's

internal resources have impact on each family member, each individual impacts the whole family and there is always interaction.

Alifanovienė and Kepalaitė (2008, 30) analysing Vygotskian the understanding of disability note that physical or psychiatric disability is not only organic, but also a social phenomenon affecting child development. These phenomena affect members of the whole family. Related to the occurring phenomena, the family experiences stress. Weiß (2001, 5325) notes that the stress-buffering model is needed to overcome crisis.

Social support models usually focus on the individual, but I apply it to the family system. Berger and Coopersmith (1984, cited in Ho and Keiley, 2003, 247) write that better results can be achieved by dealing with the whole family as a system than by dividing it into individuals.

Professional social support presupposes the possibility of adjusting the coping behaviours of family members to reduce the harmful effects and gives positive psychological, social and physical consequences.

For developing the system view towards the social support concept Lazarus & Folkman (1984, cited in Hartley *et al.*, 2005) the terms internal and external resources will be integrated into social network perspective.

The main systems theory ideas were taken from Bronfenbrenner (1979, cited in Pawson *et al.*, 2005). Systems theory reveals connections among functioning levels as well as shows the impact of the economical, political and cultural contexts on the analysed social phenomena.

Bronfenbrenner's systems theory (1979, 1997, cited in Bowes *et al.*, 2001) gives the social network concept as having quantitative parameters, understood as having many possible social support providers. The same social network in different levels can be analysed from the perspective of qualitative parameters.

The social network concept spans 1800 years of history. The very first investigators of this concept were Durkheim and Tönnies (Freeman, 2004). Later the social network concept was analysed by various scientists in 1950–1960 (Katz *et al.*, 2004) and acknowledged as a perspective towards clients as the stream of social support.

In recent years the social network has been widely analysed by various Lithuanian and foreign authors[8]. Various scientists analyse the social network concept differently with some similarities. Authors (for e.g., Elovainio *et al.*, 2003; Litwin, 2003ab) consider the social network as a small community interconnected with relations depending on affinity, social role and identification (Grigas, 1995, 250), social status, assistance (Granovetter, 1973), and interests (Grigas, 1995, 250; Vėbraitė, 2000; Večkienė and Večkys, 2003).

All social networks have primary and secondary groups reliant on the strength of expressing relation (Guščinskienė, 1999). Micro, mezzo and macro social networks are diffusive from this point, because a family being a system reacts to a crisis situation seeking social support from close or authoritative persons.

The classic definition of social support (Cobb, 1976, cited in Malecki and Demaray, 2002) describes qualitative measures as feeling loved, feeling valued or esteemed and belonging to a social network. In this way systems theory encompasses the understanding of social support as a qualitative measure. Vass (2005, 21) writes that

> *Systems theory offers the social worker a perspective which encompasses both individuals and their social environment.*

Social workers always have to think about the systems, because if we think of a family as an individual client, we firstly think that this *individual* is a group living in other groups, and social support is provided in organizing internal and external resources (Glicken, 2007, 51).

A social worker acting in the network of professionals may construct social support via different network levels. Figure 2 portrays the possibilities of a social worker to act at all the levels of the social network.

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8 Little, 1993; McLaughlin and Talbert, 1993; Wasserman, 1994; Darling-Hammond and McLaughlin 1995; Josselson, 1995; Westwood, 1996; Lieberman and Grolnick, 1997; Valackienė, 2002; Anke and Fugl-Meyer, 2003; Elovainio *et al.*, 2003; Litwin, 2003ab; Spierts, 2003; Freeman, 2004; Gvaldaitė, 2004; Katz *et al.*, 2004; Mackenzie, 2005; Pawson *et al.*, 2005; Krebs, 2006.

Micro social network

Mezzo social network

Macro social network

Intervention of social worker
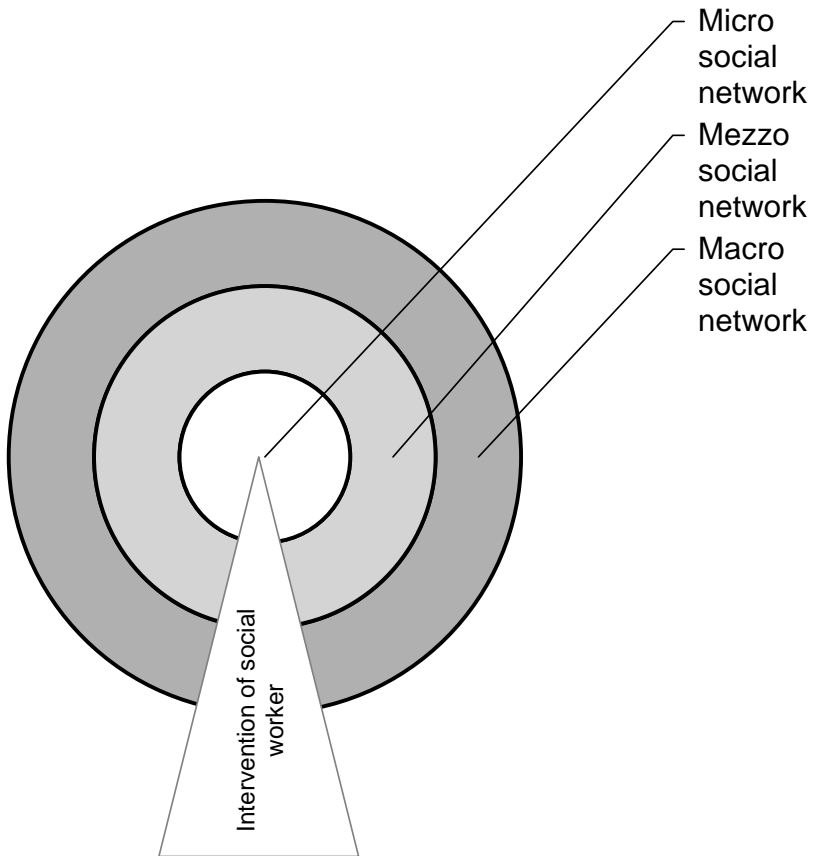
Made by Kreivinienė, using Bronfenbrenner 1979, cited in Pawson *et al.*, 2005

Figure 2.   Intervention of the social worker.

The social worker may act in the micro social network and almost be a family member (Barker, 1995, Valackienė, 2002, Gvaldaitė, 2004; Katz *et al.*, 2004). The level of the mezzo network can be called a formal social worker arena. The level of the macro network is the most complicated, when activity is practicable at governmental level.

Lazarus & Folkman (1984, cited in Hartley *et al.*, 2005) using the concepts of internal and external resources of social support find their places in the perspective of the social network as following. The internal

resource of a family are perceived as a part of the micro social network and the external resources are perceived as the *professional* part of the mezzo network. The internal resources are seen as personal resources in a close social network as describes Snell and Brown (2006) and seen through family characteristics, family interaction, family functions, family life cycle, and family relations.

The micro social network cannot be seen as an internal resource of the family, but the micro social network accommodates internal social support. Hartley *et al.* (2005) notes that the internal resources depends on personality characteristics, energy and self determination. Lithuanian and foreign scientists analysing the social network, agree that the family holds a nuclear micro social network (Markauskaitė, 2002; Valackienė, 2002; Miltenienė, 2004; Pernice-Duca, 2005; Ruškus, Mažeikis, 2007). Therefore, the family being in the micro social network perceives social support from internal resources understood as nuclear to the family in the micro social network which is determined individually for each family. Sometimes a family shares this nuclear with its closest relatives and friends (Neifach, 2002; Elovainio *et al.*, 2003; Litwin, 2003a; Pernice-Duca, 2005).

A family raising a child with severe disability may face some issues that cannot be resolved by the social support of internal resources. Support from external resources may be understood as professional support from a medic, educator, social worker and DAT specialist. Though, sometimes such social support may seem as an endless battle because of: finding proper educational institution and educators, finding medics (therapist, neurologist, rehabilitologist, dentist), and obtaining benefits.

Analysis of social support due to the stress-buffering model is the closest in the Lithuanian context, because due to changing paradigms towards disability, the medical, social and educational systems are under transformations. Analysis made by Gudžinskienė and Jurgutienė (2010, 24) of the legislations for the integration of disabled people in Lithuania, showed that this sphere is regulated fairly. They (ibid, 24) mention that the biggest problems lies in society's attitudes towards disabled people.

A family in a crisis situation perceives social support as the core. Relations in an internal resource are very close and intensive. Ruškus writes (2002, 153) that the micro system shows how members of a

family behave, interact and share roles. Though, different situations may require social support from external resources. If a family is faced with unsupportive external resources, it may lead that family back to internal resources. In such a way the family may experience a *shrinking into the family itself* phenomenon. When social support tends to be not provided through external resources, the family may close into its *safety bubble*.

Social support from internal resources is limited. Therefore the family needs issue solving in external resources that belongs to the mezzo social network. Pearson (1990, 13) draws the idea of *mutual help groups* that can be formed by parents themselves in case where they do not receive enough professional support from external resources. That means, parents can create an official organization (*diffuse into*) in order to advocate their own rights, I call this phenomenon as *leading own cases*.

The mezzo social network is the most important branch of this thesis for determining external resources. The mezzo social network has the majority of connections and help providers for families. Relationships among subjects (family, child and professionals of official organizations) are here a more formal collateral than in the micro social net.

Floyd and Zimch (1991, cited in Hartley *et al.*, 2005, 169) write that stress and negative feelings may be increased in parents of disabled children. Therefore, social support for such families must be organized on demand (Hartley *et al.*, 2005, 169).

In Ruškus's (2002, 154–155) opinion a family's mezzo network can contain various specialists that can provide social support: doctors and health care specialists, professionals of early intervention programs, other parents, the community, professionals in the healthcare system, social and financial welfare, and specialists in the education sphere. The core of social support provided by the mezzo level has almost inexhaustible possibilities.

Using the Law of Social Integration of Disabled People (2005) which is the main law describing the spheres of social support for disabled people, I define three systems: medical, social, and educational having legitimate background for provision of social support. The DAT system is not mentioned in the law; this system is seen in connection with others and takes window place. Therefore, the mezzo social network can be seen as having legitimate external resources and other possible supportive agents.

Problems dealing with these external resources may occur because of weak mediation. Hepworth (1997, cited in Baranauskienė and Gudinavičius, 2007) writes that in dealing with external resources, a social worker must be perceived as a mediator, otherwise meeting of family with specialists can be complicated by the issues. The same idea is revealed in Gudžinskienė and Jurgutienė's (2010, 24) research that there are problems of interaction between the external recourse branches.

The mediation idea in external resources will be presented using Scandinavian activity theory. Analysis of representations on social support for the family focuses on subjective representations of received social support. They are perceived as experienced realities on the basis of which families are telling of and giving the attributes of ideas towards the particular professional branches.

Families dealing with external resources develop their representations in particular spheres. Bronfenbrenner (1992, cited in Lindsay and Dockrell 2004) writes that particular environments can be perceived as especially favourable or unfavourable for a child with special characteristics. Therefore, social niceties that match a child's characteristics are perceived as an environmental niche.

The widest sphere in the social network is the macro social network. The macro social network can impact a family through discourse, system of values and beliefs, social policy, economical situation and other macro level components. Ruškus (2002, 155) notes that families and the macro social network are related, as changes of social policy can greatly affect programs of social support for families raising children with disabilities.

Ruškus (2002), Ruškus and Mažeikis (2007) writing about the Lithuanian context note that attitudes towards disability are being cumulated due to socio-educational policy towards the disabled. But also socio-educational policy impact society's attitudes towards disabled people. Perhaps this phenomenon needs time and historical *over-living*. Like Ambrukaitis with Borisevičienė's (2007, 116) review this context in the historical approach: from 1965 Lithuania had special educators in universities but it took a few decades to change the learning programs and shift from the diagnostic to the interpretative paradigm, and this process came together through political changes in law.

2.2 The Social Support as Social Construct

Social support for family raising a child with severe disability is meaningful in terms of either internal or external resources. Each resource provides some specified social support. However, social support provided by external resources may sometimes be represented by unsupportive families. For example, Gudžinskienė and Jurgutienė (2010) write that social support for many years was perceived as isolation and the diagnostic paradigm dictated the corrective models of education and curing. Ruškus and Mažeikis (2007, 45–46) also note that each year's research shows only slow changes in social attitudes towards the disabled, so, real changes can be seen only when specialists evaluate diagnosis as just one of many criteria forming special education, and treatment. They note the same (2007, 47) about political games and speculations in social integration terms, such as one day we hear that integration is fully implemented and another that integration is not possible. Such examples can be obstacles for seeing disability in a broader perspective.

The shift of paradigms from diagnostic towards interpretive has expanded our understanding of disability itself. Moving perception as Vygotsky (1924, cited in Alifanovienė, Kepalaitė, 2008, 30) suggested from less essential (physical deficiencies) towards the most important – social essentiality, expanded circle of specialists that are responsible for social support. In such a way social support for families having children with severe disabilities became the social worker's arena.

Cultural and historical conditions formed the nowadays peculiar context, as well as diagnostic traditions have left a heritage to deal with it in the future. Despite Kavaliauskienė's (2005) statement that social work is not a new phenomenon in Lithuania, she agrees with Berger (1995, ibid, 230) that the theoretical background of social work is not enough to make it a strong profession, it lacks practical implementation. Varažinskienė (2009, 125) analysing the status of social work in Lithuania notes that presenting a new profession requires the invoking of other professions that are older in their practical tradition; otherwise it will form different authoritative statutes. Tew (2006, 36) also notes that social support from external resources is impacted by authoritative relationships among professionals.

Barnes and Mercer (1996, cited in Viluckienė, 2008, 46) note that the paradigm shift noticed from the seventh decade of 20th century when branches of sociology such as humanistic, critical and radical scepticism took off.

However these interpretive ideas came to Lithuania together with the regaining of independence, around the 1990s. This notwithstanding the Lithuanian context is still covered by a perception of disability in a medical light. The research of Butkevičienė *et al.*, (2006, 130) shows that families quite often meet the diagnostic paradigm, especially when they are chagrined about the contacts with medics.

In this way specialists belonging to the same external resources providing social support speak different languages. If as Barnes and Mercer (2005, 530) write severe physical disability is seen through the perspective of functional limitations and this is encouraged by professionals, so disabled people will be seen as a problem, dependent, in need of either cure or care.

Different perceptions of paradigms and professional background may become an arena for conflicts within the external resource. Junger *et al.* (2007, 348) writes that such problems are common when different professions are meeting.

Merelopolskienė (2003, 6–7) states that a family looking for social support providers in Lithuania sets the main point not on choice, but on the availability of supportive specialists. Ališauskienė (2002, 27–29) interpose the Lithuanian problem of parents-specialists relationships – instead of creating power sharing relationships, they can be in competition. Pūras (2000, 43–44, 58) writes that for many years doctors were perceived as authoritative specialists making the right decision, even leaving a child in governmental supervision. Therefore, provision of social support in the light of the interpretive paradigm for all branches of external resources is a future challenge making little advancement today.

When external resources organize the provision of social support, specialists deal with different issues of the family. Authoritative inequalities among the specialists may occur because of several reasons. Hugman (1991, 39) thinks that differences may be constructed because of two main reasons: authority branches of the occupation and the differences of the problems with which those members work.

For example, doctors in Lithuania need more than six, sometimes even ten years to become practitioners, while other professionals, like social workers or teachers needs from 3.5 to 4 years to become a practitioner (basis level). Another aspect, that the working field of doctors is directly related to saving the lives of people, and has a long historical practical tradition.

These conditions should not be perceived as truly emerging conflicts among specialists, but as perquisites for *allocating and authoritative resources* (term used by Giddens, 1994, cited in Jalava, 2006). At least Parson's (1951, cited in Viluckienė, 2008, 46) understanding of disability as a social abnormality was inspired by its medicalization. In such a way physical deficiencies are turned into social deficiencies. Ruškus and Mažeikis (2007, 43) discussing these aspects see that today's Lithuania has a practice of social participation, integration and valorization rather as an exception than the norm.

Favourable social support from external resources could be provided if professionals were to unite in the issue-solving. It can be seen as going beyond more the conventional notions of solidarity in seeing that mutuality and alliance do not have to build on some unitary consciousness or shared identity (Baker Miller, 1991; Crow, 2002, both cited in Tew, 2006).

Instead of internal differences having to be suppressed or bracketed out in the interests of the common cause, the effectiveness of working for same goal may be greater if it can embrace the energy of mutual challenge and capitalize on the awareness to be gained from appreciating multiple viewpoints. Within this perspective, questions of difference need no longer be feared as a potential basis for subordination of exclusion, but may be valued as a resource that can open up new forms of creativity and opportunity.

Tew (2006, 38) notes that to achieve such a level in external resources is not easy, especially if forms of inequalities and oppressions exist in society. However, if specialists achieve assent, social support will be more effective and beneficial for families. Lemieux-Charles *et al.* (2006, 265) notes that such an external resource is more operative, because it encompasses different specialists dealing with specific tasks, contacts with the social network of the family and acts across particular organizational boundaries.

Social support itself is a social construct, as it does not exist as a phenomenon; it is created via an interaction process between the family and professionals. Social support is created by defining it, families create support naming it and giving it a meaning. Geelan (1997) commenting on Glasersfeld's position writes that people on social interactions construe meanings based on their own experiential reality.

The interaction of family-specialists is an active process in which the meanings of social support are constructed and can be represented (Butler *et al.*, 2007, 285). Everyday practice creates social reality of the social support mechanism existing in Lithuania that society understands as canon.

The historical conditions in Lithuania determined the later spread of the interpretive paradigm ideas. Therefore the physical aspects of disability were used as a tool for discrimination. As Dewey (mentioned in Danforth, 2008) notes, focusing on physical deficiencies is orientated towards creating the superiority of one group over another. Sheppard (2006) names such an act as outsiding. Marlow and Rooyen, (2001) names this phenomenon as *habitat destruction syndrome*[9]. Such perceptions obstruct provision of social support for family efficiency. Even more, Sheppard (2006) writes that social work dealing with and promoting new ideas can also be excluded just because of provision of social support for excluders in society. Berger and Luckmann, (1966) and Gergen (1985, both cited in Hiersteiner and Peterson, 1999) call it as marginalization by more powerful truths.

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9 Facts showing that disability is perceived in society as *habitat destruction syndrome* are testified in the official statistics of the Ministry of Social Security and Labour. For example, some of the financial benefits to families raising a child with cerebral palsy are almost inaccessible. According to the statistics of Ministry of Social Security and Labour, Lithuania has aprox. 70 thousand people with movement disability. Last year 685 applications to convert homes or block of flats for special needs were received throughout the whole of Lithuania. But only one third (262) of applications were satisfied because of financial or other shortcomings. Some of the applications were rejected because of too low a value of the home or if the adjustment value was almost equal to the value of the home. In all conversion of home cases, parents have to receive consent of neighbors. Also if a family lives above the first-second floor, they also cannot apply for conversions. Such a situation shows that: the most vulnerable families living in the harshest conditions and in low valued homes cannot apply for betterment of their life conditions. Also they have to move from the living place if they live above four meters. Another fact that families feel obligated to the goodwill of neighbors to sign the agreement for installing a lift.

Therefore, analysis of representations of social support gives the possibility to reveal the family's individual perceptions on specific supportive behaviours from people in external resources.

Social support is constructed in the everyday interaction process; parents and professionals negotiate it and then construct an interpretation of it (Urek, 2005, 452). Summers *et al.* (2008, 131) writes that regularly occurring events consist of habituated activities. In such a way social support can be perceived as Berger and Luckmann (1971, cited in Payne, 2006, 139) note an agreed set of understandings about the world that is an accepted and stable social reality.

Floyd and Zimch (1991, cited in Hartley *et al.*, 2005, 169) and Музыра and Аболонин (2007) write that families with severely disabled children are faced with different challenges in their lives that impact the prevalence of stress and negative feelings, sometimes resulting in depression.

Therefore social support for a family raising a child with severe disability gives need to receive social support from external resources as a stress-buffer for re-constructing stability. In this way social support is seen as the possibility to reduce the negative effects of a stressor as *perception of competence (of external resources) influence subsequent interactions* (Fisek, Berger and Norman, 1991 cited in Bonito, 2007, 261). If support is not received, prolonged stress may reduce a family's abilities to adjust the coping behaviour that leads to negative psychological, social or physical consequences.

Social support can be understood in various ways and even have different meanings that are constructed by both sides of the interaction process: professionals and families. I have a goal to develop a concept of social support conjunctive for all external resources systems: medical, social, educational, and DAT. In this way, despite the professional boundaries, division of labour and different spheres of issue there will be a possibility created to speak the same language in different professional contexts.

Various authors describe the term social support differently with some aspects of coherence. For example, Wilton and Plane (2006, 302, 304), Parrot and Madoc-Jones (2008, 190) describing the evaluation of social support emphasizes parental satisfaction with the provided services. Satisfaction is possible if there is communication between families and

specialist professionals attending. The same point of view is held by Hunt *et al.* (2004, 123).

Hill (2002, 237), Olsen *et al.* (1999, 277), and Mulvaney and Kenderick (2006, 311) analysing social support as a helping element adds the possibility of easing coping with stress conditions. Anderson *et al.* (2002, 393) expands this understanding that stress can be measured on a scale with reference to current stress events. Howe (2006, 103) sees social support as service provided by various agencies that may reduce maternal stress, increase sensitivity and improve children's feeling of security. A broader social support concept is held by Sanders and Roach (2007, 161), Riley *et al.* (2008, 15), and McGuire (2007, 125). They state that social support can be understood as supportive networks with developed social contact and social interaction where parental confidence is built. The same idea was developed by Huotari (2008, 92) complementing that networks are usually taken over professionals. Elfert and Mirenda (2006, 581) and Mavropoulou (2007, 138) comment that the most meaningful support can be derived from parental networks[10], Statham (2004, 594) categorizes such support through advocacy, individual casework, and social skills training.

Despite various overviews and authors' ideas, the classic ideas of the understanding of social support are seen as the most beneficial for the analysed phenomenon. Malecki and Demaray (2002, 1) describes early Cobb's (1976) social support sharing into three components: feeling loved, feeling valued or esteemed, and belonging to a social network. However, analysis of representation of social support requires a more detailed explanation of social support. Therefore, I decided to use social support understanding used by House (1981, cited in Peterson *et al.*, 2009), Lazarus & Folkman (1984, cited in Martz *et al.*, 2010) and Tardy (1985, cited in Malecki and Demaray 2002, 1). They (ibid) depicted the content of social support as: emotional, instrumental, informational, and appraisal. Tardy (ibid, 2) also describes social network as a source of individual support.

These social support ideas were expanded by Cohen and Wills (1985, cited in Davidson and Demaray, 2007) theorizing two models of functioning social support. The first model focusing on stable social

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10 Self-supporting parental groups.

support networks is not beneficial for my thesis, as I have the idea to investigate the representations of social support by families dealing with crisis in a non-stable network. The second way of social support perception is the stress-buffering model. Carlson and Perrewe (1999, 514–517) write that a family raising a child with severe disability experiences stress, therefore the stress-buffering model reveals the coping mechanisms that can reduce the negative effects of stressors.

Carlson and Perrewe quoting (1999, 514–517) various researchers[11] examine social support as an intervening variable that is placed in the causal path between stressors and strains. Essentially, the argument can be made that after a family perceives stressors in the environment (e.g., news about disability), resources are mobilized from which social support can be sought (external and internal). Thus, social support reduces the effects of the stressors on strains. In this case social support provided from internal and external resources can directly reduce the family's stress (Staines and Pleck, 1983; Thomas and Ganster, 1995; Thomas, and Thomas, 1990).

Greenhaus and Parasuraman (1986, cited in Parasuraman *et al.* 1992) note that this approach is consistent with the direct effects approach, which has been partially supported (suggesting that social support, is directly related to the outcomes (psychological, social and physical). Groungaard and Skov (2006, 300) withholding this point of view add that effective social support is always concentrated on possibilities in the child and identifying positive aspects.

Cohen *et al.*, (2000, cited in Davidson and Demaray, 2007) explains the stress-buffering effect materializing in two ways. First, if a family believes that support resources will be available in problematic times; this belief improves that family's ability to cope with and handle such a crisis. And second, if a major stressor does occur, social support can reduce the harmful consequences of such a stressor, including the effects on the family members' health and behaviour. Rogers (2007, 140) and Wong *et al.* (2008, 344) summarized these ideas creating the understanding that social support directly affects family health, improves health by acting as a buffer to stress, makes stress less likely, and facilitates recovery from crisis. Burgess and Gutstein (2007, 80) added that it improves the quality of life, King *et al.* (2006, 365) – that it creates a feeling of being understood.

11 Johnson, Thomas and Riordan, 1994; Sheffield, Dobbie, and Carroll, 1994.

Peterson *et al.* (2009, 488) cites House's (1981) expanded understanding on four main stress-buffering components. Emotional support can be understood as the provision of empathy, love and trust, instrumental support is the provision of tangible goods, services or aid, informational support is the communication of information for problem-solving, and appraisal support is the communication of information relevant to self-evaluation (ibid, 488).

In summary, I present the resulting social support concept that joins all external resource specialists and can be applied in any of the fields with a peculiar context inside.

Social support is perceived as emotional concern, instrumental aid, information, and appraisal based on communication and assistance for family raising a child with severe cerebral palsy; gained or perceived as possible to gain when needed from external resources as a stress-buffering mechanism and impacting a family's positive psychological, social and physical outcomes. This social support concept focuses only on external resources this concept will be held in the whole thesis further.

2.3 The Social Worker as Mediator: Scandinavian Activity Theory

Scandinavian activity theory is applied in the thesis to strengthen the position of social work in the provision of social support. This theoretical assumption detects social work via the mediation process in interconnections with other professionals.

Scandinavian activity theory[12] reveals the context of the realization of social support (emotional concern, instrumental aid, information, and appraisal) using specific tools, rules and division of labour among professionals.

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12 Activity theory developed by Leont'ev and Rubinstein was unknown outside the Soviet Union till the middle of the 1980s when it was picked up by Scandinavian researchers. The earliest non-Soviet paper cited by Nardi is a 1987 paper by Yrjö Engeström: *Learning by Expanding*. Kuutti notes that the term activity theory *can be used in two senses: referring to the original Soviet tradition or referring to the international* (Barab *et al.*, 2002). Therefore, the activity theory used in this thesis refers to the international understanding and is called Scandinavian activity theory or Modern activity theory.

Social work has many faces in the social support process, though, only the mediator role is important in the analysed context. Activity theory being a psychological and multidisciplinary theory has a set of perspectives interlinking family level with social support at the specialists' level. Figure 3 portrays the provision of social support when the social worker is in the role of mediator and using rules and tools to incorporate other professionals for achieving a welcomed outcomes for family.

Barab *et al.* (2002, 78) writes:

> *When discussing activity, activity theorists are not simply concerned with 'doing' as a disembodied action but are referring to 'doing in order to transform something', with the focus on the contextualized activity of the system as a whole (Engeström, 1987, 1993; Kuutti, 1996).*

Social work as mediating is seen as acting in order to provide better social support and its achievements for the family. Fjeld *et al.* (2002, 155) notes that the *subject* (social worker) interacts with the other specialists in external resource in order to help the *object* (family in disability situation). This thesis constructs the idea that families in particular periods of life battle with stressful burdens and need to receive social support from external resources for adjusting adaptive behaviour.
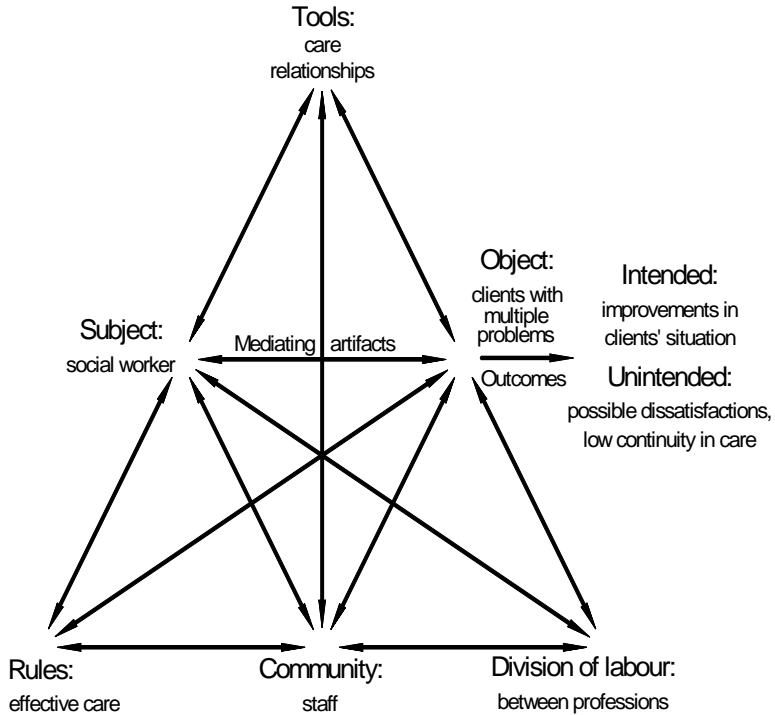
Engeström, 2007; Tuomi-Gröhn, Engeström, 2008, 31.

Figure 3.   The work activity of a social worker .

Sheppard (2006) notes that families in a stress situation are more likely to take a passive position than actively fight for the needed support.

Figure 3 shows that social workers activate social interaction among the professionals for supporting the family in the way it needs. The social support context is seen in this figure as rules and tools. Fjeld *et al.* (2002, 155) writes that via the process of social support family members can rebuild social interactions and *internalize* this capability into mental activity.

Engeström and Miettinen (1999, cited in Nilsson, 2003, 60) write that social work's importance lies in the conceptualization of provision of social support via the mediation function. The social worker as active agent deals with other professionals and they together locate the social

support on the demand of the stressful situation. Huotari (2008, 83) notes that activity theory represents a specified view of provided social support in any period of family life.

Vaičekauskaitė (2007ab) describing various family researches made in Lithuania, notes that stress is one of the most statistically important factors in the context of disability. Gedvilienė and Baužienė (2009) describing the family's situation raising a child with locomotive disability note that it is an everyday stress experience.

Engeström's (cited in Paavola *et al.*, 2004, 560) sociological approach that

> *Human beings do not live in a vacuum but are embedded in their sociocultural context, and their behaviour cannot be understood independently of that context (Engeström, 1987; Engeström, Miettinen & Punamäki, 1999)*

gives a full picture of the social support context. When a family is dealing with stress, the stress-buffering model may be applied via mediation and in sharing the specialized issues among the professionals. However, this external resource deals with family stress not only depending on their inner peculiarities, but also depending on the existing historical-cultural background.

Mediation in social work does not have clear practical implementations. Petraitienė *et al.* (2006, 25) states that social work as mediating could be the core of social work when constructing social support for a family in a disability situation. Baranauskienė and Gudinavičius (2007) note that despite changes in paradigms towards the disabled, mediation in social work is only being started to be spoken of. Therefore, I will overview the international understandings of interactions between the family and external resources.

Soar *et al.* (2005, 35) and Flynn, (2005, 408) describing the mediator states that the mediator's role is first of all facilitating open dialogue between the disputing parties, but at the same time remaining independent and neutral throughout the whole process. The mediator promotes constructive communications between the parties (Barsky, 1999, 482). Provision of social support for families via mediation is seen as the social worker's dealing between the families and the external resources that affect them (Kiselica, 2004, 843).

The mediator promotes reconciliation, settlement, compromise, or understanding among two or more parties. The social worker and specialists of external resource are the participants of the mediation process in order to provide social support (Petraitienė *et al.*, 2006, 25). The mediator's role assumes that the mediation process creates choices in acting for the stress-buffering effect in a particular situation (Davidson and Demaray, 2007).

Notwithstanding the thesis analysis of representations of social support, it is advantageous to apply the mediation aspects of Parsons' (cited in Arzenšek, 1971) conflict model for revealing the mediation function in the interacting process.

Parson (cited in Arzenšek, 1971) analysing interactions in society, describes forms of communication from negotiation to litigation. Figure 4 represents forms of possible interactions for providing social support.
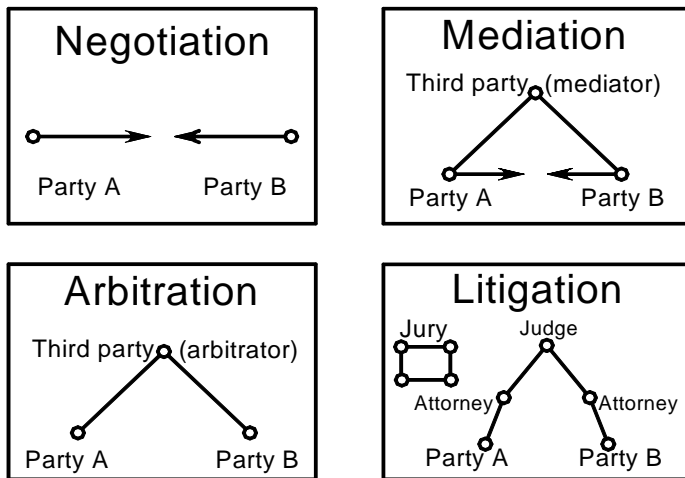
Parsons, 1991, 484.

Figure 4.   Four methods for resolving conflict.

Negotiation involves direct communication between two parties (Parsons, 1991, 484–485). Usually the Lithuanian support model is seen as negotiation between two parties: the family and a professional in external resource that can be medic, educator, social worker or DAT professional.

Rullo (2001, 214) notes that if a family finds a solution together with a professional, the circle closes and the family experiences provided social support.

Narhi (2002, 333–334) and Holmes (2005, 673) discuss the content of a family-social worker negotiation which is understood on subjective representations, as how the family perceived addressed issues of welfare, how attention was paid to the family's understandings of needs, as well as the informal process by which they co-operate together, primarily through negotiation. Negotiation as a process between professional and family is seen as a social construction of *negotiated reality*. This reality tends to be reflected in the representations by families.

Professional negotiation is seen as the creation of interpretations of social reality and possible social support (Urek, 2005, 452). When everyone in this process makes suggestions and all share a similar understanding about good practice and each has a place for sharing expectations, over viewing demands (Leigh and Miller, 2004, 264; Moran *et al.*, 2007, 145).

Parsons (1991, 484 – 485) sees mediation as a continued process of not finding social support in negotiation and describes it as if conflicting parties cannot negotiate a solution, a third party is needed to mediate and promote communication and conciliation. The mediating process is more complex than two-sided negotiation. This situation emerges if a family meets professionals and negotiation is not socially supportive without the social worker's intervention.

Such a model of the mediating process can be viewed in Lithuania only theoretically, as working model can be implemented when all joints are integrated for provision of social support. Social work in Lithuania lacks its implementation in practice. Therefore, some other professionals may act as more authoritative figures in the mediation process.

Such a situation would not correspond to the mediation idea where equality among parties is set. Sallee (2003, 349) writes that social work as a profession is still in its formative stages as ever since social work began to evolve as a distinct profession, its definition has been debated. Kavaliauskienė (2007) mentions many debates by various scientists (as Baird, 1972; Flexner, 1915; Banks, 2001 and others) about social work from the questions if it is a profession to the power of social work. However as Berger (1995, cited in Kavaliauskienė, 2007, 231) notes social work during history faced many battles to become recognized.

Ramsay (2003, 335) states that in the 21ˢᵗ century the definition of social work is changing and the domain of practical social work becomes mediation. Gilgun and Abrams (2002, 43) note that social workers proving social support may act not only be mediating between external resources, but also acting in larger systems.

Despite theoretical-ideological foreign ideas, social work practice as permeation with different levels of mediation either externally or in lager systems is not so widely spread in Lithuania. This understanding is directly related to the historical approach and practice. In the official declaration on social work of the Ministry of Social Security and Labour of the Republic of Lithuania, there is no clear understanding on social worker's roles as well as is absent his role in external resources, described as networks of other professionals.

The social worker according to the Ministry of Social Security and Labour of the Republic of Lithuania[13] is described as very general

> *Specialist who helps individual or family to solve their social problems according to their abilities and with their involvement with due respect to a human dignity and by increasing their responsibility based on partnership between the individual, family and society.*

Varažinskienė (2009, 129) analysing the basis of social work legislation notes that social work still lacks historical practice understanding that it has remained so for a long time. She (ibid, 129) also writes that legislation regulating social work practice is still developing in Lithuania.

Expanding an understanding of mediation when the solution was not found via the mediation process, arbitration can be reached. If a third party is unable to promote negotiation, *arbitration* may be used, a process that leaves much less power with the participants than negotiation or mediation. The arbiter does not attempt to promote communication and negotiation between the parties but, instead, much like a judge, hears both sides of a conflict and decides the resolution. And, last, if arbitration is unsuccessful, the parties may resort to *litigation*; each party is represented by an attorney and, if a jury is involved, the decision is made by an outside group through the intervention of attorneys. The parties in conflict do not have to talk to one another. In this conflict

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[13] www.socmin.lt

resolution strategy, the participants retain the least power (Parsons, 1991, 484–485).

When we speak about social support constructed towards the family, the social worker as a specialist closest to family applies negotiation for analysing demands, needs, expectations, and resources. The same way other professional may negotiate with concrete family and meet their needs. When two-parties are unable to solve the situation, the social worker or other professionals may form a working group, where the social worker acts as mediator in order to provide social support for the family. Then the social worker helps to hear both sides: professionals and parents. Mediation should be perceived as an active process where different tools, rules and artifacts are engaged for achieving positive outcomes for the family.

Prakapas (2007, 14) analysing the legislative discourse of social work in Lithuania writes that in the brief historical approach many positive changes have already been implemented. He (ibid, 14) mentions the main problem – the practical implementation of measuring quality. From my point of view one of the legislative shortcomings could be mentioned as the left open possibility for each institution having a general description about the social worker[14] develop his own official calendar with duties and functions of social workers. Such practices depending on a concrete institution may turn social workers into event organizers, nurses, special educators, and teachers.

Drawing analysis back to social support via mediation providing, Figure 3 portrays family-orientated help including Bannon and Bodker (1991) and Foot (2001, 10) described aspects:

1. **Hierarchical structure of activity:** Activities (the top-most category) are composed of goal-directed actions – providing social support. These actions are performed consciously. Actions, in turn, consist of non-conscious operations.

2. **Object-orientedness:** Objective and socially or culturally defined properties. Our way of doing work is grounded in a praxis which is shared by our co-workers and determined by tradition. The way an artifact is used and the division of labour influence the design. Hence, artifacts pass on the specific praxis they are designed for.

14 Formed by the Ministry of Social Security and Labour.

3. **Mediation:** Human activity is mediated by tools, language, etc. The artifacts as such are not the object of our activities, but appear already as socio-cultural entities.

4. **Continuous Development:** Both the tools used and the activity itself are constantly reshaped. Tools reflect accumulated social knowledge; hence they transport social history back into the activity and to the user.

5. **Distinction between internal and external activities:** In contrast to traditional, Activity theory emphasizes that internal mental processes cannot be properly understood when separated from external activities that is the interaction with the outside world. A basic notion of Scandinavian activity theory is that the family participating in an activity does so because it wants to achieve a certain goal. Its interest is directed towards the object – social worker of an activity which the family tries to use and modify to achieve and anticipated outcome (satisfaction of provided social support). The family's interaction with this social worker is mediated by tools, creating the basic triangle of Subject, Object, and Mediating Artifact.

Such an activity process is working as social support via mediation (Sallee, 2003; Denzin, 2002, Peled and Leichtentritt, 2002; Linhorst, 2002). Ramsay (2003, 334) writes that this model helps to act social worker family-centered.

Fuller (1975, cited in Zapf, 2005) conceptualizes that the existence of the self and otherness entities depend on their relationship to one another. Social work claims to be relationship centered, with its domain focus on social support for family.

Community comprises various individuals and/or sub-groups who share the same general object (Huotari, 2008, 84). The social worker has to take care of the family's satisfaction with services provided by various professionals, mediate helping to communicate. It is necessary to appraise that satisfaction with services primarily pursued as intermediate outcomes enhance specific emotional states (self-efficacy, self-esteem of single family member), social interaction and marital/family interaction (Rosen *et al.*, 2003, 214–215).

The *division of labour* refers to both the community and the specification (Huotari, 2008, 84; Haug, 2005, 133). When professionals in external resource divide labour, they use decentralized decision making, team-based policy, and participative management. Evans and Davis's (2005, 768–769) position is that flexible work provides greater opportunities for engaging in role making.

Rules refer to the explicit and implicit regulations, norms and conventions that constrain actions and interactions within the activity system (Engeström, 1987, 2007; Huotari, 2003). The human activity system is self-directing. It develops by resolving internal contradictions and external contradictions between the system and the environment. Contradictions are not the same as problems or conflicts; they are historically accumulating structural tensions within and between activity systems. On the one hand contradictions in the work process appears in the work as disturbances, breaks and dilemmas and, on the other hand, as innovations, attempts to resolve the contradictions of human activity individually or together in a new way (Huotari, 2008, 84–85).

Flynn (2005, 412) writes that for social work professional roles in the mediation process are clear, the same as interaction balance – there is always an ethical responsibility to construct social support for the family. Various interactions among professionals balancing techniques should be used by the mediator to contribute to the positive representations of a family receiving social support.

Each working specialist acting in external resources and dealing with other professionals has to know the rules at the core of their profession, no matter if it is medical, education or social work. Hare (2004, 413), Carrilio (2007, 528), Chan and Ng (2004, 313), and Taylor (1999, 311) write that social work since its inception showing its concern about people who are coping with the problems and vicissitudes of living. Bidgood *et al.* (2003, 405) has the idea that meetings of different professionals can be paraphrased that instead of presenting the understanding of social support as fragmentized action orientated towards the family, each professional knowing his professional boundaries must interact via the mediation process for the family's sake and move beyond the expert professional paradigm, instead of it using the idea: *think outside the box.*

3 Provision of Social Support
in Various Branches of the Helping Net

The diagnostic disability relation to medical support described by Hewitt-Taylor (2005, 41) writing that developments in medicine and technology mean that each year more and more children survive with severe health problems that require long-term medical and technical intervention. The same situation is seen in Lithuania. The data of the Ministry of Social Security and Labour[15] counts over 250 thousand disabled people in Lithuania that were given social benefits in 2008. Children with disabilities compound 6% of this number (around 16 thousand). The number of disabled people in Lithuania corresponds to the numbers given by the United Nations Organization, that usually 10% disabled people compounds of all the population. The number of people suffering from severe disability is more than 33 thousand, including children and adults.

Despite the rapidly changing political and cultural contexts from the early 90s, it has taken some time for attitudinal change towards the disabled. Therefore, the main legislation serving as a background for changing social attitudes towards disability was *Neįgaliųjų socialinės integracijos įstatymas*[16] released only in 2005. This law not only changed the attitudes, but also opened new possibilities for disabled people.

Various Lithuanian scientists had been working on research in order to make positive movements in legislation concerning disability. Ambrukaitis, Stankevičienė (2002) made studies on the law of special education. Kasparavičienė, Sabaliauskienė, Rimkienė (2002) analysed services of early intervention as social support for families in disability situation. Various questions of social integration were raised and analysed by Grincevičienė (2002), Žalimienė (2002). They analysed problems related to day care centres, Ruškus's (1997ab, 2001, 2002) ideas mainly focused on the mechanisms of social construction. Problems in meeting special needs were analysed by Ališauskas (2001, 2003), Kaffemanienė (1996), Kaffemanas (2001), Gudonis (2001). Questions of social integration in the society were raised by Ruškus (1997, 2001, 2002),

15 www.socmin.lt

16 Law of Social Integration of Disabled People.

Gailienė (1998). Ališauskienė (2002), Ališauskienė and Miltenienė (2004) draw analysis towards the collaboration of professionals with parents and the development of early intervention services for families in disability situation. Vaičekauskaitė (2004) introduced the questions of children's disability independency development. It is almost impossible to mention all the scientists whose works impacted juridical changes before 2005. Therefore, mentioning additionally, the main authors were: Pūras (2000), Butkevičienė (2000), Balčiūnaitė (2001), Daulenskienė (1998), Ivoškuvienė and Balčiūnaitė (2002), Karvelis (1997), Ambrukaitienė (1997), and Prasauskienė (2003).

Together with this law Lithuania opened a new list for disability understanding. This act was the first sign of disability's formal acceptance as *social problem* not *individual* as before. Wasserman (cited in Lekan, 2009, 216) calls turning towards the interpretivistic paradigm as a shift from disability as a problem perception, when social support was organized no longer due to deficiencies, but general appreciations of inner features are noticed and valuated.

Why this law was so important to Lithuania? First of all, this law created new terms, portrayed a functioning system of social integration with three main constituents: *Medical*, *Social* and *Educational* systems that were guaranteed by the state. The Ministry of Social Security and Labour[17] states that this law was a

> *Legal act of our disability model conforming to European context and understanding.*

This law was important in the creation of a longitudinal idea of social support construction. It is said that disability has to be perceived in perspective of life circle emphasizing not only treatment possibilities, but as *new level* in the context of quality of life.

The Ministry of Social Security and Labour from 2005 reorganized the Governmental Commission of Medical and Social Expertise under the Ministry of Social Security and Labour[18] resolving it into: Service of Disability and Working Capacity under the Ministry of Social Security

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17 www.socmin.lt

18 Valstybinė medicininės socialinės ekspertizės komisija prie Socialinės apsaugos ir darbo ministerijos.

and Labour[19] and Commission of Issues under the Ministry of Social Security and Labour[20]. This division was important for giving a right and voice to the disabled and their caregivers if they were not agreed on the solution of the Service of Disability and Working Capacity.

The same law changed the understanding of *disabled child*, as before it was a child up to 16 years, now – up to 18, the same understanding as for *normal* children in Lithuania. Also this law guarantees the meeting of special needs in any age of disabled person. The Ministries of Social Security and Labour (Social resource), Ministry of Health (Medical resource), and Ministry of Education and Science (Educational resource) became responsible for collaborative meeting of special needs.

Due to the Law of Social Integration of Disabled People (2005–07–01) children with severe disabilities and their care givers have rights to various benefits.

- **Benefits in the medical sphere:** 100% of compensatory remedies that are included in the list of compensatory remedies[21], compensatory base price of medical rehabilitation included in the compensatory list, 90% base price compensatory of rehabilitation in the convalescent home[22].

- **Benefits in the transport sphere:** a right of prioritized border crossing to another country by car with a disabled child[23], other priorities using a car with the sign *disabled*[24]; 80% discount of the ticket price for a child and one travelling caregiver for the train, ship and bus ticket (if the company is on the government list)[25].

- **Benefits in the accommodation sphere:** 20% of the balance of credit taken for buying accommodation is financed by the government[26],

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19 Neįgalumo ir darbingumo nustatymo tarnyba prie Socialinės apsaugos ir darbo ministerijos.

20 Ginčų komisija prie Socialinės apsaugos ir darbo ministerijos.

21 Sveikatos draudimo įstatymas (10 straipsnis).

22 Sveikatos draudimo įstatymas (11 straipsnis), LR Sveikatos apsaugos ministro įsakymas V-50.

23 LRV nutarimas 2006–06–01 Nr. 524.

24 LR Socialinės apsaugos ir darbo ministro, LR Vidaus reikalų ministro ir LR Sveikatos apsaugos ministro 2005–01–28 įsakymas Nr. A1–20/1V–23/V–67.

25 Transporto lengvatų įstatymas (5 straipsnis).

26 Valstybės paramos būstui įsigyti ar išsinuomoti įgyvendinimo įstatymas (2–1 straipsnis).

a right for betterment of social accommodation conditions if one family member has less than 10 square meters in the living place[27]; a right to receive social accommodation from the local municipality, they are put on the list from the date of applying[28].

- **Benefits in the working conditions:** an employer is given 12 months grant aid in employing a mother/father raising a child with disability up to 18 years[29]; employees have the right to receive one paid day off per month or 2 hours shortened working time per week[30]; 35 days for holidays each year while raising a child with disability[31]; has the right to receive free secondary juridical help if it is needed for representing the interests of a disabled child[32]; obtaining a passport or identity card is free of charge till the age of 18 years[33].

    Other social support mechanisms are guaranteed by a variety of acts concerning three special needs groups:

- **Means of technical support.** Means of technical support to the value of up to 1500 Litas[34] are given free of charge. 95% of the price of an electric wheelchair is compensatory once in 8 years. Repairing and battery changing is 80% compensatory. A disabled person has the right once in 4 years receive compensation up to 2500 Litas for obtaining an active type of wheelchair[35]. Children have the right to be given deaf-aids (both ears) up to 12 years once in five years free of charge[36]. All forms of orthopaedic treatment are compensatory[37]. Endo-prosthesis is compensatory if bought at the minimum price during the post operation period[38]. Adaptability of living space for

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27 Gyventojų aprūpinimo gyvenamosiomis patalpomis įstatymas.

28 Gyventojų aprūpinimo gyvenamosiomis patalpomis įstatymas (11 straipsnis).

29 Užimtumo rėmimo įstatymas (26 straipsnis).

30 Darbo kodeksas (214 straipsnis).

31 Darbo kodeksas (166 straipsnis).

32 Valstybės garantuojamos teisinės pagalbos įstatymas (12 straipsnis).

33 Rinkliavų įstatymas (6 straipsnis).

34 The Euro and Litas official rate from 2002–02–02 is 3.4528 Litas for 1 Euro (www.lb.lt).

35 LR Socialinės apsaugos ir darbo ministro 2005–08–23 įsakymas Nr. A1–238.

36 Privalomojo sveikatos draudimo tarybos 2001–03–30 nutarimas Nr. 2/10.

37 LR Sveikatos apsaugos ministro 2006–03–31 įsakymas Nr. V–234.

38 Privalomojo sveikatos draudimo tarybos 1999–09–28 įsakymas Nr. 3/4.

people having severe disability of movement is possible using 80% of governmental and 20% of municipality budget resources[39].

- **Means of financial support.** A caregiver (mother or father) is given a benefit of amount 2.5 basic benefits or 1.5 basic benefits (other caregivers) if a need for steady nursing exists (for nursing a child up to 24 years). A caregiver (mother and father) is given a benefit of amount 1 basic benefit or 0.5 basic benefits (other caregivers) if needs of special steady help exists for child up to 24 years. Purchasing a car and its technical adjustment is possible in compensatory for price up to 32 MGL[40]. Compensatory for transport expenses is possible for amounts up to 0.25 MGL[41]. 20% of MGL is paid if a child up to 18 years is attending high school[42]. Compensatory payments are provided in educational institutions and at home[43].

- **Social service.** General and special social services are provided according to the catalogue of social services[44].

Despite the overviewed acts that make various guarantees for families raising child with severe disability, financial aspects are not the most important in the current situation.Ališauskienė (2007, 22–23) comparing various aspects in constructing social support for families in disability situation within the European context writes that greatest problems occur in coordination among the medical, educational, and social sectors, also family orientation and child support in a family context needs to be improved. Ruškus and Mažeikis (2007, 95) fulfil this

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39 LR Vyriausybės 2006–06–28 nutarimas Nr. 638.

40 MGL can be transcribed as *minimum level family of living*. This parameter is changing due to economic changes in Lithuania, though; the amount of 1 MGL is approximately 125–130 Litas. The minimum level of family living is the sum of all family incomes per month shared for each family member. This minimum level of living has to guarantee the minimum socially accepted level for meeting organic needs of food due to physiological norms, minimum level of clothing, shoes, accommodation, householding, sanitary and hygiene supplies, flat, utilities, home comforts, meeting the needs of transport, relations, culture and education (Gyventojų pajamų garantijų įstatymas 1 str.).

41 LR Socialinės apsaugos ir darbo ministro ir sveikatos apsaugos ministro 2005–05–04 įsakymas Nr. A1–120/V–346.

42 LR Vyriausybės nutarimas 2006–02–13 Nr. 152.

43 Specialiojo ugdymo įstatymas (25 straipsnis).

44 Socialinių paslaugų įstatymas; Socialinės apsaugos ir darbo ministro 2006–04–05 įsakymas Nr. A1–93.

idea writing that the majority of benefits create a double problematical situation: first of all, disabled people may feel eliminated from society the same way as society cumulates negative attitudes towards the disabled if the social support is understood only as a mean of giving benefits.

After the overview of the general system existing in Lithuania, I will draw a broader analysis in each sphere of social support guaranteed by law and additionally Dolphin Assisted Therapy.

3.1 The Medical System as Social Support

Nowadays Lithuania has a wide spectrum of various specialists that deals with different problems of special needs in the medical sphere. I am speaking of *physical therapists, psychiatrists, speech therapists, occupational therapists, play therapists* etc. Terms as speech, occupational, play therapists are brand new in Lithuania's context, as about a decade ago the main specialists taking care of disabled child were doctors and *defectologists*[45]. The situation was the same with the determination of disability, till 2005 in Lithuania all disabled people were categorized into three levels of *validation*. That means all due to their disability status were representatives of 1st (severe) invalidity, 2nd (middle severe) invalidity, and 3rd (least) invalidity groups. Nowadays the situation has changed[46] though problems in the disability sphere emerge constantly.

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45 Defectology – a science widely used during the Soviet period in Lithuania. Specialists were called *defectologists*. Defectology as a science analysed people's deviations from detected norms. People with mental problems were categorized as *debile, imbecile* and *idiots*. This terminology and science which violates human rights and honor is no longer in use in Lithuania.

46 It is related to an already overviewed law released in 2005. The Ministry of Social Security and Labour of the Republic of Lithuania passed the bill concerning the social integration of disabled people. They were no longer categorized as *invalids*, new terminology described them: *disabled* and *having three levels of working capacity*. From 1 July 2005, the disabled people over 18 until they reach the age for the old-age pension are awarded the capacity to work level instead of a disability group. The capacity to work level is set at the interval of 5 percentage points, i.e. if the person is recognized as having 0–25% of the capacity for work, he is deemed to be incapable of work; in cases of 30–55% of the capacity as partially capable and in cases of 60–100% of the capacity as capable for work.

The research of Butkevičienė *et al.* (2006, 128) showed that families dealing with issues of a child with disability still faces bad communication with medics. Farrell *et al.* (2001, 765) notes that negative representations are quite often led because of the delegated role to give disappointing news about a child to its parents. Vehkakoski (2007, 288) analyses this situation where in severe disability cases families have to deal with the rise of new stressful diagnostic situations, therefore such frequent contact with medics is initially stressful.

The cumbersome change of paradigms from diagnostic to interpretative in the medical sphere resulted from several causes. The first of the reasons is the historical – cultural background that laid the footprint for the medical disability approach. Finn confirms (2008, 113) the idea that doctors' are maintaining a historically developed position of social and material advantage over other professionals, therefore it is also difficult to see equal relations with patients.

Howson (2009) analysing the medical context in the paradigm change from diagnostic to interpretative notes that for many years the physical requirements were equal to economic productivity, therefore norms of normalcy were created. Reindal (2010) criticising the social models writes that when disability was described as a situation caused by social barriers only, it also created a confused understanding about disability itself.

From this point of view social support in the medical sphere due to its context as an emotional concern, instrumental aid, information, and appraisal are segmented to the initial assignation of concrete instrumental aid as fundamental.

The second reason is related to initial background. Medics had and will always have their roots in bio-medical sciences, which means their professional interest centres on the psychical and psychiatric determination of the client. The child is perceived in the patient role. Turner (1987, cited in Howson, 2009) notes that the development of clinical medicine was itself dependent on access to and examination of the human body. It grew rapidly from the eighteenth century as the number of hospitals expanded and provided a new kind of space in which people were gathered and who were available for examination and inspection. In such a way the majority of fundamental statistical comparisons were made.

Armstrong (1995, cited in Howson, 2009, 2) writes that observations of and comparisons between bodies helped to establish the biophysical averages and norms. Kruse (2003, 498) writes that the problem of discourse on disability emerges when disabilities are equated to medical *treatment*. Discourse is problematic if conditions that are not medically *treated*, but still are decided as treated. Kruse's idea lies in the explanation that in severe disability cases families may need a child's treatment as patient because of occurring illnesses during its lifetime, but severe disability itself cannot be defined as an objectivised determining factor. Daugėla (2006) cites Meyerson's (1948) idea that impairment is only a variation of the body to which we accommodate a negative evaluation.

The research of Ališauskienė (2005, 25) showed that many of the medics in Lithuania represent the expert model[47] as belonging to radical understanding. Mcinnes and Lawson-Brown (2007, 348) note that social support in the medical sphere depends on each medic.

Treatment raising a family's positive representations strengthens the family's confidence; unsupportive treatment strengthens only mistrust and suspicions (Jalava, 2006, 58–59). Rentsch *et al.* (2003, 41) puts a broader understanding on the medic as a social support basis: the role of the medic includes the sharing of information with other specialists, setting common goals, planning, and setting patient management, however in not all cases it is possible. Howson (2009) notes that concentrating on the biomedical model of disability forms the perception of bodily and personal tragedy that assumes the dependency of those experiencing impairment. Shakespeare (1994, ibid, 3) writes that such social perceptions have the potential to disable those who are the subjects of imagery in ways that accentuate the *otherness*.

For the following years the medical system in Lithuania has been under change[48]. For more than five years the Ministry of Health of the Republic of Lithuania has been balancing between making and not making radical

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47 This model places specialists of medicine in an expert role – they accept all decisions and control treatment situations. The expert model leaves the leading role and high professional competencies exceptionally for the specialists. Parental functions are restricted; they are not fully advised and usually take a role of patient (Ališauskienė, 2005, 25).

48 LR Sveikatos apsaugos ministerija. *Tolesnės sveikatos sistemos plėtros 2007–2015 metmenys.*

changes in healthcare practice. At the moment the medical sphere is represented as overloaded with too much documentation work, lack of specialists, having examination limits (such as 5–10 minutes for seeing a patient), financial limits in sending a patient for deeper examinations, financial limits in compensatory allocation. Practically it means that the laws discussed in the previous sections about compensatory drugs and sanatoriums are theoretical understandings. Not all families can receive and use these resources because of set limits or have to pay for additional examinations and resources.

Rentsch *et al.* (2003, 416) notes that documentation is the basis for the construction of social support among the professionals. Legislations by the Ministries Education and Science, Health and Social Security and Labour of the Republic of Lithuania[49] accepted in 2002 eliminate medical specialists in on-going actions. The law emphasizes the position of medical specialists as very narrow – only the diagnosis of disabilities in the seeing, hearing, movement, somatic and neurological spheres. Special education may be organized on statement of diagnosis.

The complicated situation that was raised by the Ministry of Health in Lithuania pawned both sides – medics and patients. From the care procedures, usually the medical practitioner in Lithuania has the possibility to briefly evaluate a patient and fill in a considerable amount of documentation. Therefore communication between doctor and family is in a strained relationship from its beginning.

Analysis made by the Ministry of Health of the Republic of Lithuania[50] showed that the health system till 2007 was full of problems: growing number of hospitalized patients, medical practitioners supporting a clinical attitude towards patients, no holistic examination of patients, patients were not feeling as partners of the doctor while dealing with illness. Therefore, the Ministry of Health has been looking for some reforms for bringing a more professional attitude towards the patient after 2010; at least the final goal of the Ministry of Health was such. However, the first experimental months in 2009, showed that more health procedures were being paid for by consumers, queues to see specialists grew into longer than before, and some offices were suspended.

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49 Valstybės žinios, 2002–08–30.

50 www.sam.lt

Negotiation between doctor–patient[51] is based on a formal and impersonal relationship (Nelson *et al.*, 2004, 153; Clifford and Burke, 2004, 317). In 1977 the World Health Organization set one of the main aspects of qualitative treatment – when this relationship is based on communication. That would broaden the understanding of disability from a medical setting diagnosis to a broader – holistic. The holistic approach expands the understanding of medical support from only instrumental to communication based: information providing, appraisal and emotional support. Social support in the stress-buffering model explains that the context of support is inter-related with positive outcomes of each family member. Kurz *et al.* (2008, 91) and Groungaard and Skov (2006, 297) write of research that showed a relationship of incommunication between doctors and parents of a child with disability that influenced the outcome declination.

3.2 The Educational System as Social Support

Formally, all disabled children in Lithuania have special educational needs[52]. Due to the Bagdonas (2003, 4) survey, all disabled children are now called as *special needs children*, as this term has very close relations to the understanding of rehabilitation, as integration is the final goal of this process. Gedvilienė and Baužienė (2007, 122) citing Galkienė (2003) discuss a possible conceptual change from *special needs children* to *person having special needs*. Because in such a way educational discourse would avoid concentration on distinction, as person may have special needs because of impairment or talent.

The context of education as social support is one of the most vulnerable in Lithuania. Educators, special educators, psychologists, teachers, speech therapists and other workers in the educational system are the first practicians experiencing changes in paradigms. Rapid changes in

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51 Due to Bronfenbrenner, theory (1979, cited in Bowes *et al.*, 2001), *client, patient* is not a single person, but the whole family experiencing the disability situation because of disorder of one member of the system.

52 LR Švietimo ir mokslo ministro, LR Sveikatos apsaugos ministro ir LR Socialinės apsaugos ir darbo ministro 2000 m. spalio 4 d. įsakymas Nr. ISAK–1221–527–83 (Valstybės žinios, 2000, Nr. 85-2608; Valstybės žinios, 2009, Nr. 55–2184), 7.3 punktas.

law and disability discourse have produced many new concepts – from integration to diversity – in some of the institutions creating phenomena that I call *disability understanding gaps*. Augienė and Ruškuvienė (2005) write that in these processes representations of educatibility of children with special needs are not sufficiently investigated. Therefore, it is not clear if there is coherence between new education ideas and practice.

For example, ideas of inclusion were spread as new ideas for special needs children[53]. Not having a clear understanding of inclusion, the representatives of the Ministry of Education and Science of the Republic of Lithuania presented the new European understanding of disability inclusion without any limits using the term *diversity*. A shift of paradigms must have coherence with practical contexts. As Danforth (2008, 52) presenting Dewey's point of view towards education of special needs children, notes that the physical and social coexist in finding development in the scope of human experience.

Ališauskas *et al.* (2008, 124) citing authors Ališauskas (2002, 2005, 2007), Ališauskienė, Miltenienė (2004), Ruškus (2002), Ruškus, Mažeikis (2007), Šapelytė, Ruškus, Ališauskas (2006) writes that even if nowadays the education of special needs children is full of confronting different approaches, special education is obtaining inclusive paradigm features. He (ibid, 124) notes that the practice of special education is less associated with specialized institutions and educating is organized on individual needs.

According to Augienė and Ruškuvienė (2005, 57) the educational sphere is one of the most problematic spheres of practice. They (ibid, 57) describe the educational context as depending on dominant social concepts. Therefore, after changes of political and social conditions, have to change the education methods and aims of the education of children with special needs.

The law of the Ministry of Education and Science of the Republic of Lithuania declares[54] procedures for integration into secondary school for children having special needs up to 21 years. The mentioned law declares three levels of children's disabilities: severe disability, average disability and light disability that can be set for a child differently dependent on

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53 www.sppc.lt

54 Valstybės žinios, 2005–03–26; Valstybės žinios, 2004–05–22.

disability prognosis[55]. Children with various problems can be integrated[56] into general secondary schools. Despite the possibilities to be integrated, the law does not define clearly how this process should seem and what specialists are responsible for successful integration. Not all integration cases of children with special needs are successful, practice shows that sometimes children with light disabilities return to special institutions after unsuccessful integration.

Ališauskas *et al.* (2009, 131) notes that the amendment of the Law on Education (2007) describes special educational support as a constituent part of education means helping to ensure efficient education of persons with special education needs. Special educational support is provided by speech therapists, special educators, typhologists and surdologists.

The educational context also involves psychologists. Lefton and Brannon (2003, 26–27) write that psychologists are specialists that study nearly every aspect of life, not only to understand how people behave but also to help them lead happier, healthier, more productive lives. The World Health Organization defines disability first of all as a psychosocial phenomenon usually meaning restrictions for the family from the society aspect (Vesterdal, 1998, 25). The main importance will be attached to psychologists and special educators as they are mostly related with provision of social support for the family, not only for a child with special needs.

Specialists in psychology are quite wide-spread in Lithuania. These specialists can be found in medical institutions, NGO's, private centres, and special centres. However, the majority of families receive professional support from psychologists in sanatoriums, as children with severe cerebral palsy this service is fully or partly[57] compensated by the state or in their educational institutions.

Psychologists who provide social support for families experiencing disability situations may be split into two groups: those, who work with families before the child enters an educational institution and those that work with families in special educational institutions.

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55 For example, diagnosis can be set for a period of 6 months, 1 year, and then reviewed or diagnosis can be set up to when a child turns 18.

56 *Integration* term is used for this purpose in this thesis.

57 The compensatory for a sanatorium depends on the severity of a child's status and the financial situation, www.litlex.lt.

Legislations on psychologists' social support for families in disability situations were accepted by the Ministry of Education and Science of the Republic of Lithuania in 2004. This omits psychologists within a child's educative context, therefore, some observations are held in this thesis.

By order of the minister of Education and Science[58] psychologists can provide help for special needs children at schools, Pedagogical psychological services, special pedagogical and psychological centers, kindergartens, specialist schools (like sport school or art school), and professional schools. The main aim of such psychological consultation – to help children recover their spiritual harmony, capabilities to live and study. Therefore, to achieve their main goal, psychologists detect child's problems and provide help in order to solve them and strengthen parents' and educators' capabilities to communicate with special needs children. It is also said that psychologists may help as single specialists in collaboration with other specialists representing other institutions.

The majority of legislation describes the psychologist's functions as gathering information on a child which may be called psychodiagnostic and collaboration with other psychologists. In such regulation a question of collaboration with other professionals is left open. Another point is that there are no regulations for social support after a child leaves school.

By order of the minister of Education and Science[59] the main aim of help provision is to improve a child's education processes in a family. Therefore, psychologists work in order to help parents effectively educate their child. Help may be provided as institutionalization (for children from one to six years), as pedagogical consultations to widen parents' competencies, as psychological evaluation (for a child up to five/six years), as collaboration with parents together with their consultations, as special pedagogical help (for child from birth till five/six years and parents as educating programme), and as social pedagogical help for parents. This help according to parents' written request may be provided from two governmental institutions: The Pedagogical Psychological Office and The Early Correction Centre[60]. Intensity for consultations and provision of help depends on the decision of the local administration.

58 Valstybės žinios, 2004–06–10, Nr. 92–3384.

59 Valstybės žinios, 2003, Nr. 116–5290.

60 Early intervention services are provided for families raising children with disabilities up to three years in Lithuania. Early intervention is based on multi-

Ališauskienė's (2007, 24) research into early intervention services in Lithuania revealed that parents are scarcely satisfied with the support to parents and factors of social environment: including other family members and relatives, as well as educational and social institutions in the work of the early intervention services, psychosocial support to siblings and other family members, relationships with professionals, organizing parents' groups, and information about financial support.

Later research by Ališauskienė and Čegytė (2008, 89) showed that the problems of professionals working in the early intervention services lies in the content of preparation. Professionals are too much orientated towards specified knowledge directly related to their profession and too little of specialized competences, related to social support in dealing with families and other professionals.

Another branch, that is very important for constructing social support in the educational sphere in practice – educators and special educators. Historically educators have taught in separate, isolated classrooms that afford little opportunity for collaboration. This model has changed nowadays. At least parents in Lithuania have the right to choose what kind of institution a child with a disability attends. For some of the families finding an educational institution may be a serious challenge, as some remote regions lack professionals or institutions. Fleming and Monda-Amaya (2001, 158) write that in comparison to the historical disability approach totally new forms of collaboration have been developed and integrated into schools, including one-to-one consultation between general and special educators, small teams of teachers working together, and co-teaching.

There are two kinds of institutions for children with severe disabilities in Lithuania: state and private. In comparison of price paid for one and another institution, usually parents choose the governmental sector, as the difference can be even eight times less[61]. Educators in both sectors usually spend up to eight hours a day with a child; though there are state institutions with day and night care provision. The situation of

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disciplinary, inter-disciplinary and trans-disciplinary collaboration as early childhood intervention is provided by the team of educators, psychologists, social workers and medics (Ališauskienė, 2005, 19).

61 Aproximate average comparison. The majority of governmental schools are free of charge.

such institutions is more similar to the situation in the Soviet period, as families that live in countryside cannot find a proper school for a severely disabled child and it is easier to bring the child to a school about 100 km away on Monday from home and leave it for whole week.

By order of the Minister of Education and Science[62] the special educator provides special educational help to children with special needs. The special educator carries out the following functions: makes pedagogical evaluations of a child with special needs, collaborates with other educators, parents, other specialists, specialists of pedagogical psychological office, creates individual and group development programs, helps the child to understand educational content, advises educators how to adapt educational material for special needs children, draws methodological help to educators, parents and other people related with the education process, enlightens the school community about special needs, and forms its positive attitudes towards children with special needs.

Stuart *et al.* (2006, 48) presents the idea that educators are directly responsible for a child with disability achievements, development, integration, and inclusion into children's society. Educators are responsible for building a strong home-school partnership with families because parents understand their children in ways teachers cannot. Similar understanding was fully implemented in Lithuanian schools for *normal* children till Lithuania regained independency. After 1990 this system collapsed as a *bad Soviet example*, therefore parents are now responsible for meeting educators and raising social support for themselves. It is not surprising at all if in practice parents see the educator once a year, if a child is taken from school only at weekends.

Educators have to recognize a child's individuality and use more responsive strategies to help *different* children (Zaffran, 2007, 29). Castaneto and Willemsen state (2006, 310) that educators' representations towards the disabled are directly connected with involvement in schools for disabled children.

And changing negative societal attitudes toward individuals with disabilities should be one of the goals (Gindis, 1999, 335). The situation is revealed by recent Ruškus and Mažeikis's (2007, 84) research, educational institutions are far away from the formation of positive attitudes towards disability. Ruškus's (cited in Ruškus and Mažeikis, 2007, 43) research

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62 Valstybės žinios, 2006–01–14, Nr. 5–171.

in 2000 showed that the majority of educators are very sceptical about the idea of practical implementation of social integration. The very similar research presented by Miltenienė (ibid, 43) in 2005 revealed even more problems. Educators tend to remain authoritarian rather than cooperative in relationships with parents and children, or even tend to form competitive relationships with other specialists in educational institutions (speech therapists, psychologists).

The research of Baranauskienė *et al.* (2008, 155) showed that there is a connection between competencies of educators and their representations towards inclusive education. When educators experience satisfaction with work and the competence is high, educators tend to accentuate the fortes of the disabled.

The qualitative analysis of Giedraitienė and Kreivinienė (2007, 48–49) showed that in comparison to the social and medical spheres, the educational institutions take the most important role in a family's social supporting schema. Educators and special educators play the most important role because of the constructed emotional context in relationships.

This last mentioned research creates a hope for the suggestion of Nelson *et al.* (2004, 162) that nowadays or in near future educators and families will appropriately engage on the one hand, in an equal partnership to meet the needs of the child, and, on the other hand, they may be in a relationship where the educator provides support for intensive emotional challenges the family is facing, such as severe disability or terminal disability of a child. Private schools for severely disabled children are working more on this model than those of the state, because of broader financial resources. Usually in a private school parents have more possibilities to meet all teaching and non-teaching staff, discuss working methods, nutrition specialties and other individual needs.

Augienė and Ruškuvienė (2005) write that in comparison to the situation before Lithuania regained independence, special education has experienced radical changes. They (ibid, 58) mention one of the main change in the educational context – establishing new institutions orientated towards the educational needs of children with severe disabilities.

The research of Ališauskas *et al.* (2009, 142) shows that special educational support is the most effective in the activities of identification,

assessment, and direct support of the child. The same research (ibid, 142) reveals that families feel too little involved in the solution making and social relationship processes. Notwithstanding the favourable legal context, parents still feel estranged and without any rights in the system of education, providing support for their child: often teachers are not willing to listen to the problems important for the family; while parents going to attend parents' and teachers' meetings accept the role of a passive listener in advance.

In summary, the educational system of external resource varies in diversity of opinion with inclusive education signs. Factors related to social support as a united system are still lacking and need to be improved in the future. The positive sign of changing paradigms is that disability being associated with education in secondary schools without segregation.

3.3 The Social System as Social Support

Social system as a possible social support branch will be viewed from both positions – social work and social education, because those two professions have very much in common.

Leliūgienė *et al.* (2006, 64) writes that the beginning of the social work/social education professions developed in a context of social reforms, under the infrastructure of social service and a base of legislation formation. After many discussions, in Lithuania both professions are held integral and complementing each other. Later regulation of both professions allowed the conformation of their management.

Despite the fact that the social work profession does not have along historical approach, few formation stages can be accentuated. Leliūgienė *et al.* (2006, 64) writes that during the period of 1990–1991 the term *social work* was accepted, also the need for social work because of restructuralizations emerged. Bagdonas (2001, cited in Makštutytė and Naujanienė, 2008) dates the beginning of qualifying of social work professionals in Lithuania as 1991–1992. The period 1992–2002 Leliūgienė *et al.* (2006, 64) calls the professionalization of as social work as a profession. During these years the social work profession was introduced into almost all universities and colleges of Lithuania, social work programs were formulated, also the

legislation base was under change, strengthening the social services arena. The period from 2002 and lasting up till now Leliūgienė (ibid, 64) calls strengthening social work as a professional sector. These years are important in developing social work research and social work practice, speaking of quality of social work.

Leliūgienė *et al.* (2006) notes that from the first years of teaching the profession of social worker/social educator many discussions arose because of the distinction between these two branches. The first legal attempt to solve this question was both professions being incorporated in the Classificator of Lithuanian professions (1999). Later, in 2001, both professions were ratified into two different branches of science: social work as belonging to social sciences, social educator – to educology sciences. Such a formal distinction of both professions still leaves open doors for obtaining additional qualification. In the legislation regulating both professions are determined the simple possibilities to move from one profession to another.

Families, raising a child with disability know better the *social educator*[63] than the *social worker*. The difference is very tiny in those two definitions. By order of the Minister of Education and Science of the Republic of Lithuania[64] the main functions of social educators are: to help children to adapt in society, community, educational institutions or other social institutions.

The social educator works together with educators, main class teachers, other specialists, parents, and the community. The social educator follows ethical and value norms: respect, openness, tolerance, uniqueness, non-judging, empathy, acceptance, confidentiality, trustworthiness. The social educator works individually[65], makes evaluations, helps to tackle problems[66], and works in preventive programmes. Also they help parents

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63 The *social educator* due to regulation is a person who has professional qualifications of a social educator and gained it in college or university or a person who has professional qualifications of a social worker or in social work and has additionally gained professional qualifications of a social educator or in educology, also a person who has professional qualifications of educology and has studied social educology with not less than 64 credits (Valstybės žinios, 2001, Nr. 8–235).

64 Valstybės žinios, 2001, Nr. 8–235.

65 For example with person – child, parents, educators, other specialists.

66 That are essential for children's individually, like meeting a child's needs, safety guarantee or other similar.

to educate their child, understand the child's social and psychological needs, and inform parents about the possibility to obtain social and pedagogical help.

Additionally the social educator collaborates with main class teachers, other educators, specialists and administration in dealing with socio-pedagogical problems and seeking as effective problem solving as possible. The social educator is always in contact with the local community, various institutions, together with partners (from other institutions), and informs and educates society. This specialist is responsible for initiating and implementing various projects, looking for and seeking resources for families raising children with special needs. The social educator advocates for the child's rights when needed and visits children at home if the main class teacher cannot. Observing each child's safety and wealth social educator implements the following functions:

- Evaluation (gathers information, makes analysis, draws conclusions).
- Consultation (advises, helps, consults).
- Correction (empowers, helps to adapt, mobilizes, makes more active, stimulates).
- Managing (organizes, plans, makes decisions, concentrates).
- Education (informs, explains).
- Coordination (initiates contacts, sends/receives information).
- Legal (predicts negative phenomenon/behaviours and helps to avoid them).
- Social education.

The main aspect of this order is that the social educator is responsible for mobilization of professional groups for solving social problems, and responsible for the collaborative environment. Therefore, this law clearly shows that the social educator is directly responsible for multi-professional group formation at school or even in wider contexts.

The term *social worker* is wider than its general understanding. A social worker may act not only in educational institutions, but also help families in dealing with external resources in the social support content.

Prakapas (2007, 15) writes that legislation regulating social work is very broad – from the Constitution of the Republic of Lithuania to the code of ethics of the social worker. Bagdonas (2001, ibid, 15) notes that even during an economical crisis there were seen no obstacles in

developing a contemporary social support mechanism via social services which institutes the social work basis. Analysis of the social system as social support mainly focuses on the legislations passed by the Ministry of Social Security and Labour of the Republic of Lithuania. These legislations cover social worker functions and the benefits for families raising a child with severe disability.

Due to the Ministry of Social Security and Labour of the Republic of Lithuania[67] social work in Lithuania is mainly provided through social services. The older act of social services' term specified for Lithuania's context was unclear. An early act of Ministry of Social Security and Labour[68] said that

> *The essence of social service is described differently by various authors; therefore, one social service term does not exist.*

Such an act by a minister gave social workers the possibility to make their own interpretations. Though further specification in this act defined the mentioned term more broadly. The main aim of such help is to assist a person or family that has lost abilities to take care of life or participate in everyday life, because of age or disability of social problems. The social worker's aim in this process is to help a person or family solve social problems, empower them and raising their responsibility based on family-society collaboration.

Later acts, of the Minister of Social Security and Labour (not valid now, also) in 2003[69], in 2005[70] defined social services and created categories as *special social services*, *institution social services*, *communal social services*. The newest act (valid now) of the Ministry of Social Security and Labour (2006, Nr.A1–93) splits social services into *general social services* and *special social services*. This act clearly defines who can use these services, where and what are *general* and *special* social services.

As my thesis concentrates only on families, raising children with severe disabilities (up to grown-up), I will therefore overview what help can be provided for such families. Families, raising children with severe disability

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67 www.socmin.lt

68 Valstybės žinios, 2000–08–02, Nr. 65–1968.

69 Valstybės žinios, 2003–05–07, Nr. 43–1989.

70 Valstybės žinios, 2005–02–01, Nr. 15–481; Valstybės žinios, 2005–03–24, Nr. 38–1252.

have rights to the **general social services**: information[71], consultation[72], mediation[73], supply of clothes and shoes[74], transportation[75], sociocultural service[76], personal hygiene and care service[77], as well as others. Families, raising children with severe disability have rights to the **special social services**: help at home[78], forming social skills[79], critical crisis overcoming[80]. The edit of the analysed act in 2008 (Valstybės žinios, 2008, Nr. 2–72) complements service with the term *care service*. Families, raising children with severe disability have rights to the ***social care services***: social care during a day[81], short-term social care[82], and long-term *social care*[83].

Research by Bitinas *et al.* (2010, 64) on the quality of social services in Lithuania revealed that service users are not involved in the process of service planning, also social workers face shortages of finances, service space, and service transport. As well as this social workers face a huge workload, therefore there is a lack of people working with risk group people.

71 Various institutions, like social services, at home, schools, hospitals, etc.; frequency – one-off.

72 Various institutions, like social services, at home, schools, hospitals, etc.; frequency – till resolution.

73 Various institutions, like social services, at home, schools, hospitals, etc.; frequency – till resolution.

74 Social service institutions, frequency – on demand.

75 Social service institutions, frequency – on demand.

76 Social service centres, frequency – on demand.

77 Social service institutions, frequency – on demand.

78 Provided in family's home, frequency – up to 10 hours per week; consists of not more than 3 general specified social service content.

79 Social service centers, family's home, frequency – on demand; consists of not more than 3 general specified social service content.

80 Provided for children with disabilities on demand in social service institutions or by mobile crisis team locally.

81 Children with disabilities, in social care centres/at home, frequency – from 3 hours a day, up to 5 days a week in institution; 2-8 hours per day, up to 7 times a week at home.

82 Can be defined as *breathing-space* service; provided in social care institutions for children with disabilities, not less 8 hours per day, up to 1 month at home; not less 12 hours per day, up to 6 months per year or up to 5 days a week without term in institution.

83 Provided in social care institutions for children with disabilities, frequency – all the time till the age of 21, or 29 years as youth-care.

The act of the Minister of Social Security and Labour of the Republic of Lithuania (Valstybės žinios, 2006–07–20, Nr. 79–3123) writes that a social worker working with a family in a risk situation[84] has to collaborate with various specialists: educators, other social workers and educators, specialists from social service offices. In this situation, the social worker has to be prepared to effectuate the following functions: make analysis of a family in social risk, prevent social risk situations, define the need of social services, plan and implement social care, measure the effectiveness of social care, frame a team of working specialists: educators, social educators, psychologists, also gather information, write conclusions. Acts of the Ministry of Social Security and Labour of the Republic of Lithuania[85] mainly discuss the qualifications of social workers, their education, and liberties. All of them broadly define the social worker's help possibilities.

Social workers as social support providers are specialists who administrate governmental programs and apply them for families (Holosko and Leslie, 2001, 204). The newest act of the Ministry of Social Security and Labour[86] on social work in Lithuania regulations that a family raising a child with a disability is one of the social worker's clients. The social worker has to be ready to implement the following functions: plan social service, evaluate effectiveness of social work, and define the needs of social help[87]. When implementing functions, the social worker has to be aware of the methods of working with a family, collaborating

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84 *Family in risk situation* can be family raising a child with disability. However, the act of the Ministry of Social Security and Labour (2006, Nr. A1–212) generally describes that *risk* families are those who do not take care of their children, when parents have alcohol dependence, governmental aid (financial) is spent not for children's purposes, when parents do not take care of children's education, leave them in institutions, ignore orders of doctors, commits acts of violence against children. Therefore, the concept used by Leliūgienė (2003, cited in Guščinskienė and Kondrotaitė, 2006, 17) that a family in a risk situation is a family for which social functioning is disturbed by subjective or objective causes is seen as more beneficial.

85 Valstybės žinios, 2006–08–05, Nr. 86–3375, Valstybės žinios, 2006–08–26, Nr. 91-3586.

86 Valid from 2006–07–01; Valstybės žinios, 2006–04–20, Nr. 43–1569.

87 It includes gathering information, activating social network, collaborating with family, empowering, seeking resources in complex – involving social, medical, educational institutions; mediating for the family and other institutions, massing other specialists for the evaluation of the family's needs.

methods with other institutions, and specialists. One of the main things in the analysed act is the overviewing of the social worker's capabilities.

Due to the mentioned law, the social worker has to know how to work with a family, also how to mass external resources for dealing with the family's social problems, activate society to provide help for such families, consult and mediate for the family in external resources. Also the social worker has to know how to activate contacts in the micro social net, mass other specialists to provide help for the family, coordinate social service providers, educate society, and have other capabilities.

Additionally, the social worker has to assess the family's achievements and results, initiate and overview the need for social services, mass other specialists for evaluating the effectiveness of the help provided. As well as itemize whether mediated help for the family was provided or not, and mediate for another help seeking, still gather information about empowered family and initiate support if needed, disseminate information to governmental institutions and local administrations about circumstances that impact the manifestations of social problems and initiate suggestions about law changes.

Despite the wide legislation base regulating social work functions and social services, some research shows that there are huge problems in social support of families in disability situations. Butkevičienė *et al.* (2006, 124) states that families in disability situations still face many problems in dealing with external resources, and the most actual problem mentioned in many researches by Lithuanian scientists – lack of information, financial support and emotional support.

Makštutytė and Naujanienė's (2008) research revealed that social workers dealing with change patterns of clients note features designated on the diagnostic model. Another research of Ivanauskienė and Varažinskienė (2007, 23) shows that the concept of the social work profession has not been shaped by society: even social work practitioners mix it with other professions and ascribe activities and knowledge of other professions to it. Such results show that social work is a profession under development and only practical history will strengthen social work professionalism.

Providing social support for a family raising child with severe disability must strive for professionalism. Yip, writing (2008, 246) about social work professionalism indicates social workers' reflectivity in their practice.

Ruch (2000) citing Habermas, (1973), Ruch, (2000), and Van Mahen (1977) shares four sections of reflection *technical reflection* as related to technical rationality and knowing. Hatton and Smith (1995, ibid) note that it involves problem solving with behaviours or skills. There are several levels of social workers in Lithuania. Basic level of social workers can lack these mentioned skills but have others, like helping in daily life, communication.

The second section is *practical reflection*. It seeks alternative responses, enhances professional understanding and affords personal insights into professional practice. The third is *critical reflection* (Ruch, 2000). Critical reflection is based on Habermas's (1973, ibid) critical and emancipatory sources of knowledge. It transforms practice by challenging the existing social, political and cultural conditions and structural forces that distort or constrain professional practice. Also it involves ethical and moral critiques and judgment. And finally *process reflection* relies on psychodynamic theory and focuses on the unconscious and conscious aspects of reflection, especially in terms of transference, and counter-transference between the worker and the client. It also involves the development of a reflexive self in interaction with others.

These four mentioned professional reflections allow the social worker to operate effectively on a family's external resources via mediation and deal with various problems. Pincus *et al.* (1979, cited in Payne 2002, 272) notes that social work cannot be understood as working with a family without systemic perspective. The social worker providing social support from external resources is the main professional who initiates action and the activity process orientated towards positive outcomes of the family.

Rullo (2001, 211) writes that despite professional social work having many faces, social workers can implement roles such as clinicians, advocates, case managers, political activists, and mediators. The social worker mediating can create interactions with other professionals having special knowledge and skills to deal with the family's issues (Pearson, 1990, 13).

Summarizing, the social worker has all the skills and reflections guaranteed by law to provide qualified social work for a family raising a child with severe disability. So far social work is weak as a profession

in mediation with other specialists. Practice shows that social workers quite often mass other specialists working in the same institution and do not gather information about the family in a broader social context. The problem arises because of several reasons: other laws[88] narrow social work functions, lack of financial and other resources, time budgets are easily exhaustible, and social work does not hold authority in comparison to other professions.

3.4 Dolphin Assisted Therapy as Social Support

Animals have always been meaningful in people's lives (All and Loving, 1999; Hatch, 2007). Various legends and tales show the significance of various animals for people. The domestication of animals that began 2 000 000 years ago and is proceeding nowadays, as it is meaningful for both collaboration and the impact on each other's social sphere (Šinkariova *et al.*, 2008, 239). Even in ancient Greece it was mentioned that contact with animals helps to improve the emotional and physical condition for people (Macauley, 2006; Nimer and Lundahl, 2007) despite this fact animals have only been used for therapeutic purposes since the end of 18th century (All and Loving, 1999; Heimlich, 2001; Velde *et al.*, 2005; Macauley, 2006).

DAT is a very popular animal assisted therapy for children and adults (Marino, Lilienfeld, 2006; 2007a; 2007b). Probably because of that DAT is a very controversial theme (Acquaviva *et al.*, 2003; Lilienfeld and Arkowitz, 2008). The majority of discussions arise among specialists comparing the DAT programme with the traditional helping net (medical, social and educational systems) in contrast (Humphries, 2003; Marino and Lilienfeld, 1998).

Lilly around the nineteen sixties was the first in the world who hypothesized on communication between humans and dolphins as beneficial to human beings. This theory was referred to as the abilities of dolphins in teaching communication. Later on this basis Smith started various researches (cited in Humphries, 2003).

It is believed that various researches in this new field of animal assisted therapy could exalt therapeutic impacts on the participant's medical, social

88 For example, health care providers are not involved in the collaborative system.

and psychological spheres (Curtis, 2000; Brakes and Williamson, 2007; Kreivinienė and Rugevičius, 2009; Acquaviva *et a*l., 2003; Brensing *et al.*, 2005). Therefore parents tend to try this kind of social support (animal assisted therapy) instead of or in addition to other therapeutic methods. Professor Nathanson of Florida University, doctor of psychology sciences, noticed that children with disabilities react to dolphins more positive than to any other animals. On such a basis he started scientific research (Nathanson, 1980; 1989; 1998; Nathanson *et al.*, 1997; Nathanson and deFaria, 1993). His researches are very broadly published and discussed not only in the USA but also in Europe.

Scientists from the USA (Brensing, Linke *et al.*, 2005; Brensing and Linke 2003; Nathanson, 1998), Ukraine (Lukina; 2005), Germany (Fersen, 2005; Breitenbach *et al.*, 2006), and Israel constantly publish new studies on improvements after receiving DAT. It is stated that after DAT children increase their verbal communication, communicational behaviour, and physical functioning (Kreivinienė, 2005; Kreivinienė & Rugevičius, 2009).

There exist various theories analysing the impact of dolphins on the participant starting from the echolocation effect on the structure of the human cell to sound therapeutic healing (McKinney *et al.*, 2001; Brakes and Williamson, 2007). There are listed three main theories:

- *Reinforcement theory*. The main idea of this theory is that dolphins may be used as motivator/reward for improving attention span. The content of this theory withholds the hypothesis of lack of attention and operant conditioning (Sokolov, 1963, Zeaman & House, 1963; Lewis & Harwitz, 1969, Moskowitz & Lohmann, 1970; Kurtz, 1996; Miller, 1980, Foxx, 1982; Tof, 1998 all cited in Nathanson *et al.*, 1997, Nathanson, 1998; 2007).

- *Theory of the impact on brain waves.* The main idea of this theory is that communication with dolphins may have a positive impact on brain waves (De Bergerac, 1998, Walter & Walter, 1949, De Bergerac, 1998, Robbins, 2002, cited in Brakes, Williamson, 2007 cited in Nathanson, 1989; 1998; Nathanson and deFaria, 1993; Nathanson *et al.*, 1997).

- *Sound impact theory.* The main idea is that dolphins emit high frequency sounds that are outside the human hearing range. Such sound emissions have a positive impact on the neurophysiologic

hormones (Chengwei *et al.*, 2005; Vanderbilt, 2005; Verfuβ, 1996, Au, 1993, Moore and Pawloski, 1990, Foot, 1980, cited in Brensing & Linke, 2003 and Brensing, 2004; Cole, 1995; 1996; Birch, 1995; 1996).

Various Dolphin Assisted Therapy aspects have been analysed by Lithuanian authors: Rugevičius, Kirkutis, Žakaitienė, Šostakienė, Kirkutytė, (2006); Šostakienė, Kirkutytė, Baliūnienė, Kirkutis, Rugevičius, Kreivinienė (2007), Kreivinienė, Rugevičius (2009). The main idea of DAT organized at the Lithuanian Sea Museum[89] is based on the reinforcement theory. Though, it is impossible to speak about reinforcement in cerebral palsy cases, and then the DAT programme has another mission – relaxation, positive emotional experience and support. In severe disability cases, therapy is organized closer to the German tradition of DAT understanding (see Breitenbach *et al.*, 2009) that DAT is seen rather as whole family therapy programme that gives positive emotional experience and improves interaction between family members.

In recent years Kreivinienė and Vaičekauskaitė (2010, 3544) conceptualized DAT as having a strong impact on the positive components on a family's sense of coherence, especially in severe disability cases. Their (ibid, 3548) research showed that changes to the child in behavioural, emotional, and social competencies are significantly influential on the functioning of the whole family system. After participation in DAT positive changes are observed in children in interpersonal communication, behaviour, speech, perception of rituals and other spheres tend to decrease the family's continuous stress and tension. Research results have revealed that qualitative changes of children with diversified development disorders can be reasonably interconnected with the sustaining of family health.

The Lithuanian Sea Museum organized two scientific researches (2003–2006, and 2007–2009) on the DAT programme. Biomedical research (2003) involving scientists from Klaipėda University, and specialists from Klaipėda Seaman's Hospital. The purpose of the mentioned research was to investigate the impact of Dolphin Assisted Therapy on children's suffering from autism disorder, behavioural, cognitive, socio-emotional spheres and the psychoemotional state. The set of research

89 Dolphin Assisted Therapy in the Lithuanian context is directly linked to the Lithuanian Sea Museum. In Lithuania Dolphin Assisted Therapy is only organized in this museum.

subjects consisted of 21 children suffering from autism (F84.0) in both experimental and control groups.

The research team was formed of: rehabilitologist, psychiatrist-psychotherapist, psychologist, social worker, dolphin trainers, electro physiologist, children and parents. Research results showed that children from the experimental group after 10 sessions of DAT exhibited increased functioning of sensory motor, sleep, and self-independency. The best results were shown in decreasing of sensitivity to touching. Changes in cognitive functions during this research were not observed (Šostakienė *et al.*, 2007, 729–733; Rugevičius *et al.*, 2006, 101–103; Kreivinienė & Rugevičius, 2009, 25).

Kreivinienė (2008, 115) writes that dolphin assisted therapy is very popular in Lithuania and neighbouring countries, because of several reasons: positive social attitude (that may be formed by the media, as professor Ruškus, (2002, 18–20) states in constructions of the social attitudes model[90]), and other reasons. These reasons were analysed by Ališauskienė, (2002, 27–24); Ruškus, (2002, 156–162); Gvaldaitė, (2004, 9–10); Mitchell and Sloper, (2002, 74); and Dempsey and Keen, (2008, 43): disappointment in the traditional social net and other related factors such as coping with children with disability, ineffective curing process, lack of information or information that is not given in a proper way, misleading in the labyrinth of the social system, services provided by professionals crucial to the family-centered approach; depression, growing stress, loneliness, alienation, and tiredness.

In other words, the situation described can be labelled as the family's disappointment that was caused by the unhelpful internal and external resources. Such a desperate situation may affect parents' passiveness, which I call *swimming down the river* while waiting Dolphin Assisted

90 Social attitude is seen as psychological to the logical structures of some social objects (DAT) on human beings consciousnesses. From my point of view, extremely positive attitudes towards DAT might have been formed in recent years; just after publishing the data from biomedical research. Each member of our society has archetypical attitudes in their consciousness about dolphins (in old times dolphins were mythologized and attributed to some mystical animals) as a friendly and well-wishing animal. Subjective interpretations are cumulating, emotional evaluations while effects on public opinion about such objects is being formed. Vision of the world is constructed from collective opinions and its emotional, cognitive and symbolic elements impact the way of thinking for some groups (this time socially violated groups – parents raising children with disabilities).

Therapy as an alternative social support provider. Notwithstanding the mentioned negative DAT facts, I see DAT as an effective social support provider for families raising children with severe disabilities. Therefore the link between the traditional helping net and Dolphin Assisted Therapy is very powerful.

The same success leads not only the DAT programme in Lithuania, the same situation exists in a worldwide context. Therefore, attitudes towards DAT are so different: either very positive or negative. It depends on DAT's place in the general traditional net. Nowadays there exist some different research streams that are generating different social attitudes towards Dolphin Assisted Therapy as social support. Those streams can be divided into various groups according to main purpose (business or social support), methodology (treatment or emotional impact), ways of work (swimming, operant conditioning, or both).

All DAT programmes can be partially divided into three main groups based on the model of work:

1st group: Dolphin Human Therapy working as clarifying DAT elements. Professor Nathanson of the USA, in 2007 (181–194) published his first science-based study on reinforcement effectiveness using animatronics and real dolphins. An animatronics dolphin called TAD[91], was designed and built as an alternative reinforce and compared with real dolphins for 35 children with disabilities, representing ten diagnoses, seven countries, and five languages. An ABA[92] design and analysis examined three clinical issues. He did not find significant difference between dolphins and TAD in eliciting orienting responses of touching and/or saying words to children within the ability groupings of moderate or severe levels of disability. For children with profound disabilities, TAD was significantly more effective in eliciting the orienting response of looking. Third, response times to either dolphins or TAD were the same whether reinforcement was given from a platform or in water. Interaction with TAD provided the same or more therapeutic benefits as interaction with dolphins, without environmental, administrative/legal and practical limitations, including the high cost, associated with dolphins.

This programme is meaningful because of social support construction towards whole family. Not only does the child receive help, but the family

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91 Therapeutic Animatronic Dolphin.

92 Applied Behaviour Analysis.

meets various specialists, working as a multi-professional team due to the family-centered helping method, therefore the DHT programme consists not only of the impact of dolphins for a disabled child, but also many other specialists' consultations that can strengthen the family as a whole.

2nd group: Dolphin Assisted Therapy working as treatment with the aid of dolphins. Usually such a programme is met in Turkey and Ukraine: Sebastopol, Eupatorium. The data obtaining from these centers states that dolphins are able to cure various peoples' illnesses and disabilities by disseminating echolocation waves. Usually medical representatives work in all these centres.

The criticism on this stream mostly occurs from USA scientists. Marino and Lilienfeld, (2007a, 239–249) made a meta-analysis of the majority of research material in the DAT sphere (Antonioli, Reveley, 2005; Lukina, 1999; Servais, 1999; Webb, Drummond, 2001). They found that in all research placebo, novelty and effect as amazement factors were not evaluated therefore, studies can be decided as having much methodological lackings, and doubtful conclusions.

It is impossible to disregard the criticisms made by Marino and Lilienfeld. The method that may treat disability sounds scientifically doubtful; however parents in risk situations wish for personal miracles that may reduce constant stress rising from the child's unchanging disability. Each of the parents would like at least to *try* even the most doubtful *treatment* as they wish and need to believe *in case* it helps as an existing possibility.

3rd group: Dolphin Assisted Therapy working as operant conditioning and a tool of alleviating the psychoemotional state of participant and family. Almost all DAT centres are from European Union countries (Lithuania, Germany, Italy, and Spain). The majority of those centres are governmental or half governmental; their primary goal is based on research. The hypothesis of dolphins' abilities to heal by emitting sounds is rejected, all investigations are scientifically proved. Antonioli and Reveley (2005 cited in Marino and Lilienfeld, 2007a, 239–249) research was evaluated as being the *nearest to research validity* as the side effects were strictly controlled.

Therefore, DAT is perceived as having the possibility to become a significant programme for social support for the family because of a few arguments:

- Such help is not an overspending of social support for families, the programme is based on the average family's financial possibilities. Sometimes the costs are less that other forms of help provided by other private specialists.

- The worldwide known critics towards DAT (Marino and Lilienfeld, 2007ab) are focused on the parents' misled and unrealistic expectations. Though using DAT as a stress-buffering model would not generate unrealistic ideas about the possibilities to cure a child. Similar visions are based on the following research, as Stringer (2004) seeing DAT as social support in the context of education, Chengwei *et al.* (2005) describes DAT as useful in severe disability cases, Antonioli and Reveley (2005) highlights the emotional aspects of DAT, Sherwood and Athena, (2005) see DAT support in the social connection and acceptance perspective.

The DAT programme at the Lithuanian Sea Museum was launched in 2001. In the two years after the opening registration there were such a number of list-children that up to the begging of 2008 registering was postponed. Parents from Lithuania, Russia, Poland, Latvia, Ireland, and Belarus hoped to bring their children to DAT (Lietuvos jūrų muziejus, 4–9). The DAT programme at the Lithuanian Sea Museum is not very well explained and suggests family-only service for communicating with dolphins. The programme is quite small and has ambitions to grow in the near future by opening a new facility for the DAT programme and other therapies. Such a facility and the formation of a widened professional team may form superior services as social support for families. The achievement nowadays for this facility would be creation a family centred service facility with wide connections on the external resources and befriending atmosphere.

Dolphin Assisted Therapy in my thesis is seen as a social supporting programme improving the family's social, psychological and physical outcomes in society. Applying stress-buffering understanding DAT can be as a *re-charge* for the whole family exhausted by the negative emotions and dealings in the traditional helping net.

4 Realizing the Study

This chapter focuses on the description of all research stages. The description is starting from the generation of the idea to its practical implementation. Also grounding for my personal position in this research is given. So far there exist different DAT programmes and discussions on the impact on children with disabilities, I note that DAT is not analysed from this point of view in this thesis. The main analysis is based on revealing subjective representations by families on social support in the medical, social, and educational systems where DAT holds window position to the analysed phenomena.

4.1 The Researcher's Position in the Research

The idea of constructing this section is mainly based on my professional interest in revealing an untraditional sphere of research – the representations on social support from external resources in connection with DAT.

As it was discussed in previous chapters, Dolphin Assisted Therapy is a controversial topic not only in Lithuania, but also all around the world. Various scientists (Acquaviva *et al.*, 2003; Lilienfeld and Arkowitz, 2008; Humphries, 2003, Marino and Lilienfeld, 1998; Nathanson, 1980; 1989; 1998; Nathanson and deFaria, 1993; Nathanson *et al.*, 1997) for the last few decades have been discussing the main issue concerning DAT – whether it is a method for helping disabled children or not, can it be called a *miraculous* helping method for those, whom other external resources – medical, social and educational systems are powerless to help. And the main question what is DAT – science or fiction?

From my personal point of view, those questions cannot be answered so easily and unambiguously. It is because of many factors, like professional methodic and backgrounding discourse used, the financial aspect (as it is a high cost therapy), the ethical question of animal rights, and the most important thing – professional certification[93].

93 At the momement there are no international and in some countries national certifications for animal therapy programmes. I think there has to be raised at least national norms for professionals working in such a sensitive sphere as disability. It is

The position of the Lithuanian Sea Museum as a governmental institution has always been to put research first over financial aspects. Therefore, in eight years two major researches have been made and one is newly founded in collaboration with scientists of Klaipėda University. The same is true of social support programmes which are always run on the museum's financial resources[94].

Summing up so many appraised questions it is important to mention that this thesis is not intended to measure any changes in the participants before and after using Dolphin Assisted Therapy. Likewise my aim is not to show that Dolphin Assisted Therapy can be a substitute for other external resources.

The research was based on revealing the representations of social support from external resources by families raising children with severe disabilities. Dolphin Assisted Therapy is seen as an additional social support branch to which families represent social support. Research focuses on representations that families make about being faced with different professionals in search of social support during their stressful periods of life.

Neither miraculous treatment ideas, nor unrealistic pre-understandings about DAT are held here. And the questions about the changes in the participants are for the other scientific branches to answer, not social.

Notwithstanding all discussed issues, I must acknowledge the unique opportunity to make my research in the Lithuanian Sea Museum. The ideas about similar investigations had been cumulated constantly during my practical work as an educator over several years. Meeting more than 300 families of DAT participants I experienced some practical problems and barriers faced by parents in practice if they needed to access the resources of social support. Some of the participants could be designated as socially, medically and educationally desolated children. And this statement should not be taken as my intention to label or somehow humiliate other people.

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important for the creation of service quality in order to use animal-assisted therapy as a social support element.

94 For example, the last social programme was for children who had experienced abuse. Together with the Organization of Children Rights this programme was launched in 2009, and the most vulnerable families come for DAT free of charge and many private organizations also were involved in this project.

This research was launched because of the excitement of my personal and professional social work values. The topic of research is very sensitive; families were revealing their biggest issues and stressful situations that were related to life, distress, comedowns. Sometimes during the interview I faced discomfort in hearing representations on social support. Wong and Heriot (2008) describe such a situation as learning through discomfort. If we treat the discomfort as an open possibility to learn and develop then it will be possible to tame that discomfort. Therefore, Wong and Heriot (2008) suggest to approach the discomfort as a starting point for change in researcher himself.

Another point that was revealed during the interviews – what my research would change. Almost all families during valedictory meetings said they hoped my research would change something. Taking the role of voice giver to the families, I took the ethical responsibility of representing the perceptions of social support they valued and social support they could not reach. Interviews revealed a subjective point of view of the content of social support. Families were speaking not only about emotional concern, information, instrumental aid, and appraisal they faced and attributed subjective ideas for professionals they had met, but also they were speaking of feelings facing such ideas of professionals in social support.

Social support in the medical, social and educational systems still remains a problem. The DAT position in research revealed the most vulnerable parts of social support practice, as well as social work weak position in mediating. Therefore, the voices of families must be heard regardless as children with disability have the right to a sterling life in our society with due dignity.

The same can be said about their families. My practical work showed that there are some gaps in understanding between the parents (as consumers[95]), and specialists (representatives of social support). Therefore, such a situation creates the idea of searching for social support from alternative resources. Dolphin Assisted Therapy is one of the strongest alternative therapy branches in Lithuania, theoretically we could consider

95 Term used by Lindsay and Dockrell (2004) it is important here for showing that parents should have more power in service using, despite the fact that they use governmental sector services. But *consumer* is more than *service user*, as *consumer* contains the point of view of parents towards the quality of interaction with professionals.

that we have about 16 thousand disabled children and each month we receive new calls from 2% of parents with requests to put their children in the list.

My position as researcher is to see the problems and opportunities of the medical, social, and educational systems in order to provide social support for families raising children with severe disability. And I call Dolphin Assisted Therapy a *miraculous window* for the researcher to investigate families' representations on social support in the medical, social and educational systems.

4.2 Research Participants and Ethical Dilemma

This section has been constructed in order to describe the research participants and view my personal ethical dilemma on choosing research participants.

Adhering to the principle of confidentiality, any information that might identify a specific person or institution has been changed or removed. Table 1 holds all important material about the families who participated in this research; some facts are removed in order to preserve the confidentiality.

Table 1.   Information about research participants.

Case No.	City	Family members	Age	Diagnosis description[1]	Interview conducted[2]
001	Biržai	4	9	Severe cerebral palsy, displegia, situation after legs-lengthening operation, developmental disorder, blindness, ecopresis, enuresis.	2007/10/13 2007/10/16
002	Elektrėnai	4	9	Severe cerebral palsy, discynetic paralysis, respiratory infections.	2007/10/13
003	Klaipėda	5	7	Severe cerebral palsy, spastic tetraplegia, generalized asymptotical epilepsy.	2007/10/27 2007/11/05
004	Palanga	4	7	Severe cerebral palsy, symptomical epilepsy.	2007/10/27
005	Kaunas	5	6	Severe cerebral palsy.	2007/11/12
006	Mažeikiai	4	12	Severe cerebral palsy, spastic displegia, deafness.	2007/11/12
007	Vilkaviškis	4	4	Developmental disorder, child is not walking, tone of muscles high and low, strabismus, farsightedness, hearing difficulties.	2007/11/26 2007/12/03 2008/02/10
008	Plungė	4	14	Severe cerebral palsy after meningoencephalytus, child is suffering from severe involuntary movements, when he wants to do something and cannot, cannot talk or chew.	2007/11/26 2007/12/06 2008/07/20
009	Kupiškis	4	7	Severe cerebral palsy	2007/12/08
010	Telšiai	5	4	Severe cerebral palsy, spastic tetra paresis, symptomic epilepsy.	2007/12/09

[1] The translation is made from the papers parents presented in the first meeting, content is not changed.
[2] The first date shows planned interview with parents that was held in the Lithuanian Sea Museum. The following dates show when additional information was gathered in eye-to-eye contact or by phone.

Table 1 represents all essential information for selecting families for interview. The information shows the family code to maintain the family's confidentiality, the city where the family came from, the number of members in the family, age of the child with severe disability, medical description of the diagnosis, and time when the interview was conducted.

In the starting stages of construction of my research I was faced with an ethical dilemma related to the description of interview participants. Table 1 reveals some social factors and the main information from medical descriptions of the child with severe disability. This information can be called diagnostical, emphasizing impairments. Therefore, from the first glance, it may seem contradictory to Vygosky's proposal (cited in Yanbin, 2009, 102) that:

> *We should adopt positive classifying methods to assess disabled children, and to measure disabled children from the perspective of strengthening is more appropriate than merely from the perspective of disability.*

The research was shaped in a way that comprised four spheres of analysis: medical, social, educational, and DAT. The representations of social support by families in the medical, social, and educational systems were shaped to reveal their past experiences of *par excellence* experienced and re-told again during the interview giving the subjective sense of attribution ideas, generalization and emotion. Those families had never tried Dolphin Assisted Therapy at the Lithuanian Sea Museum, therefore, they did not have *a priori* experience to form their representations on social support in this system. The families were asked to represent social support in this system as a projection to the future. In such a way the interviews conducted were joining the construction of reality with the history of logic as if the families were *looking through* the DAT window that gives a projection of the future while at the same time recalling their representations of social support in a particular historical family life period of the past.

Therefore, for developing the question of solving the ethical dilemma I have to ground my choice of this untraditional research design:

1. Dolphin Assisted Therapy was launched in 2001 as a programme for disabled children without movement problems. About 50 children each year could participate in the DAT programme at the Lithuanian Sea Museum. Each child coming to the DAT programme was gathered from the list in numeral order. The list of possible participants was compiled from phone calls or letters. From 2001 parents could register their children on the DAT list only two times. Registering periods lasted only for one month, because of the huge number of applicants. Till 2007 none of the children on the list having cerebral

palsy being were accepted to participate in DAT because of diagnostic limitations. This decision was considered reasonable for their special requirements in the unfriendly environment. Despite this fact the mentioned children were still included in the list of possible participants, hoping for environmental changes. In such a way the list made in 2001 contained many families that had been included about six years previously.

2. As researcher and worker of the DAT team, I had some constructed pre-understandings about the families raising children with severe disability. My idea was to investigate the representations of social support by families that had had the widest experience of interactions with medics, educators, and social workers. This idea was based on the physical condition of the child, as the vastest contacts with external resources are made when children suffer from various problems and parents have to deal with many different specialists even at the same time.

3. Interview themes were constructed revealing the disposition of external resource: DAT took a window place revealing the view towards the medical, social and educational systems. Such a disposition had a special goal – to investigate not all families' representations of social support, but only for a particular historical period. All families were on the waiting list for the DAT programme for three-six years. It was a beneficial situation for me as a researcher. I investigated the representations of social support from the day of registering for DAT till the family's coming in for research. In this way, I sharply decided for myself which historical aspects of social support are important. In other words, entering sensitive research, the researcher must be sure of all research aspects, therefore the *zone of intimacy* should not be encroached unnecessarily. When the researcher enters this zone because of too little experience or curiosity and picks *grey* material not useful for research, it can be called *entering other soul with rubbers*. Therefore, my strict determination of the family's historical context helped to open the DAT window and see why families register children, what was the situation in other external resources, what expectancies were held and how everything changed at their time of actual arrival to DAT. It was also important if families still after so many years expected to receive social support from DAT, so what was its content and how was it related to other external resources.

4. The last point explaining the medical aspect in my research is the DAT programme. For participating in the research families were invited for two weeks in the Dolphin Assisted Therapy programme free of charge. As the medical situation of the children was serious, a common sense medical aspect must be applied. Some of the families were not invited to participate in the research and this decision was based on medical arguments.

After broader explanations of condition used to choose the medical aspect as one of the main factors for research, I will ground its position in the social constructivism approach.

Oliver (cited in Viluckienė, 2008, 47) in 1983 shaping the understanding of academic disability on the interpretative paradigm criticized the biomedical model. Watson (ibid, 47) described the idea that it is not impairments that are making people disabled, but the social system creating barriers for social participation. Such an understanding eliminates the biological factors substituting them with social factors. Viluckienė (2008, 48) notes that in such a way disability is analysed as a construct of the social system and impairment is left aside as an individual body feature of no account. Williams (1999, cited in Viluckienė, 2008, 49) criticizing the social model because of its main focus on disability and impairment distinction calls such an understanding embodied.

Kruse (2003, 498) cites Butler and Bowlby (1997, 413) that:

> *Acknowledging the role of embodied experience that impairment plays in the lives of disabled people does not necessarily mean the need to return to models based on the view that disability is caused by individual impairment.*

That means defining some biological aspects in the research was in order to give voice to the families about social support and does not mean that I base my study on a diagnostic approach. It is rather an act of not being *somathophobic*[96]. Research does not neglect biological factors of a child and sees social support as the possibility for sterling functioning of family in society. The stress-buffering model of social support is seen as allowing the handling of a family with particular problems during its lifetime and increases the positive social, physical and psychological consequences.

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96 Williams (1999, cited in Viluckienė, 2008) writes that representatives of the social model seem to be obsessed with a strange fear that Spellman named somatophobia, that is to say a strival to discard everything related to body or biological origin.

Therefore, in solving this ethical dilemma I explain putting biological facts of a child as a situated construct.

Qualitative interviews with ten families raising children with severe disabilities[97] were conducted.

These families were chosen from a list formed in 2001 (and complemented in 2004) at the Lithuanian Sea Museum during the registration to DAT. The list was made in the form of electronic data, the number of possible participants was about 160 families that hadn't received DAT. The criteria of sample:

- Family is raising a child with severe disability.
- Age of child from 4–15 years.
- Being registered on the DAT list from three to six years.
- Candidates to be first time to the DAT programme at the Lithuanian Sea Museum, but it could be tried in other countries.
- Full family[98]: mother, father at least two children. One child suffering from various disabilities, the second and following children being healthy.
- Child with disabilities attends an educational institution.
- Child is not suffering from epilepsy.

Stages of selection interviewers:

- Pre-stage of research. In this stage I generated ideas about possible research. I had clear view that representations of social support from external resources will be investigated within the DAT window perspective. Therefore, I had the primary idea that a family should suit the following criteria: the child should attend school and both parents should be in the family. Therefore, I carefully looked through the list of possible research participants searching for the affirmation that the research was possible. The problem was that list contained different information to what I had expected, descriptions were focused on medical diagnosis only. A bare few children held information on social factors. Facing this issue, I had to clarify biological factors

97 Families were gathered from those who raise children with cerebral palsy as a general diagnosis (spasmodic cerebral palsy (G80.0), discynesic cerebral palsy (G80.3), ataxic cerebral palsy (G80.4), cerebral palsy of infants, indeterminate (G80.9). Children with complex disability were taken as priority over other possible participants. Unfortunately restrictions for participation were aphasia with epilepsy (F80.3), and epilepsy syndrome (G40).

98 I formed a personal approach of *full family* in research in order to have as much homogenous a group as possible.

first before collecting secondary information. Therefore, reviewing the list I saw that families raising children with severe disabilities were the ones that waited the longest period of time in DAT. Also a complicated diagnosis of the child predicted that families would have contacts with various external resource branches. Ascertaining that there were about 50 families raising children with severe disability who could fit by diagnostical description for research I presented the research idea to the head of the Lithuanian Sea Museum. After this, I was given permission to launch the research.

- Preparation stage of research. This stage lasted for about two months while the facilities needed were obtained and until the DAT team was prepared for work with children suffering from severe disability.

- Primary selection stage. Primary selection was made on the holding data (general descriptions of a child's state). In this stage I had telephone conversations with 50 families on the research and additional information was gathered. The additional needed information was the following: if the family still wants to participate in the DAT programme, if the family has one or more children, if the child with disability attends school, if the child is not suffering from epilepsy. If all the criteria during the interview were matching the criteria of sample, other information was gathered concerning suitable time tables for families, as the whole family needed to be invited to participate in the research. Also agreement for participation in the research was discussed.

- Secondary selection stage. From the additional information 13 suitable families were gathered for research. Priority was given to the families that had waited on the list the longest period and for families having a child with more signs of severe disability. Three other families were held in reserve. In the research process one family decided to quit the research as their child was suffering from a severe form of epilepsy[99]. Therefore this family was substituted for by another. In this selection stage 10 families were selected to participate in the research, each family had to fill in official documents required by the Lithuanian Sea Museum, also sign a juridical agreement on the

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[99] Parents gave misleading information about the child's epilepsy during a telephone conversation in order to get into the research and when the juridical documents were sent, parents said that they did not suit the requirements.

participation in research[100]. It was very meaningful for both sides. As the research was made before the Dolphin Assisted Therapy sessions, the agreement therefore contained not only research data, but also information about future sessions with dolphins.

- Finalizing. At this stage I created a research list of the families that were participating in the research with all information I had about them and prepared an interview calendar. I met each of the families every two weeks.

One of the main aspects in the agreement was the principle of honesty from both sides (participant and researcher). As I raised the very heavy question for myself – to gather 10 families raising severely disabled children, I had to get as much honest information about the child's status as possible. I could not put any child at risk by letting him participate in sessions while suffering epilepsy, wounds, stomas or any other serious health restrictions. Under such circumstances the therapy could be inappropriate with children's life situations. Therefore, one family that was mentioned before who lied about the child's epilepsy, though obtaining the research material (agreement) they decided to decline their participation.

Summarizing, this research had to be strongly built not only on the scientific basis, but also on juridical and ethical bases, as the children were suffering from severe health problems. The undisclosed or withheld information could cause serious health problems or even death. The same can be said about my personal position and system of values. The topic of research is very sensitive. Therefore I had to clarify many aspects for myself as well as each question having to have coherence with the analysed phenomena. Otherwise the research could be intruding upon the family because of inexperience or curiosity.

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100 For the participants the special agreement form was prepared to clarify the position of researcher, participant (family) and the Lithuanian Sea Museum. The agreement noted the many responsibilities of the researcher and the Lithuanian Sea Museum for each family's safety. For example, it was noted that each family was participating of their own free will and they could withdraw from research at any stage, that Lithuanian Sea Museum undertakes to conduct the DAT sessions, and other concrete obligations.

4.3 Construction of Interview Questions

The majority of ideas for the research questions were raised during my practical work in DAT. During practical observations I noticed that quite often parents come to the DAT programme with negative experience of medical, social and educational institutions. Families usually lack social support and have limited understanding about the possibilities of receiving helping from external resources.

Observations showed that families' situation can be defined as vulnerable especially if the child has severe disability, like cerebral palsy, mental disorder, vision impairment, hearing problems, and other leading problems. Families were coming into DAT with some sense of cumulative consumptive visits to various specialists, and felt their low fructification deepened worries and stress.

Sometimes I had to face a family's preparation to be defensive of somebody, as if I was like *just another specialist*. After having many years of practical experience I shaped the ideas of research that were complemented by studying legislations.

The final research questions were based on the Law of Social Integration of Disabled People (2005) and further practical observations. The mentioned law is the main document for constructing social support in Lithuania. Therefore, all other documents are just fulfilling this main law. This document clarifies social, medical and educational support for families raising children with various disabilities. Also the main principles that assure diverse understanding of disability are mentioned: equal rights, equal possibilities, prevention of discrimination, versatile participation, self-sufficiency and security of freedom, accessibility to resources, compensation for disability, decentralization, destigmatization, transition and flexibility of institutional work, and meeting different needs.

The logic of constructing a whole dissertation was due to inductive reasoning. Burns (2009, 27) notes that inductive reasoning can be explained as in the common conception of science, scientists observe the physical world, notice regularities, and derive scientific laws from these regularities.

The fifth article of the Law of Social Integration of Disabled People (2005) describes the social integration system as: provision of medical, professional and social rehabilitation service, also meeting special needs

with forms of special help, supporting occupation for the disabled, pensions and benefits, education and equal rights in social participation. By no means are any alternative therapies or methods not discussed in the law.

When I constructed my research themes, for me it was most important to take into account those articles of the mentioned law that concerned only matters of families raising children with severe disabilities. Therefore, professional rehabilitation and social participation as an act of own volition was taken out of the analysis.

Due to the law, I made a framework in which social support would be extended as research analysis: medical, social and educational. It was decided at the very beginning of the research that Dolphin Assisted Therapy would take a window place in the system of research.

When the spheres were determined, I had another challenge – to construct a social support concept. As it is based in the third article of the Law of Social Integration of Disabled People (2005), all institutions must work on the principles of transition and flexibility, therefore, my goal was to determine a unified social support concept that would be applicable in each institution. I did not have any intention of distinguishing medical, social and educational support.

The main idea was to build a social support concept that would be commonly understood in each institution and for each specialist. Theoretical analysis of the ideas of Carlson, Perrewe (1999), Parasuraman *et al.* (1992), Groungaard and Skov (2006), Rogers (2007), Wong, Heriot (2008), Burgess, Gutstein, (2007), King *et al.* (2006) enabled me to synthesize these ideas and develop a unified social support concept of external resources:

> *Social support is perceived as emotional concern, instrumental aid, information, and appraisal based on communication and assistance for a family raising a child with severe cerebral palsy; gained or perceived as possible to be gained when needed from external resources as a stress-buffering mechanism and impacting the family's positive psychological, social and physical outcomes.*

This concept was the basis for constructing deeper research questions for exploring social support from external resources. It was impossible to avoid gathering some material of social support derived from *internal*

resources, therefore, some research questions were included, but the results were not broadly analysed. Internal resources were touched as little as possible. Families were giving information, as it was absolutely impossible to avoid questions about internal social support.

Also, sustaining acts of the Ministry of Social Security and Labour of the Republic of Lithuania[101] the social worker's position was determined as mediator. The social worker is seen not only as a direct social support provider, but more as a catalyst for accelerating social support in the system as a whole. It was particularly favourable to use the Scandinavian activity theory and system's theory for constructing such a research framework.

After I had formed the aim of the research, I also prepared the operationalization for substantiating the logical structures of social support from external resources. The questions were shaped to reveal the representations of social support by families raising children with severe disability. Operationalization makes a broad picture of social support from external resources and the reliance of representations on not only attributed ideas towards professionals, but also on availability or other related factors that have impact on the representations of social support.

Table 2 shows the main interview themes, sub-themes and first level sub-themes.

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101 Valstybės žinios, 2006–07–20, Nr. 79–3123; Valstybės žinios, 2006–08–05, Nr. 86–3375, Valstybės žinios, 2006–08–26, Nr. 91–3586; Valstybės žinios, 2006–04–20, Nr. 43–1569.

Table 2. Main interview themes, sub-themes, first level of sub-themes.

EVALUATION OF CONDITIONS: FAMILY'S RAISING CHILD WITH SEVERE CEREBRAL PALSY – SOCIAL SUPPORT FROM EXTERNAL RESOURCES

√ PSYCHOLOGICAL ASPECTS:
    • Psychological situation of family.
      -accepting disability (adults' perspective);
      -accepting disability (siblings' perspective);
      -accepting disability (internal resources' perspective);
    • Family's dealing with external resources.
      -support provided by social system;
      -support provided by medical system;
      -support provided by education system.
√ SOCIAL ASPECTS:
    • Social support from medical institutions.
      -working specialists;
      -qualification;
      -social support attainability;
      -frequency of visits.
    • Social support in social institutions.
      -working specialists;
      -qualification;
      -social support attainability;
      -frequency of visits.
    • Social support in educational institutions.
      -working specialists;
      -qualification;
      -social support attainability;
      -frequency of visits.
√ ECONOMIC ASPECTS:
    • Funds of family.
      -general economical situation of family;
      -paid medical services, drugs;
      -paid specialists' services (for child with severe cerebral palsy).
    • Economic situation of family.
      -pensions and benefits (accessibility);
      -disability as determination for economical situation.

SOCIAL SUPPORT CONSTRUCTED TOWARDS DOLPHIN ASSISTED THERAPY IN CONNECTION WITH SOCIAL SUPPORT FROM EXTERNAL RESOURCES

√ PERCEPTION OF SOCIAL SUPPORT FROM EXTERNAL RESOURCES:

- External resources: social, medical and educational systems in connection with DAT.
  -medical treatment: interaction aspect (in collaboration, consultations);
  -consultations in social systems: interaction aspect (in collaboration);
  -educational help providing for child: interaction aspect (in collaboration, consultations);
- Perceptions about Dolphin Assisted Therapy programme.
  -course and purport;
  -therapeutic help: interaction aspect (in collaboration, consultation);
  -qualifications of specialists.

√ REASONING WILLINGNESS TO PARTICIPATE IN DOLPHIN ASSISTED THERAPY PROGRAMME:

- Social support constructed for Dolphin Assisted Therapy programme (future projection).
  -connection between representations of social support: future projection and support from medical system (accessed/non accessed help);
  -connection between representations of social support: future projection and support from social and educational systems (accessed/non accessed help);
  -perceived social support benefits from the Dolphin Assisted Therapy programme.
- Constructing Dolphin Assisted Therapy sense.
  -sense for whole family;
  -willingness to try everything (what other alternative methods family pursued);
  -inapproachable Dolphin Assisted Therapy as catalyst for seeking;
  -hopelessness in external resources (medical, social, and educational systems) as catalyst for seeking Dolphin Assisted Therapy.

KNOWLEDGE CONSTRUCTION ABOUT DOLPHIN ASSISTED THERAPY

√ KNOWLEDGE TRANSITION FROM EXTERNAL RESOURCES IN PERCEPTION CONSTRUCTION:
    • External resources (professionals).
      -knowledge transition from medical representatives: representations, prognoses, recommendations;
      -knowledge transition from social representatives: representations, prognoses, recommendations;
      -knowledge transition from educational representatives: representations, prognoses, recommendations.
    • External resources (non-professionals)
      -mass media: articles, TV shows, reportages;
      -scientific information: material about Biomedical research.

In constructing the research a questions the use of Dolphin Assisted Therapy emerged. This additional social support branch was engaged because of personal understanding that representations of social support for families in social, medical and educational systems will be revealed more coherently if *looking through* the DAT window. Such perception was constructed because of two historical family projections: speaking of social support gained in the social, medical, and educational systems they were representing a past period related to the present time and projection to the future represented a context of social support for families' related to DAT.

Also while constructing the interview questions, I experienced difficulties in deciding the starting point of families' stories. The decision was to start from registering for the DAT programme to the family's coming allowed me to shape this historical conjunction of past representations and future representations of social support. Also such a construction of research questions allowed me to concentrate on the main aim of research and avoid information related to the emotionally-harsh descriptions of the child birth situation.

During my practical work I noticed an existing sequence on social support from external resources. When parents seek social support, they hope that their needs will be met, but if they are not satisfied, then they have a choice: not to seek it at all shutting into *family bubble* or as Marlow and Rooyen (2001) note seek it in as many resource providers as possible

to find this support. Therefore, the families participating in my research were so carefully gathered: diagnostic aspects could be determined as *objectively* most serious (in comparison to other children with disabilities on the DAT list), families had been waiting on the DAT list for more that three years, their social situation was as much as possible common: almost all families had 4–5 family members, a child with disability which was attending school.

Questions for the interviews were raised through three main interview themes. My purpose was not to ask directly about the social support that various external resources had rendered, but rather with a sense of seeing the system through the Dolphin Assisted Therapy window:

1. *Evaluation of conditions: families raising a child with severe cerebral palsy – social support from external resources.* In this section the main aspect was to reveal the family's representations of the process in seeking social support. Some questions were formed in order to construct the family's portrait: how families represent the representations of specialists towards them. The meaning of this section was to proceed from the *starting point* of social support: how the family came to the decision to register the child for DAT, how the family deals with disability (if a need of external intervention occurs), what institutions they had faced while searching for social support, also what the family role is in seeking social support from external resources. The main aspects in which the questions were constructed: psychological, social and economic.

2. *Social support constructed towards dolphin assisted therapy in connection with social support from external resources.* The meaning of this section was to reveal how experiences in the medical, social, and educational systems may impact/not impact the seeking of DAT as a social support. Therefore, I had the intention of seeing exactly when parents decided to apply for Dolphin Assisted Therapy. It was very important how families felt, behaved and acted when after registration to DAT nobody called to invite them to participate. Also this part was important for revealing the representations of other social support seekings/not-seekings by families.

3. *Knowledge about dolphin assisted therapy construction.* This section was constructed to reveal whether the specialists from the medical, social and educational systems encouraged these families to participate/

register for Dolphin Assisted Therapy, what information was given about this method of social support, and how they motivate those ideas. The interest lay in revealing the representations by families towards the DAT programme: how they argued why they needed this social support, what it can give to the family, what sense it has to the whole family, and if it had, how families picked the information *they needed*[102] and how they constructed their beliefs on this social support branch.

4.4 Gathering Research Material

Data gathering interviews were carried out in 2007. The interviews lasted from one hour to three hours each and were audio-video taped and transcribed verbatim. All interviews took place at the Lithuanian Sea Museum. All interviews were taken a day before Dolphin Assisted Therapy in order that the respondents should not have any preconceptions about it. It was expected that families would bring their representations of previous social support from external resources and give representation projections for future social support concerning DAT.

All interviews were made by me personally, families knew that I was a person making research but not that I was working in the DAT programme. All the interviews were made communicating face-to-face between me and the whole of the participant's family.

Researches (such as Dellve, Samuellson, Tallborn, etc., 2006) show that stress experienced because of disability is the same for all family members, therefore, all family members must be involved in the interview. My research showed that it is common for one family member (e.g., the mother) to want to represent the family as a group opinion on the question, therefore so-called *physical participation* cannot guarantee a qualitative and creative interview. Pelchat *et al.* (2003, 239) notes that it is quite often noticed in family research that there exists a contradiction between the fathers' and mothers' or children's opinions. These contradictions show that family members have different standards for evaluating their experiences.

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102 I mean that some interviews showed the possibilities for families to choose information they need: families neglect negative information on DAT and accept, withhold and represent positive information. The informant also plays an important role here.

Therefore, as a researcher I sometimes needed to contrive a way of hearing the answers from all family members in order to avoid *group decision* expressed by the mother only. Everybody's thoughts were welcomed and in order to get as much information as possible some of the questions were asked twice to reveal not only the mothers but also the father's or siblings' opinions as much as this was possible. In order to reveal the representations that family constructed together while meeting different professionals, the *unit of interview* took part: mother, father, child with severe disability and siblings.

This research was very interesting practically as in order to answer some questions about social support from external resources family members had different opinions and they discussed during the interview about *what their true family answer would be* to one or another question. It seemed that in discussing they were creating a general representation of experienced or projected social support.

My previous research (Giedraitienė and Kreivinienė, 2007) exploring provision of social support by various institutions made a very good example of the difference when you are holding an interview with one respondent and a family together[103]. I enjoyed the process and the main thing I succeeded in revealing was the *family's representations of social support* in the four components of external resources: social, medical, educational, and DAT. Family interviews represented the social support concept developed group. These representations were combined with the family's social support reached from internal resources. Also I could observe during the interview how social support affected the family as a system, how a family explains the social support phenomenon. Gabb (2009, 37) writes about this phenomenon that interviewing a family, a researcher can gather not only *where*, *when* and *how* was experienced, but also see *how* parents and children, and siblings relate to each other. I was like a witness to the family's internal support.

During the whole interviewing process some caution was needed, as I focused on deeply personal issues and experiences. Despite the fact that I have no intention to analyse the most sensitive part of family life – experiences and reactions to knowledge about a child's disability, though

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103 This research was shaped to reveal parent's experiences in social, medical, educational institutions and interviews conducted with one of the parents raising children with autism disorder.

for some families social support projection towards the DAT programme was coherent with their primary experiences.

Campbell *et al.* (2002, 312) writes that a researcher who is interviewing a family should have an essential skill that can be called *caring for families*. I tried to keep professional in the research together with demonstrating empathy to the unique situation of the family. It was important to have personal contact with all family members during all research stages: from first call to the conducted interviews to their leaving. In such a way between the families and me a trustworthy contact was built and strengthened. During the repetitive calls families answered the additional questions without tension and willingly.

Despite all respondents being gathered by chance, having strict social and medical criteria, but not geographical, the respondents were representatives from the whole of Lithuania (see Table 1). It again reveals that Dolphin Assisted Therapy is very popular in the whole of Lithuania. I do not have the initial idea of using a geographical aspect, as it would be too hard to gather families for research. Families were gathered from various cities of Lithuania: Elektrėnai, Palanga, Kupiškis, Klaipėda, Vilkaviškis, Telšiai, Plungė, Biržai, Mažeikiai, and Kaunas. However, the research results showed that social support analysis on the social, medical, educational systems in connection to DAT is only partly dependant on the region a family lives in, as the more common behaviour is to seek support in any region of Lithuania in case it is impossible to get it in the region lived in.

4.5 Data Analysis and Credibility

The research logic by design was based on inductive reasoning. Csapó (1997) notes that the inductive method is one of the oldest methods of instruction. Cañadas and Castro (2007, 68) write that there are two traditional types of reasoning considered: inductive and deductive. Haig (2005, 371) writes that:

> *Inductive method undoubtedly addresses an important part of scientific inquiry. (…) Deductive method, with its focus on theory testing, speaks only to one, although important, part of the theory construction process (Simon, 1977).*

Mahootian and Eastman (2009, 61–62) analysing the differences between inductive and deductive thinking note that since Francis Bacon introduced induction into the practice of empirical science 400 years ago, it has been considered as a weaker mode of scientific inference, relative to the time honoured deductive reason. They (ibid, 62) note that deduction is typically presented as that mode of inference that moves from general principle to particular instance, and for which there are well known and ancient rules. Induction, is the classical, Aristotelian mode, and is inference that moves from many particular instances to a general principle.

The research idea to analyse representations of social support for families came from the observations of families coming to DAT and discussions with them. Miles and Huberman (1994, cited in Henwood, Pidgeon, 1994, 229) write that a researcher has to be aware that

> *Social phenomena exist not only in the mind but also in the objective world.*

Therefore, before entering the research I investigated researches made by other Lithuanian authors on families raising children with disability issues: Butkevičienė *et al.* (2006), Ališauskienė (2005, 2007), Augienė and Ruškuvienė (2005), Ališauskas *et al.* (2008; 2009), Ališauskienė and Čegytė (2008), Ruškus (2000); Ruškus and Mažeikis, (2007); Miltenienė (2005), Baranauskienė (2008), Giedraitienė and Kreivinienė (2007), Vaičekauskaitė (2000; 2006; 2007ab).

Having particular examples of low social support from external resources I wanted to expand the knowledge of these phenomena in connection to DAT. In other words, reveal the representations of social support by families raising children with severe disabilities via the DAT window. The opening question on families' representations of social support from external resources the investigational inquiry lied in revealing the generalization on subjective representation of social support. Having an analogous set of families I wanted to develop from the singular family's representations of social support to a generalization.

Mayring (2007) citing Lincoln and Guba (1985, 110) on critics of generalization writes that:

> *The only generalization is that there is no generalization.*

However, further Mayring (2007) discusses that from a constructivistic point of view all phenomena are time and context specific. Choosing DAT as a window place to reveal the social support phenomena, I constructed a logic of generalizations: based on a particular time (fixed historical period of social support) of family life analysis and context – representations of social support by families were based on their practice which was experienced in the context of a changing paradigm of disability (moving from diagnostic to interpretative). Mill (cited in Zappen, 1993, 193) writes that:

> *What is true of certain individuals of a class is true of the whole class (7:2888)*

Due to the logic of Mill the revealed representations of social support by families raising children with severe disability can be generalized into representations of social support by all families raising children with severe disability that registered children to the DAT programme. Moilanen (2000, 379) writes that even if the interpretations are not the whole truth, they describe the subjective social world from the point of view of families. In such a way I can have various interpretations of the social world that can be generalized.

Newton (2009, 106) discussing the question of credibility of research writes that social constructivist approach withholds a position that the main question stands not on true/false findings, but created realities. Therefore, the researcher's reflexivity and impact on the research process has to be evaluated. The researcher's reflections have to be viewed as opportunities and possibilities to provide insights into the practice.

Feldman (2007, 23 – 24) discusses the existing middle between naïve realism and radical constructivism while seeking research credibility. The main credibility idea is not only implementation to practice but the result as improvement with concrete direction. Analyses of families' representations of social support from external resources gave me the possibility to analyse their *created reality*. As a researcher I take the role of mediator *translating* families' realities into research findings.

Another important point mentioned by Kimberlin and Winterstein (2008) is *constructed credibility*. I constructed research credibility deciding on:

- *Sampling the respondents.* Families were gathered very carefully taking into account all mentioned criteria as following: similarities on their historical approach (on a waiting list), social situation, diagnosis of children, social participation of the child. A phenomenon related to credibility occurred unexpectedly during the interviews when it appeared that families were telling their stories which were very similar to each other. Sometimes a sense of repetition was occurring or some of the families were even creating the same *terminology* for phenomena.

- Duncan (1989, cited in Elo and Kyngäs, 2008, 109) notes the sample is *representative of the universe* from which it is drawn. The primary amount of possible respondents numbered about 160 (each family being on the list of DAT), after deciding the criteria of research the number of possible research participants decreased to 50, after telephone calls to each of the participants it was clarified that only 13 families matched all research criteria. At the final sampling stage (when families needed to sign juridical documents) it appeared that one family out of 13 had falsified the data for being picked for research, therefore, the total number of possible respondent families was 12, from which due to criteria of precedence on the list 10 families were picked as representative of the universe.

- *Participation of families.* Johnson (1999, 283) writes that discussion of the researcher's interpretations with actual participants is meaningful for verification and insight. The families after the first interview spent two weeks at the Lithuanian Sea Museum. Therefore open-coding was applied on re-watching the filmed interviews for discussing the categories with families. Meeting the families we together discussed the meaning they put into the text, the main idea of such meetings was to verify my understanding of what the family represents. As far as my research goal was to give voice to the families, in such a way data credibility seemed for me the most sensitive, echoing truth of families. In such a way not third parties (like it is in peer review), but the families themselves were the experts of their told truths. Habermas (1973, 215, cited in Moilanen, 2000, 384) writes that in gathering feedback it is meaningful to construct the unforced dialogue so that participants can evaluate and strengthen their arguments. Therefore, I can say that together with the families we created primary categories reflecting the idea as closely as possible of their reality and meaning. Such meetings with families helped me

in avoiding my personal point of view in constructing the primary categories. Also, I could have been mistaken while interpreting all the data relying on only my thinking.

- *Simmering down.* Such a decision was made by me after all interviews conducted and having partially processed the data with primary codes discussed together with the respondents. A purposive and conscious decision was based on the sensitiveness of the topic. Despite the fact that I had followed all the principles of social work research ethics, I realized that after having partially processed the data I would not be able to objectively construct higher codes of the data without fusing with experiences of the respondents. Therefore it was decided to put this *searing* material away for simmering-down until the moment of my subjective readiness to make abstractions of the categories. More than a year passed after this decision before I again took the material and started reading it through and making abstractions on the categories that had been discussed with the families.

As far as I did not have any goal to test any theory on previous knowledge and the purpose of the study is focusing as a deductive analysis of content, my method of data analysis was inductive analysis of content, as Mariampolski (2001, 53) notes it is a method that derives a new meaning from the printed text. Elo and Kyngäs (2008, 109) describe it as moving from the specific to the general.

As the research was directed towards revealing the construction of representations, the analysis of content was the most helpful in making valid inferences from data to context (Robson, 1997, 272). Content analysis allowed me to analyse the spoken representations as *meaning of communication* or *meaning in the text* (Henwood, Pidgeon, 1994, 227).

The conceptual ideas for data analysis were derived from Huberman and Miles (1994, 431, cited in D'Cruz and Jones, 2004). Miles and Huberman (cited in Henwood and Pidgeon, 1994, 229) view qualitative data analysis as an integrative and integrated process with three components: data collection and reduction, data display and drawing and verifying findings. D'Cruz and Jones, (2004) use the broader Huberman and Miles (1994, 431) design for creating structural logic, which has been applied in my research. It is seen as a four-stage process.

The first stage was to ***gather raw material.*** This stage was implemented at the Lithuanian Sea Museum, I made video and audio tapings. The video material was used later in another research, as my thesis research from its conception had the basis of concentrating only on text material, not video. Also video material was used for over-viewing the interview and coding the data. The original data is kept in it's original Lithuanian language in the archive at the Lithuanian Sea Museum.

The second stage, was what Huberman and Miles (1994, cited in D'Cruz and Jones, 2004) named *partially processed data*. After I had gathered the raw material, I had to transcribe all the material onto paper and in such a way ten different stories were written on paper of families raising children with severe disabilities. These interviews were transcribed after the meetings and discussions on the codes with the families.

During the interviews I made many comments on the interview content. Elo and Kyngäs (2008) name such comments as latent content. Other comments that were made during repeated interviews on the telephone or meetings were accommodated into the family's primary interview, because these were not my assumptions, but actual speech of respondents. Before entering data analysis I decided to focus only on manifest content, not the latent.

The most important aspect in this stage was withholding a relationship between the families and me as researcher. A fortnightly contact with each family allowed me to gain data in various situations and complement it with examples; comments that were not mentioned in the interview, and also to discuss the categories together with the families. Another point is that there were *different situational realities* for each family – if they spoke to a researcher during the interview and a *researching friend* had approached the family.

Taking into account Miles and Huberman's (1994, cited in Henwood, Pidgeon, 1994) critiques that there is always the danger of poor reliability, I decided to remove some research *data*. All the additional comments given by parents on DAT were not included into the final data. I think if I used those comments, I would lose the external validity, contextual sensitivity, and flexibility, mentioned by Miles and Huberman (1994). I had a few serious reasons for that: the social representations given by parents towards DAT were too emotive; my primary research idea was

to measure representations with no prior experience, and using this data would raise questions on ethics and my personal reflexivity.

The third stage was ***coding the data***. After the each interview with a family I used video-taped material for creating codes for the data. These codes were discussed with the research participants and re-arranged till they acquired their true meaning. Later, when the semi-structured interview material was transcribed I transferred the coding schema we had discussed with the families. As far as the language of the texts was Lithuanian, the transcribed texts were not translated into English as whole texts. I did not have the intention to translate whole texts because of the cultural context and for better understanding during coding procedure. I mean that some of the words considered as *slang* cannot be clearly translated into English; therefore it is better to understand the *true* meaning in Lithuanian. The ideas were brought to the reader as close to the content as possible without loosing its sense in English.

Also as the whole family attended the interview, it was not possible to translate some of the syllables of children that can cause more misunderstandings in text and widen the *gap* that is mentioned by Denzin and Lincoln (2003).

I have not applied any computer program for making this process easier and have arranged the data analysis manually. This decision was based on several reasons:

- Open coding was used. Elo and Kyngäs (2008, 109) describes this as putting notes and headings in the text while reading it. My notes were made on re-watching the videotaped material of family interviews. After discussions with the families the primary categories were discussed, and transcribed into paper texts incorporating the categories of the families as well as my own. More than a year passed before I took the written texts again for developing higher categories from those we had decided together with the families. Reading the texts, notes and headings again I marked which categories belonged to the same meaning, or could be incorporated. The main goal was to write down all the aspects of the content of different interviews; therefore, each interview was read through again many times.

- I had interviews of only 10 qualitative families. They were very long and the material took many hours to read through. However, while I was creating the categories and analysed data, there was always an

under context. Each created category is not only a *creation* from the *complex of words*, but has *sense of reflexion of the context*.

- My main idea was not to achieve an *uncoloured* content analysis with *naked words* that can not always draw the whole picture of the experienced phenomena (Angelique and Culley, 2000; Brabant & Mooney, 1999; Krippendorff, 1980; Milburn, Carney & Martinez, 2001, cited in Baker & Stahl, 2004). I took into account Riessman and Quinney's, (2005) criticisms that researchers often try to summarize the content and put only frequency counts of the text from which the picture of the issue may disappear. Therefore, I decided to put in the broader texts of analysed phenomena leaving the picture that had been drawn by the families. Such a *phrasal analysis* was more beneficial to the picture of the social support schema in Lithuania as represented by the families. Patton (1990) and Sandelowski (1993, both cited in Elo and Kyngäs 2008, 112) note that authentic citations increase the trustworthiness of the research and indicate from what kinds of original data the categories were formulated.

- The last stage of data analysis was creating a ***coding scheme***. Having all texts with additional comments by the families and our discussed primary categories, I started to create a schema for the whole coding. This stage was made in two steps. First, having the smallest categories decided on with the families I grouped them into basic themes and later in each theme the category abstraction was made from those smallest categories going to the higher ones.

Therefore, in the first step I took excerpts from each case and grouped them by the basic themes according to the content:

- Representations on the situation of the family itself.
- Representations on the experience in the medical sphere.
- Representations on the experience in the social sphere.
- Representations on the experience in the educational sphere.
- The connection of Dolphin Assisted Therapy to the medical, social, and educational spheres.

In the final stage, I had a result consisting of huge pieces of texts distributed into some kind of sphere *of interest* with categories that had been primarily decided together with the families. After that the list of categories was grouped from the smallest to the more complex. Burnard

(1991), Downe-Wamboldt (1992), Dey (1993, all cited in Elo and Kyngäs 2008, 110) note that the aim of grouping the data is to reduce the number of categories by collapsing those that are similar or dissimilar into a broader higher orders of categories.

The purpose of creating categories was to provide a means of describing the social support phenomenon. Dey (1993, cited in Elo and Kyngäs 2008, 110) notes that when formulating the categories by inductive content analysis, the researcher comes to a decision, through interpretation, as to which things to include in the same category.

Abstraction meant the formulation of the general description of representations of social support through the generating of categories. Each higher category was named for its content-characteristic words. The abstractions going to higher categories were grouped together as far as was reasonable and possible.

Table 3 represents the main categories: medical, educational, social systems and Dolphin Assisted Therapy. The last category was occurring in three mentioned systems. When working on the coding schema, I noticed that the families were often comparing their preconceptions of DAT to other systems. Therefore, the analysis of DAT was also constructed in the light of the medical, social and educational systems.

After the process of abstraction, the data was coded into four main sub-categories: *evaluation of professionals*[104], *applied representation towards the child, applied model of work* and *result of intervention*. These sub-categories were the first level of sub-categories. Some of the first level sub-categories contained second level sub-categories.

For better understanding the categories will be overviewed top-down showing the logic of shared categories from the highest to the smallest ones.

In the category of the medical system, the evaluation of professionals sub-category was shared by the following first level sub-categories: cold-blooded, passive neglecters, chemical interventors, side takers (second level of sub-categories: opposers and compliers), power draggers, supportive (based on personality).

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104 All the material about the concrete facility and concrete professionals as personalities was taken out because of ethical research reasons. The detailed information is known for me, but in the texts names were substituted into letters as 'X', 'Y', 'Z' etc. as much as was required.

The representations towards the child sub-category was shared between first level sub-categories: labelling (second level of sub-categories: generalizing, blaming, limited organism), experimental (second level of sub-categories: cannot harm more and, harming not judging), unequal equality (second level of sub-categories: cheating on something, calming down, physical abnormality as social abnormality), adjusting (second level of sub-categories: hostage of the system and object of another system).

The applied model of work sub-category was shared into first level sub-categories: supportive, puzzled, limitations, clear medical, and other (second level of sub-categories: insensitive, bribery, based on parent activity). Sub-category result of intervention was shared into three first level sub-categories: positive result (second level of sub-categories: depending on *favour*, on intervention, on alternative methods, and communication), negative result (second level of sub-categories: no longitudinal observations, no trials-searching, lack of communication), neutral result (second level of sub-categories: disability acceptance and gaming).

In the category of the educational system, sub-category evaluation of educators, three first level sub-categories were shared: supportive or in a broader sense – creating a safety niche for children; non-satisfying and methodologists. The first level sub-category of supportive educators was shared additionally into three second level sub-categories: meeting needs, realizing themselves, and accepting parent-over position. The non-satisfying first level sub-category was mainly based on the representations by educators on the child as a burden and the second level sub-categories were: based on an unfriendly environment, on complaints, on labelling. The first level sub-category of methodologists was shared into the second level sub-categories: know how (to reach a child), open to parents (flexible).

The sub-category representations towards the child was shared into the first level sub-categories: orientated towards the child's strengths (second level of sub-categories: become-orientated and normal), orientated towards the child's weaknesses (second level of sub-categories: disgraced and segregated), burden. The applied model of work sub-category was shared into only one first level of sub-category – individual. This first level sub-category was shared into the second level of sub-categories: as

inclusion and as segregation. These sub-category result of intervention was shared into two first level sub-categories: development and limited representation (towards the disabled).

In the category of social system, a sub-category of social workers was shared into the following first level sub-categories: misunderstanding (but helping), titular (second level of sub-categories: absent, general specialist, theoretical image), and professional (second level of sub-categories: informators, appraisers, and bureaucrats).

The sub-category of representations towards the child was shared into three first level sub-categories: emphatic, burden, expecting poor. The sub-category applied model of work was shared into four first level sub-categories: red-taping, informational, none, and needed. The sub-category result of intervention was shared into three first level sub-categories: word of mouth, unsatisfactory and rare meetings. The unsatisfactory first level of the sub-category was additionally shared into three second level of sub-categories: bribery relationships, lack of financial support, leading own case.

Dolphin Assisted Therapy was used as a window to reflect additionally overviewed systems and draw a deeper analysis of the lack of social support experienced in one or another social net compounding. Therefore, analysing the DAT sphere four sub-categories were reflected: the medical, social and education systems dealing with DAT. And the last category was DAT as a providing of social support: the expectations of families (future projection). The sub-category of the medical sphere dealing with DAT was shared into six first level sub-categories: missing joint, functional benefit, recommendation of doctor, doctor's indulgence, natural stimulant (miracle), child's chance for expression.

In the sub-category of the educational sphere dealing with DAT five first level sub-categories were separated: inspiring, sceptic, putting the same power, progress and winning. The last first level sub-category *winning* has a sense when two parties fight, a third wins overall, and therefore it is more negative than positive, and is included in this explanation.

The sub-category of the social sphere dealing with DAT was shared also into five first level sub-categories: constant neglecting, acceptance, human neglecting-animal acceptance, being in the process, and hope for betterment (second level of sub-categories: child perspective and family perspective). The last sub-category expectations of families were shared

into the five first level sub-categories: happiness, relief & relaxation, instrumental aid, last hope, safety niche for the child.

It was mentioned earlier that I decided not to put additional words into the analysis, but phrases for picturing the situation. Because of such a decision after the analysis of each category, I have drawn summaries and an overview on the analysed system.

Table 3.   Research analysis schema.

Representation of External resources	Variables		Medical system (excerpt)	Educational system (excerpt)	Social system (excerpt)
Social support providers: professionals	**External:** Emotional concern Instrumen-tal aid Information Appraisal **Additional (internal):** Child's status Internal resources Normality-*invalidity*	**VARIABLES AS ACTIVE PROCESS**	*doctors were cold-blooded*	*they are educating my child*	*information giving and that's it*
Social support providing: representations towards child (stress level/ repertoire)			*neurologist acknow-ledges my interest about my child*	*they always complaint about my child*	*child is a burden*
Social support providing: applied model of work			*we felt as if our child was like an experimental guinea-pig*	*they are sharing information with us, asked our opinion*	*a feeling of relieve came as I realized that I am no longer alone*
Social support providing: result of intervention (achievements/ expectancies)			*drugs are not helping him*	*it took one year for the kindergarten to prepare for accepting our child*	*the law existed for 10 years, but I did not know about it*
Construction the meaning of provided social support			overview	overview	overview
Expectations of families (future projection)			**Dolphin Assisted Therapy**		

The analysis is displayed so that it is possible to see the whole picture of representations on phenomena. Miles and Huberman (1995, cited in Onwuegbuzie and Leech, 2006, 245) note that in qualitative research, numbers tend to be ignored, but the *number of times* as well as *consistency* are judgments based on counting.

Therefore phrases or used words were counted and the number is given in brackets (for example (5) shows number of cases that had the same experience or even used the same words, and phrases. In cases where no brackets were included, it means that it was said in a single instance. In such a way the representations of one family were seen as single cases in the context of all given representations rather than counting the prevalence of used words in each case.

After the research stages, the data was *interpreted*. When I had fitted the data into concrete categories, sub-categories, first and second levels of sub-categories I could interpret that data. Despite the uniqueness of each research, I still found some similarities concerning social support in the system published by Ruškus and Mažeikis (2007), and Ališauskienė (2005).

The uniqueness of my research was in the analysis of the representations of the social support phenomena from the perspective of families raising children that have severe cerebral palsy in Lithuania. This research and thesis is the first in Lithuania made in the perspective of Dolphin Assisted Therapy.

The research results are *displayed* in the further chapters (5–8). Those chapters hold analysis on the representations by families due to the presented categories, sub-categories, first, and second level of sub-categories.

5 Representations by Families of Social Support Provided by the Medical System

The main medical category is analysed through four main sub-categories: medics, representation towards the child, applied model of work and the result of intervention. After the representations of social support by families are analysed, a general summary is made compounding all four sub-categories.

5.1 Medics

The main aim of this chapter is to make an analysis of families' representations of medical professionals as social support providers. The sub-category of medical professionals was split into the first level of sub-categories: *cold-blooded, passive neglecters, chemical interventors, side takers* (second level of sub-categories: *opposers* and *compliers*), *power draggers, supportive* (based on personality).

The common feature of all the families that participated in the interviews was the pointing at specific medical *personalities* working particular institutions. Families giving their representations of medical examples speak of concrete personality. Even one faced by a family example tends to create a generalized representation of the whole medical system.

The first level sub-category of medical professionals as *cold-blooded* (5) was mentioned by half of all families. The given phrases create a broader picture and these were given by families. This first level sub-category was created by those five families themselves. Family's case 008: all medics are *absolutely cold-blooded* (5):

> *I came to the neurological hospital with my 10-month old baby and wanted to seek help, but the doctor said it was dinner time for him (…). My child was contorted by a paralytic stroke (…) until I put 50 Litas into his pocket no investigations were made.*

This case illustrates that parents facing a harsh situation had to give extra money to some medic as motivation for implementing his job.

A very similar first level sub-category was raised picturing medics as ***passive neglecters*** (3). This first level sub-category reflects the representations by families of picturing medicals as not emphatic in understanding special needs. Also families point to the difference experienced from medical professionals just because they were in a hospital with a *different* child.

Family's case 007 represents that:

> *Medics seeing a child's disability tend to neglect (3): We had a case of pneumonia (…) seeing that there[105] is nothing better, we being out of spite indicated our intention to go to another hospital (…) and there medics said it would take a few hours to release our child.* Another family case 010 tells*: The child was screaming from pain but help did not reach us…*

Family case 008 talking about concrete mistakes by medics says that medics instead of *saying sorry* tend to *add insult to injury.* Family case 006 says about their neurologist:

> *It's our failure to visit him (…) perhaps it's just his character that is so.*

Timpka's (2000) research on patients and their caregivers shows that if doctors tend to ignore and not to take into account the patient's opinions about their problems it is accentuated by the caregiver's stress. As a solution for this situation Timpka (ibid) sees focusing of the social interaction. The given cases show that seeking medical support when the stress level was very intense because of the unknown situation of the child, families faced an indifference in medical institutions and this raised their stress level even more.

The descriptions about the medical professionals are directly related to the child's condition. Positive representations or some positive insights towards medical professionals are related to: their knowledge about the child's possible disability before birth (2), if disability was caused by outside factors (car accident), (1), and if a child may express himself by *language* (2). Families give much more negative, sometimes even condemnatory evaluations about the medical professionals when: child's disability was caused by the birth (6), if medics refused to believe that *something was wrong with the child* (5), and when the child's condition is very severe (4).

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105 *There* has the meaning of hospital.

The first level sub-category as ***chemical interventors*** (8) occurred in almost all families. Such a first level sub-category portrays all medical professionals who see the only means of situation betterment as taking drugs. Families understand that some of a child's features are incurable and accept the child as a personality with disability. But facing a doctor who insists on drug-taking may lead them to turn away from the whole medical system (4), the same as meeting when cold-blooded or neglecting doctor (4) suggesting chemical intervention. Family case 004:

> *As much as we met doctors, they suggested only chemical interventions.* Family case 010: *We do not acknowledge chemical treatment.*

All parents mentioned they were afraid of *chemical intervention* and had previous unsuccessful experiences searching for alternative help. Family case 004: *I'd better not ask (…) as there are no drugs for his illness.*

Some families mentioned they had closed the door to any medics. As in Family's case 008 which gives a generalization about all medical professionals in the system: t*here is a wish to bypass them.*

Sometimes even filling a tooth can be challenging: the dentist wrote:

> *Caries and mental retardation (…) I don't know why he wrote it so. He saw this child for the first time, perhaps because he had heard his scream in the ward (…). I don't see the point of medical visits (…) they are primitive (…) without any understanding of the invalids.* Families' cases 002, 004: *They prescribe medicine and vitamins, that's it.*

This case shows that a doctor seeing a child with severe cerebral palsy can label the child as a *mental retardant* just because of the child's special characteristics like untypical outfit or impossibility to communicate.

The first level sub-category of medics as ***side takers*** (9) was shared into two different second level sub-categories: ***opposers*** (3) and ***compliers*** (9). Representations by families show that each contact with medical professionals, the medic seems to be taking someone's side. The second level sub-category describing medics as opposers witness arising conflicts between families and doctors.

Usually disagreements between families and professionals arise because of a lack of communication, and information about the treatment. Opposing the process sometimes may develop into a negative relationship that leads to *curing on parents' demand* (6) or to *technical duty prescribing*

recipe (3). Conflicts force doctors rather to give what parents want instead of arguing. Though in such cases, doctors tend to stress the responsibility upon parents. Family's case 007 tells:

> *The doctor said I CAN prescribe if YOU want it (…). Such sayings terrorized me… If I WANT IT – I am not a medic…*

Seligman and Daling (1997, cited in Ho and Keiley, 2003, 244) write that accepting representations by families may also have a negative result on the child's condition. It will not help parents if medics focus only on the normative traits and miss the intervention that is essential.

Seeing parents as enemies and preparing for each visit as going to war, creates a situation that is not satisfactory for either party. Family's case 003 tells: *We split with the medics.* Family's case 009: *The family doctor refused us, because I was in dispute with her.*

Mitchell's and Sloper's research (2002) shows that a lack of information about a disabled child derived by parents have direct connections with alienation from medics. They state that good communication practice in such severe situations has to be three-sided (dimensional) through mediation. Parents see such a way of getting information as of the most practical value and worth.

The research results revealed existing problems in medical-parental negotiations. The situation could be improved if a third party were to become involved. Parsons (1991, 484) writes about social workers. Unfortunately research results show that such a possibility is only theoretical so far. Because of two reasons: further analysis reveals a lack of social workers and families represent medics as more worried about authority than treatment.

Another second level sub-category of the first level sub-category *side takers* was separated as **compliers**. Family's case 010: *I said it is not epilepsy (…) the doctor agreed.* One family giving representations of medical professionals said they *gave their recipe how to deal with them.* This recipe is needed if parents would like to construct a contact where the medic takes the role of complier rather than opposer. Family case 006 grounds their theory saying:

> *It's OUR needs, not THEIRS (…) therefore, WE have to know HOW to communicate, HOW to approach.*

This miraculous second level sub-category creates a strange relationship. Families tell of using special techniques for communicating with doctors. Like in family case 004:

> *Each parent is the best doctor (…) so in cases where you disagree, you don't argue.*

It shows that perhaps the doctor thinks that parents take into account recommendations and treatment. But in reality the family turns them into side compliers against the doctors' will. Adapted family's behaviour – making a doctor a silent complier perceived more beneficial than as active opposer.

All the above mentioned first level sub-categories have direct connection with the first level sub-category describing medics as **power draggers** (5).

Families tend to make a clear line between *them* (doctors) and *us*. Families tend to construe themselves as the *weaker part* in the process that has to adjust to some *standard of approaching* to the doctors for obtaining social support. Seeing medical professionals as constantly dragging power creates rather an alienation than an alliance.

Families interiorize segregation as *their* understanding of disability. They reflect that disability is *our* problem, not society's, not other people, just *our family's*. These ideas have connections with the understanding of the Soviet period when disability was equated to the shame of a family.

Families describe medics as power draggers saying that *they learned not to discuss and argue*, easier not to obey medical prescriptions. Such a relationship is a clearly a one-sided power-over relationship. Medics don't meet in the conversation and discussion the same parents *learned* to keep the power not to obey, as *they know better*. Dragging power into someone's side is based on lack of trustworthiness from the both sides. Jalava (2006, 58) writes that very often doctors meeting patients seek to show the expert system which they represent. A difference can be made whether or not a doctor strengthens the caregivers' confine.

The families represented perceived a lack of the medical professionals in their particular region as a serious problem (5). It means families face a lack of supportive professionals, especially in small cities. Family case 009 shows:

> *There is nowhere to seek for help if the child gets worse (…) so you sit on your nerves, tension and don't know what to do.*

Families are not speaking of a real shortage of concrete specialists, but it points to a problem that exists in finding the *relationship* and *communication*. Family case 006 says that: *You have to know HOW to choose THOSE[106] medics*. This family points to the facts about existing problems, and represents the necessary parental abilities or *sophistications* to choose the best professional due to some *existing features*. These representations reflect the family's despairs when dealing with disability in the social support seeking process they had to *learn adaptation from the context, and choose mechanisms*.

The first level sub-category of **supportive** (8) medical professionals in all family cases was related to personalization. Families tend to hold longitudinal relationships with supportive professionals. Families described supportive medics (3) and mentioned that they are satisfied with their doctors (6), the ones they chosen were emotionally concerned (2) about the child's problem, provided instrumental aid (6), and appraisal (6) for families.

Usually positive representations lead to one or two concrete doctors that are visited more often. Families tend to use expressions like *our neurologist* (4), *our family doctor* (2). In almost all cases positive evaluations were given if parents had personal contact with this professional (8). Family case 005 pictures:

> *Now we are satisfied with our doctor (…) when I call and say this is the mother of X, she already knows us, don't even have to say my surname (…) It is strange that we get into the sanatorium even without bribes (…) just a very good doctors perhaps.* Family case 001: *She[107] is so natural…how to say…I don't have butterflies before her visits.*

Jalava (2006) gives Giddens's (1984; 1990) ideas for reflecting on such a context – parental trust in doctors. That *general trust* is an ontological security that is more an emotional than a cognitive phenomenon. *Knowing, without bribes, natural, without butterflies* – this is a portrait of emotional security created via communication.

If families were making even the smallest positive remarks about the medical sphere, during the conversation they all (8) used personalization.

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106 *Those* meaning good.

107 *She* means doctor.

All eight cases were talking about a concrete medic who behaved somehow out of the ordinary way (socially supportive, instead of rejecting). Family's case 001 about a family doctor shows that the initial negative representations tend to change when help is provided:

> She seemed to me angry from the first glace (…) but later she helped us even with the courts (…) but I heard that she has the same problem in her family.

In summary, all the parents tended to set the border between *our doctor* and *them* which means *bad and not supportive doctors*. Schwartz (2006) writes that such a categorization could be a feature of a badly-functioning support system. Instead of interrupting or preventing social relationships, professionals have to support and if needed even provide knowledge from their sphere.

5.2 Representations towards the Child

The representations towards the child subcategory was split into the first level sub-categories: *labelling* (second level sub-categories: *generalizing, blaming, limited organism*), *experimental* (second level sub-categories: *cannot harm more*, and *harming/not judging*), *unequal equality* (second level sub-categories: *cheating on something, calming down, physical abnormality as social abnormality*), *adjusting* (second level sub-categories: *hostage of the system* and *object of another system*).

The representations towards the child first level of sub-category as *labelling* can be illustrated by Family case 010: *We felt discarded there… absolutely*. *Labelling* was split into three second level sub-categories: *generalizing, blaming, limited organism*.

Medics tend to *generalize* the disability theme. While families were telling of medics' representations towards their child, they designated an important aspect for this research. Representations towards a child tend to withhold a broader point of view, as professionals showed that not only was a child with disability, but *disability had the whole family*. So, when parents were telling of how doctors saw, observed the child, they quite commonly used the word *we* instead of *he*, *she* as if the whole family experienced the common neglecting perceived as a label (10).

This aspect may not only be caused by this sociological understanding, but also there can be psychological roots that family members, especially parents represent in their identification with a child.

Generalization as second level sub-category is also used in its other meaning. It was new for me to find that all families without any exceptions were faced with negative representations towards their child from medical professionals (10). If in the previous chapter's representations towards the medical profession I could find both: positive and negative, here the entire positive side fades away. The representations by families show that medics not only tend to label the whole family giving it a general understanding of *the disabled*, but also they generally act the same way with all families.

The second level of sub-category as **blaming** was also revealed in almost all cases. Families gave a view of professionals that parents are somehow considered guilty for their decision to raise disabled child in the gestation period.

Families were giving their representations as if they had one choice out of a possible two: accept *the cross that God gave* (8) or divide people into *us* and *they* or seek an abortion. Such representations show that families *learned* to put themselves into the lower position, where doctors have the right to demonstrate authoritative relationships. In accepting the blame label they do not tend to change this situation or show more activity in finding a relationship. Families give representations formed during the contact with medics as if they were guilty for having made the choice to have a *different, not perfect* but *their* baby. Another case of Family 001:

> After the birth of the child, doctors put her into an incubator, the excess of oxygen caused a relapse of the retina. So they asked if you will maybe leave… and not grow

shows the demonstrated negative representation. A medical mistake caused the child's blindness for her whole life. Instead of apologetic medics giving the family a *ticket to an easier lif*e. They suggest that the family leave the child in hospital.

Similar features can be found in Vehkakoski's (2007, 297) research about hospital staff and their attitudes towards disabled newborns. His research showed that when medics see a child who will need professional care, it is typical to perceive children with impairment as service users and

a burden in the future. Therefore sometimes deciding from the position of experts they tend to *evaluate* the efforts of a family and suggest an expert's solution.

Limited organism the second level of sub-category in the representations towards the child sub-category was met by a few families (2). Usually such a representation was demonstrated for families when doctors were presenting future perspectives for the child. Addressing attention towards weakness of children they usually saw limitations rather than opportunities. Family case 007:

> *Point of view is pessimistic towards all possibilities for changing something.*
> Family case 005: *I imagine that my child is okay, but after the visit it seems*
> *all the time we had worked was eliminated and everything had been in vain.*

Medics seeing diagnoses as a limitation disappoint parents instead of supporting them.

Families represent medical professionals as authoritative and influential by words that can be used not only for inspiring parents, but also for creating grief. Families represented that the most disappointing moment happen if after few years of intensive work with a child, medics laugh at them. Such words gives the meaning that families do not expect miracles, they just don't feel *evaluated* and *appraised* for everything they've done. Parents have to experience a sense of being good parents and see the child optimistically. Families represented that not judging might serve as an emotional support.

The first level sub-category of *experimental* representations towards the child was split into two second level sub-categories: *cannot harm more* and *harming/not judging*.

Experimental representation (5) from the side of the professionals disappointed families greatly, as instead of receiving advice or concrete instrumental actions, they felt they were participating in an experiment.

The second level sub-category when medicine *cannot harm more* as the child is *already* different faced one family participated in the research: Family case 010:

> *The child was in the role of experimental guinea-pig (…) various medical*
> *trials lead to crippled legs (…) and melting of teeth.*

The family reflected that the disabled child is seen in medicine: either as chance for experiments or some kind of weaker organism of society that has to disappear (biological mistake).

The second level sub-category when medics are *harming*, and parents *not judging* (4) was more frequent. Families accept medical harm as something that can be accepted as a pre-construction as if it was constructed as allowable. Family case 007:

> *They can say or do something mechanically, prescribe or they don't say anything that we need[108]…*

Medical experimental mistakes are allowed because they are authoritative in *collaboration*.

An interesting reflection of Family case 001: *What happened is what had to happen…* when the family is speaking of disability caused by medical mistake. This family puts a special meaning here that *everything in life has sense, there are no accidental things…* Instead of blaming or judging medics they found their own explanation of how the world is turning.

A later conversation opens that just because of a daughter's disability (blindness and cerebral palsy that was caused by a car accident) they found their social support in mutual help groups. The family joined two nongovernmental organizations and found there a *sense and happiness of communication.*

Disability of the daughter helped this family to create a tight self-help safety net, they say that money could change *nothing… you cannot change the communication we found…* This family is explaining that the child's disability is not a disaster; it is rather some difference that had to happen to their family for finding something valuable (like friendship with other people).

The first level sub-category *unequal equality* was formed due to the representations by families facing indifferent medical professionals meeting their severe case in different situations.

This first level sub-category was split into three second level sub-categories: *cheating on something, calming down, and physical abnormality as social abnormality.*

Families represent *cheating on something* (2) as a second level sub-category in talking about their harsh situations. Medics being members

108 In the meaning of do not communicate further.

of a disability commission tend to demonstrate such high power-over relationships leading to professional deviation. Family case 003:

> *When we come to get invalidity (…) we have to be prepared for disregard, waiting, and sitting (…) if come alone[109] they start defaming and not listening (…) and when I come with my daughter, she starts vomiting...*

The main point hidden in parent's words is the inflexibility of doctors (lack of emotional concern), *not listening* – not hearing parent's words (no appraisal), and no instrumental aid, as doctors do not prolong the disability without seeing *a patient*. But when the *patient* is taken to the commission, parents hear insults because of the child's reaction – vomiting.

Mcinnes and Lawson-Brown (2007) write about such unequal situations that doctors tend to lead with the ancient methods of treatment in order to remain *top-dog* or being seen as *God*, ruling over somebody, while parents remain subordinators – *top-dogs* as *underdogs*.

Such relationships lead to even deeper misunderstandings and hatred on both sides. Nobody wins and each necessary visit creates a constant stress. For such a family the medical sphere is seen as excluded from the possible social supporter's list. Who are the child and his parents to turn to for medical help? The family felt as if they were cheating on the child's disability. Needs were not met flexibly, as even for the non-professional it would be clear that raising a child with complete disability with no chances for betterment for eight years, means that child has other needs. Therefore, instead of helping, doctors tend to turn parents into potential *cheaters of the system* in order to get benefit.

The **calming down** (8) second level sub-category was formed due to reflexions of families representing the attitude they met when seeking answers to health questions. Severe disability of a child requires very close collaboration between parents and doctors, as it is impossible to neglect the need for medical intervention.

An interesting phenomenon was noticed by families and represented as if a doctor is not sure what happens with a child, he can suggest a calming down version (3) for parents. Family case 010:

> *They told me don't be afraid it's not an epileptic stroke, its just a child's whim.*

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109 Child cannot bear crowded places.

Some of the families were representing their cases sarcastically: Family case 001:

> *A neurologist says those long periods of crying are caused by of need to discharge (…) and it's healthy (…). If there is a severe pain so you will force her to say WHAT hurts.* Family case 007: *I shake him, don't understand what's going on in panic (…) and the doctor said that everything is fine, he is just weak.*

When a doctor cannot support a family with knowledge or information about what is wrong, instead of making additional investigations or just saying that they *do not know*, they tend to calm down parents. Families representing these cases were sarcastic, because their further experiences showed that children were suffering pains caused by physical dysfunctions. In all mentioned cases children were expressing their pain through crying. Families can be fragile and lost while dealing with a child's disability. Families represent that in high-stress situations they tended to believe everything the doctor said.

Bartolo's (2002) research showed that when medics or educational specialists are faced with disabled children, they can communicate without support and openness just because they may lack the skills for communication. Family case 008 illustrates such a lack:

> *The child was screaming day and night for the whole week in hospital (…) but the doctor did not react (…) now I could tear out the eyes of such doctors, but then I believed…*

Doctors do not have the ability to cope and react professionally towards the stress of parents. Therefore, avoiding confrontation they just choose to neglect and calm down.

Families represent that *fight* and *refusal* to believe a doctor's words were the first steps to receiving diagnosis and treatment. Family case 002:

> *I asked if my child was an invalid. Oh no, not at all – answered our doctor. I asked for the committal for further examination, but she refused. (…) I went on my own to a diagnostic department (…) a medic in the corridor seeing my child from afar said: he has a lesion of the head.*

The second level of sub-category of *calming down* shows that families met doctors' position towards children's disabilities that it is just *something*

they will grow out (5) and parents *are looking for diseases themselves* (7). Some of such cases resulted in children's sufferings.

Graungaard and Skov (2006, 297, citing researches of Quine & Pahl 1987; Sloper & Turner 1993; Quine & Rutter 1994; Pearson *et al.*, 1999) write that the majority of made research shows that when evaluating communication between doctors and parents about 50% of mothers are dissatisfied. And the crucial factor for parental satisfaction is the time lapse between the suspicion of disability and the diagnosis appears, or when the diagnosis is not clear.

The second level of sub-category of **physical abnormality as social abnormality** (7) was met many times in almost all cases. This second level of sub-category has a very tight relationship to the labelling representation, as if a child has functional problems he is usually labelled as *mental retardant*. Such a situation creates a category of mothers-defenders in society as Family case 009 reflects:

> *I seem as a problematic mother (…) but who will fight for my child if not me?*

Streaming for social support that was guaranteed by the state is seen as a *fight*, because the disabled is a weaker person on whom system could save money. Family case 006:

> *Doctor stroked his hand on the table and the child blenched, so – this means hearing is okay.* Family case 005: *doctor always says something is wrong with her head[110].*

Families represent medics as tending to put additional stigma on those whom they do not understand. Also families represent the humiliating methods of examination – it leads to disrespectful representation either towards the child or the whole family.

The representation by families shows use of *expertise model* in the providing of social support. Families attribute the ideas of medics as authoritative during interaction, allowing themselves be unprofessional, such as the case when using the word *head*. Head is not a diagnosis,

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110 Expression s*omething wrong with the head* in Lithuania has a sense that a person is a fool. This expression has a labelling, stigmatizing meaning.

there was a hidden meaning that the child does not understand as he should, but saying *head* is equal to pasting the label as retarded (in the Lithuanian context). Wilton and Plane (2006) write that faced with such labelling, disabled children will the next time fear the stigma and associated labelling as a child as well as fear that the label will reflect back on the parent and may prevent a family from seeking services.

The last first level sub-category in representations towards child sub-category was ***adjusting***. ***Adjusting*** was split into two second level sub-categories: ***hostage of the system*** and ***object of another system***. These second level sub-categories offspring when families were representing two main adjusting models used by medical professionals when dealing with a child. The first sub-category of the second level as ***hostage of system*** (2) portrays a situation where the medic is seen as locked between governmental allowances and families. Families perceive the doctor as being a hostage of the system in representations towards the child: Family case 009:

> When I said to my family doctor that I have a right to visit a sanatorium twice a year, she said that money was exhausted (…) so I waited in long queues at the Ligoniu kasa[111] and made a big conflict (…) but got what I had a right to. Family case 002: *they said I am not suitable to visit a sanatorium, as I am too weak physically to bear my child.*

The family represented that sanatoriums are left as remnants from the Soviet period. In not all of the sanatoriums have the environments been adjusted to special needs children; therefore, families attribute the idea of doctor in the role of arbitrator evaluating a parent's physical abilities to carry the child to all procedures there.

These cases show that families see a doctor as appointed by the government to a position of some kind of judge who arbitrates which children can visit a sanatorium and which not. Such a double situation – giving and taking back creates a real background for both sided dissatisfaction. The families represent that it should be more clearly defined by law in order not to create tensions between doctors and them.

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111 Ligonių kasos can be translated as Tills of patients. It's a governmental institution that is responsible for distributing money to the medical institutions, make agreements with medical service providers and compensate for medicines that are included in the compensatory list of medicines (www.lsveikata.lt).

As families want to use the instrumental aid (sanatorium) but cannot get this resource because of the individual decision of a doctor. In case the doctor is not providing this instrumental aid due to *objective* reasons (lack of finances), parents are *judging* that that particular doctor did not give something. They put personal evaluation into the hostage of system second level of sub-category.

The second level sub-category where a child is perceived as an **object of another system** (4) was met in almost in half the cases. Family case 007 about the doctor's words:

> *Mother, don't give your child's diagnosis prominence, nothing can be changed now be happy he is in such a family. (…) Think the doctor meant not in an asocial family (…) and that I must sit and watch his death-throes.*

Families give the meaning of a doctor's representation towards the child as if he was not a human being, some *thing* that can be replaced. The severity of the diagnosis and emotional concern about it is put in the last place; the main importance is given to care providing, like *such a family will not leave a child*. Such situation is seen by families as both-sided. From the one side as willingness to support a family saying that they are good parents and from the other that you must fight to get something, as the further context was about a dying child.

5.3 Applied Model of Work

Analysing which model is applied in the medical sphere and what are the representations by families towards the model used, it is important to mention that in 4–15 years all the parents had visited a lot doctors. Therefore, when I made the previous analysis observing the representation towards the child, and doctor himself, I found controversial meanings hidden in words given by families.

If families met unsupportive doctors or experienced any disagreement, they tended to represent these situations in the smallest details during the interview.

The positive aspects showing a change in medical sphere towards the disabled were represented by Family case 008:

Now I see some steps forward in understanding (…) but 10 years ago…

It shows that families had met not only negative experience but also positive. It seems nowadays they meet *other representations, models of work* towards their child, and it is much more positive in comparison to their past.

Trying to reflect on the meanings of all the conversations and open the locked meanings, the representations of social support by families on possible medical models were shared into five described categories. The **applied model of work** sub-category was shared into first level of sub-categories: **supportive**, **puzzled**, **limitations**, **clear medical**, and **other**. The first level sub-category *other* was shared into three second level sub-categories additionally: **insensitive**, **bribery**, and **based on parent activity**.

The **supportive** model (3) was described by families which during their visits had been faced with a concrete doctor having features of: experienced specialist, and open to collaboration with parents. It has direct implications with Sleigh's (2005) research findings that a family's well-being is promoted when the professionals that are met are positive and even acknowledge the family's expertise. The best doctors were named as those who left family space but were able to provide expert help when it was required.

Speaking about the supportive model, some of the families noticed as the most important thing – efforts that the professional put into the process rather than the final result. Family case 005:

> *We are satisfied with our family doctor as she knows us (…) she has willingness to help.*

Another case shows that families evaluate doctors' openness to collaboration. Family case 010:

> *I talk and consult with my neurologist. She accepts that I read and care about the drugs. She by no means trusts me and knows that I am observing my child.*

The main sense is locked in the word *accept*. Being a mother this woman met too much doctors with authoritative relationships, therefore, *normal* sharing of information and obligations is seen as a very special *appraisal*.

This case shows that parents feel being involved in the process. A medic examines, prescribes, but parents being at home investigate and reflect on how the drugs are working.

Watson *et al.* (2006) writes that not all doctors hope that parents might have enough information about the child and ask relevant questions. Family case 004 shows that too liberal a model in medicine is evaluated negatively:

> *They say to us, mother, you know better (…). Yes, I do know, but I cannot decide what norm of medicine he needs.*

The meaning that I can find in this sentence lies in that the problem is shared between the spheres. The mother's role cannot handle any medical *home works* and investigations. A better support would be a *right* answer given by the doctor *what exact dose* will help; at least the families put this meaning in the sentence. Therefore, these controversial results show that it is very hard to give the best answer to the question of which model the doctor should apply in practice. There is a correlation between supportive as appraisal and supportive as too liberal.

Such results show that the supportive model can be quite slippery. Some kind of middle in support scale could be representation of family case 010. They say:

> *I can tell her everything without fare, she does not blame me for my comings and willing. She says you must try everything.*

Support as not blaming – it's an obligation to each professional. An important note with meaning hidden in the words *must try everything*. One family stressed the meaning that professional did not wanted to say that medicine is useless. The doctor on the contrary wanting to support trials to expand the medical sphere inspired to look for broader understanding of problem in other spheres.

Puzzled model (9) was represented as treatment that is not understood by the families, organized inefficiently, or not understood by doctors themselves. The families opined that there cannot be more considerable heartbreak for a mother to see her child severely sick. Usually *mothers* were telling of how hopeless they felt in such situations when doctors were puzzled and did not understood how they can help. Family case 008:

For many days various doctors were visiting and watching him (…) while the child was getting worse (…). The nurses started to say that it's not an infection (…) then the doctor said…it's something… some nonsense.

A diagnosis of *nonsense* showed to the family that the doctor did not understand what was happening with the child. The doctor could be puzzled himself as he got lost dealing with the child's worsening state and the child's mother in panic. Therefore his *nonsense* diagnosis tore the mother's ideas for betterment of the child and improved stress. Instead of giving any chance or telling the truth the doctor puzzled her.

It was very common that different families used even the same words describing the puzzled model (9). This similarity shows Family case 007:

I was constantly asking for this and another for further development (…) they do not suggest anything to us. Family case 007: *We are going through the doctors and nobody tells us what to do, how to do.*

Almost all families used the same words describing their *constant* asking and searching in vain. Only one case was exceptional. It shows that families perceived the whole medical system as puzzled. But the main idea was that families felt as if they were using limited service. Families represented that the feeling was as if there was no further development, no future, and no suggestions. Application of the puzzled model families represented as a narrowing social problem into the family's individual problem. Families represented that the severe disability of the child requires more than few minutes of examination and longitudinal care, but families are faced with understanding that governmental money is limited. Families reflected that it probably shows that nowadays functioning medicine is not ready to meet very special needs, it is more like a system taking both sides hostages.

Law *et al.* (2003, 365) commenting similar situations in his research writes that for parents having children with complex developmental disabilities it is essential to have co-ordination of service and as much as possible to have this service from fewer locations. Otherwise if the service is not co-coordinated and if it is possible to be received from many different service providers, the puzzled model will appear together with parental dissatisfaction.

Another example also shows the puzzled system (8) with which families had to face. Family case 003:

> *We had to drive a few hundred kilometres out of our way only for changing the drugs.* Family case 008: *There is a lack of kindness…and elementary understanding about invalids.*

Families having children with severe disabilities think they must achieve as much support as possible with minimum efforts. Instead of that parents speak of sorrowful experiences as going to the capital no matter what distance, with a severely handicapped child in hand in order to change the medicine when it is not known if it suits. Families speak about the sense that in case it is physically or financially it is impossible, the child is left to its destiny: survive or not. Tired after sleepless nights, 24-hours care they feel absolutely trampled upon after similar solutions.

Another example shows that there is a lack of communication among the doctors themselves. Family case 009:

> *I asked about the possibility for compensation of the sanatorium expenses (…) but the doctor said the law allows this from one year and a half (…) so we drove there at this age and medics there told us we should have come earlier.*

It is hard to say if coming earlier would change something; the families cannot get the answer to this question now, but families think doctors have demonstrated competitive relationships that led to the formation of guilty feeling for parents. The family heard words like these: *you waited one year instead of putting efforts into your child's achievements.*

And the last example shows families' perceptions on the system as absurd leading to exhaustion for the whole family. Family case 003:

> *There was one time she cried all month, we did not know why. (…) Then the doctor found a few teeth needing fillings. (…) Another month was for waiting in a queue (…) also I had to take my child to a psychologist, pediatrician (…) it was not enough that my child has severe disability.*

The family was telling about the absurdity in the reams of paper that has to be filled in for tooth problems. They felt that system surely is not on the side of family.

If a family doctor takes the responsibility for the child and states that it's the same severe disability from birth, why do parents need to take the

child to a psychologist? Families represent that where collaboration is needed in reality – like changing the medicines when it does not exist or where it is not needed – filling a tooth – there is an exaggeration. And the final result parents are telling of how overtired they became with a child screaming and suffering for two months.

Another first level of sub-category for picturing representations by families was called *limitations* model (10). This model is very closely related to the doctor's representation towards the child. In all experiences of families this model unfortunately prevailed. Families were telling of experiences that take the medical system one or two centuries back in time. The model of limitations existed in 18 – 19 century for people with mental and psychiatric problems. At that time there was no distinction in those two terms. The main features were: no worry about the diagnosis[112] or about comfort[113].

These statements have been illustrated by all family cases. Family case 008:

> *If a doctor does not have dimensional perception that a child is long and the bed is too small (…)… we slept together with a child in such small beds for two nights. It is just silly that I had to show the doctor his place.*

The mother of this child felt that if she has a child with severe disability and looks for help, they are treated as deprivative people. A child with severe spasticity had to sleep in small not fitting bed together with its mother. They both were labelled and they both were treated as limited individuals. Similar ideas were opened about a doctor's representations in the qualitative research made in 2004 by the Bioethics committee of the Republic of Lithuania[114].

More than half of family cases represented that in applying the limitations model towards a child, doctors tend to behave in more of a

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112 I mean that if a child was suffering severe cerebral palsy, doctors tended to show that the child was also mentally retarded.

113 In 18–19 century there was an understanding that *such* people are not feeling pain, cold, so even operations were organized without pain killers in some European countries.

114 The research was made on the basis of the project *The Rights of Patients in Lithuania*. Discussions in focus groups showed that disabled people felt doctors' preconceptions about them when they deal with health problems. Doctors tend to put disability over health problem. (Milašius and Čekanauskaitė, www.3lrs.lt/owa-bin/ access 2010/01/03).

medically radical way. Severe disability seems to be a case where doctors do not have the possibility to do more harm (6). Family case 007:

> *In centre Z they could have made an operation for the child that he did not need (…) that I would call 'if you have a problem – we will add to them'.*

This research is not intended to measure the quantity of medical mistakes. Though, more than half of the family cases showed that in severe disability, doctors tended to decide too fast which leads to mistakes. Therefore, the *mothers* having had such experience said they felt as *being* always *in check* in order to *protect* the child. This case showed that families see the medical system as fragile and just because of a mother's fight and disagreement on the hearing-improving operation, now she has a perfectly hearing child.

The greatest problem here is again no longitudinal supervision. Families' cases show that they go to medical institutions for social support and seek stress-buffering, but instead they face medical exaggeration which does not solve the problems. It rather creates more problems and even more contradistinguishes both sides. Families meeting other medics are led by previous representations and *do not trust* anybody.

Research showed that the majority of families experienced labelling and inequality in achieving urgent medical services for their children. They represented this as help being provided first for *mentally healthy children* and *those* children with disabilities can wait (7). Family case 008:

> *I would call the hospital a madhouse (…) they cannot make any examinations as they don't have the equipment.* Family case 010: *The role of the beggar is not cosy…we are not used to (…) that's why the child's tooth is not filled yet (…) if I had money, they would fill or go abroad (…) such families are much more esteemed and not treated as outsiders in Sweden.*

These examples take us back about 60 years and it seems that the ideas of normalization of Bank-Mikkelsen and Wolfensberger appeared in Scandinavian countries which around the 1950s as yet need to be implemented in Lithuania. Families say they would like to have equal medical service in hospitals.

Families represent that *feeling as normal are the criteria* for gathering medical service. And research results shows that one family experienced the possibility to compare and choose. Family case 007:

> *I much better liked clinic X than Y as there we felt normally (…) in clinic Y they gave only bad prognosis and said that the child will grow a fool.*

Feeling *normally* here relates to not-labelling, as the contrast is made exactly in this point, like in other institution the family felt it was raising a *fool*.

Closing any doors after diagnosis – such feelings lead Family case 005:

> *I said she has a lighter diagnosis, but the doctor said she didn't want to change anything.*

Research shows that if doctors say that it's better to keep the same diagnosis, families feel disappointed. Disappointment comes when families take into account the sense of such a suggestion and perceive it as if there would not be any chance for betterment. Using the limitations model doctors see what is just right now. Families representations show that if no longitudinal supervision is organized, each time a doctor sees the child being at the same stage, while families sees the movement forward. Any child put in new surroundings seeing unfamiliar persons could be afraid. Therefore the attitude of the limitations model wins – doctor diagnoses what was diagnosed before. Family case 008:

> *I imagine my child healthy (…) but they…in that neurological clinic…they…*

No matter what progress a child is achieving, the doctor tends to leave a more severe *evaluation*. Though for families it is not only evaluation, but seeing some *action*, change, shift and betterment. Perhaps a doctor acts like this for the family's interest – the more severe the disability, the more compensated benefits a family can get, but research shows that families don't bother about that[115].

The limitations perspective leads families to accept social support with caution (8). Family case 007:

> *I am afraid[116] because it already happened being among doctors, when nobody reacted and did not do Caesarean section.*

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115 One case (004) was in the whole of the research when parents said that they expected the worse evaluation of the child's diagnosis and mentioned that those expectations are clearly related to benefits.

116 Of traditional methods – treatment.

The severely handicapped child still needs help and families are afraid again and again to re-construct lost trustworthiness, therefore they have to deal with medical questions themselves and *become doctors*.

Another first level sub-category was created due to representations by families that I called a ***clear medical*** (9) model. This model should not be mixed with the traditional understanding that if medics apply clear a medical model it has negative features. On the contrary, I found it new for me that the majority of families were addressing the best evaluations to such a model of work. Family case 009:

> *Now I have a very good doctor, she is very pleasant (…) writes all papers I need for examinations, sanatoriums, etc.* Family case 001: *We haven't got even our papers ready, but our neurologist made everything for us to get into a sanatorium.*

Families are happy in meeting experts and with clear medical representations of their situation. Families *evaluate* doctors seeing their complicated situation and those who makes everything depending on their position which means: *writes all papers*. As parents understand the complexity of the system and problem of their situation, they cherish doctors that are taking *formalities* on their own. Family case 001:

> *She is very good, always sending us everywhere to all examinations.*

This case represents that families describe a doctor who uses the clear medical model as *good*. When the doctor sees that situation is unclear with the child, she sends the child to all examinations. The family mentioned they were happy having the same doctor for the child for ten years. This doctor meets the needs of family: enthusiastic about treatment, holds a positive point of view, and *normal* understanding about medical support. Where *normal* means examination before treating. Family case 002:

> *When the child gets sick we call an ambulance. The doctor makes the vaccination, she comes to our home, and I don't need to go with him to health centre.*

Only in two cases of families who participated in research were they raising children with critically severe disability. Those two families represented the most experiences from contact with medical personnel.

The first family at the beginning of interview said: *we suspended any contact with them* on the basis of unsatisfactory support provided by this branch of external resources. The second family was also dissatisfied with the majority of contacts, but what is most interesting here is *what* medical help they see as important. The answer could be found in the words: *she comes, therefore we don't need.* The doctor understanding the severity of the case visits the patient's home and makes the necessary procedures. When family case 002 was telling what is most important, they did not mention any personal features of the doctor. They were directed towards descriptions on the child's health and what medical instrumental help the doctor provided. This family did not even mention sharing the information.

When the clear medical model is applied in commission of disability or an ordinary check is made due to the regulations, families are not satisfied (3). Family case 004:

> I don't say that doctors are bad specialists (…) but seeing a child for the first time and after 15 minutes of examination to make a synopsis of the disability – it's unreal (…) only a glance is not enough for seeing that his condition is severe.

Families see that disability cannot be stated after only seeing a patient for 15 minutes. The model used in commission of disability was already touched upon before, when analysing the limitations model. But the main difference between those two understandings is that the limitations model applied when families were dissatisfied with the model and representations are addressed towards personnel and their point of view. And when families speak of the clear medical model, they are also dissatisfied, but mention that they are dissatisfied with the system and the medics are evaluated positively.

In both cases, either dealing with the clear medical or the limitations model, families represent the same needs. They want detailed checks and a holistic approach: how the child is acting in his daily life, if he is in process of change or not. There exists some kind of trap in this system: doctors are given a limited time for each patient, they are organizing their time on quantity not quality and governmental regulations require parents to take their child every year for repeated examination. The main

trick is hidden in huge wishes and low possibilities. I mean that repeated examination was constructed not in order to fatigue parents but for seeing exactly a child's process as active striving to change and betterment. It seems that the Ministries of Social Security and Labour together with the Ministry of Health have to review these procedures as at the moment, exactly fatigue and dissatisfaction with the process is achieved. Such a situation is not perceived as beneficial from all families' perspectives. It is clear from representations by families that doctors act in commission as if it were a technical obligation.

One family that was dissatisfied with the clear medical model (1) mentioned an aspect of power-over collusion:

<p align="center">family↔over↔doctor.</p>

Family case 009:

> *She kicked us out of her office… because we asked what belongs to us (…). That retired doctor thought she was a very big commandant.*

Families are speaking of doctors that sometimes tend to cross the professional line and use violence if power-over a relationship gets over-turned by the parent's initiative. Though fight again leads to lost relationship and parents have to start their search for another medic.

The first level sub-category of the medical model I called *other* can be shared into three second level sub-categories: ***insensitive, bribery, based on parent activity***. The features of the *other* type model I found in all the stories of families.

The ***Insensitive*** model (10) was experienced by all the families and often not just once. Family case 008:

> *Treatment is organized from ceiling (…) as the fact of disability has been constituted.*

Diagnosis of *severe disability* shadows any health problems. Doctors are perceived as insensitive as they do not take into account the essential stream of knowledge about a child's condition from the knowledge of parents. They definitely know if the child is reacting/ looking *this way* or *differently to what he should.*

Sometimes insensitivity may lead to parent's aggressive politics – fight or a model I called ***based on parent activity*** (8). Family case 005:

> *In a small city nobody cares about your problem (…) so I started fights for the seeking of examine.* Family case 007: *Now it is the same (…) I have not only this child; therefore I know what a child must do (…) then demand further observations.*

It seems that families construct a rule for the parent-doctor relationship: families are mediating between professionals and child in order to prove the child fell ill. I mentioned only two cases that look almost the same, but all eight cases were represented the same. That means families must be *active* and ready to *prove* that a child is different, perhaps sick. Families talked about the based on parent activity model in different cities and regions of Lithuania.

The most complicated second level sub-category and model based on ***bribery*** (7). Family case 007:

> *When the child got maturation of the eyes we drove to clinics (…), I paid to the till for an operation (…) but the doctor said you would do better if you gave that money to me (…) so I had no option but to open the cabinet's door and ask my husband if we had any money left (…) so I put that money on his table and said 'have it'… for a few days I felt downtrodden…a horror.*

This family felt downtrodden instead of supported. Being in a helpless situation they could not refuse to pay additionally because the child could have gone blind; time was not on their side. Another situation: Family case 006: *I asked to be examined… but they didn't… they were 'sleeping'…* suggests what doctors were waiting for.

An already overviewed family case 008 when the desperate mother had to pay *50 Litas as a compensation for 'wasting the doctor's dinner'*, and other cases shows that they had to pay money *because it is like a reward ahead for normal communication*.

We must notice that few years ago an act was released by the Lithuanian government where it was stated that a patient has the right to give a present to his doctor and it is not treated as a bribe. The doctors themselves were against this law and last year it was repealed. The main question is what actually is put in the *bribe* concept here? If parents are

paying taxes and according to the main law – the Constitution of the Republic of Lithuania the essential health service is free of charge. So, that means parents are not trying to buy a service. And in this case we are speaking of procedures or communication, that were organized in working time, planned and it is already paid for through the tax policy or in a till so that it should means parents had in mind a *quality* of service. As no additional service procedures were held or planned, no private consultations were made; doctors were getting their wages for work with those patients from their health institution.

5.4 Results of Intervention

Despite more negatively the overviewed sub-categories, first and second level sub-categories, families in general were more positive when speaking of the result of intervention. Some of the families said many negative things, mentioned inappropriate working models, personalities and personal qualities, but were satisfied with the final result. Such a situation is perceived as more beneficiary than for other parents whose process perceived the same negativity as the result.

The sub-category the *result of intervention* was split into first level sub-categories of: *positive*, *negative* and *neutral*. Various personalities and different institutions were evaluated differently, therefore many opinions were given. The first level sub-category *positive result* was split into the second level sub-categories: *depending on favour, on intervention, on alternative methods, and communication*. The first level sub-category *negative result* was split into the second level sub-categories: *no longitudinal observations, no trials-searching*, and *lack of communication*. And the first level-category *neutral result* was split into the second level sub-categories: *disability acceptance* and *gaming*.

Families that perceived interventions as *positive result* (8) more often were using the words *our doctor* or were speaking about a particular clinic or sanatorium where successful interventions had been made. These successes were *depending on* concrete *favour* (1). Family case 009:

> *This year we visited a sanatorium even four times. (…) Everything depends on the doctor (…) He can give a committal or not.*

For some of the families a positive result was perceived as depended on successful *intervention* (2). Raising a child with severe cerebral palsy means *living* in a sanatorium and constantly *rehabilitating the child* by various procedures, therefore here the result was very satisfactory. The actions of doctors helped to improve the physical condition of the child as much as it was possible. Other families evaluated a very professional care by doctors. Family case 001:

> *That centre takes care of such children very well (…) so she now walks more easily (…). The operations helped (…) as before, she could stand only on the tips of her toes and could not withhold her weight.* Family case 002: *Earlier his spasticity was heavy, now he is more relaxed (…) can even lift a finger himself.*

All the achievements of children are valuated as capabilities and the development of self-sufficiency. Instrumental support for children is generalized as if the support had been given to the whole family.

Parents tend to feel satisfaction with the relationship based on open *communication* (3) with a doctor even if the result is negative as facing with a diagnosis. Family case 010:

> *When we were in the clinics and the child was 5 months old, the doctor said they are going to suggest invalidity. I asked how is it possible to see that, as I did not. They said you will see when he needs to sit (…) and they were right.* Family case 003: *There they made all examinations and really proved we would have serious problems.*

Families were happy because of *paid attention to* the problem earlier than parents. In this case parents avoided visits to many specialists' in order to prove they were right that *something was wrong* with a child.

For a family disability diagnosis is always a new sphere that has to be discovered therefore they evaluate as positive the supportive mechanisms of information and instrumental aid. Family case 007:

> *Doctors in clinics were very helpful; they told us if it was better to start going to kindergarten (…) and practical suggestions were very useful.*

Families represent that professional information was understood as appraisal also, as doctors understood that there are peculiar issues that families would not know.

The same way as if a doctor sees a family's refusal to use *chemical drugs* he can help in seeking ***alternative treatment*** (2) that is also evaluated by families as very supportive. Family case 004:

> *This doctor helped us to find the genetic centre in St. Petersburg where we visit a homoeopath twice a year.*

Families were satisfied with the connection built and felt thankful for helping them to find *their* perception of treatment.

The majority of the mentioned second level sub-categories were based on medical supervision that guaranteed *quality* of service. The positive result and humanity, sensitivity that can be called *emotional concern* and understood as the best reached help that gives absolute satisfaction with the relationships built with the doctors. Family case 007:

> *Over all, the main thing was understanding… the Neurologist was always repeating not to surrender and see his achievements…* Family case 003: *she settled our affairs (…) so we did not have to take our child.*

Empathy with *understanding* and helping in *affairs (instrumental aid)* is the core of medical treatment for some families. Ališauskienė (2002, 34) writes that professionals may seek parents' involvement in problem solving; but not all are ready to knowledge how to do that and what would be effective. Sometimes parents and professionals may be scared of each other's communication therefore competition elements may appear. Therefore, negative results of intervention sometimes can cause lack of two-way communication.

Negative result (7) of intervention was also mentioned by the majority of families, though six families were telling of other medics with some more explanatory representations towards them, and one family was critically crucial to the whole system. The first level sub-category *negative result* was split into three second level sub-categories: ***no longitudinal observations, no trials-searching,*** and ***lack of communication***.

In general almost all cases describing negative results sound the same as Family case 010:

> *I thought if we went to clinics, doctors would surely help. But there even I needed help.*

Medical intervention as a negative result was always perceived when families met with an unfriendly environment in medical institutions, like shockingly lack of communication, disrespectfulness and no supervision.

The second level sub-category *no longitudinal observations* (2) was based not only on the fact that medics tend to observe a child and prescribe drugs without further continuum, but more based on how families felt in meeting such results of intervention. Families described how they felt blocked in their searching and even felt doubtful whether they were *mentally healthy* constructing so many conflicts. Family case 007:

> *Sometimes I feel obsessive, can even say I have mental problems, but what I can do if nobody says anything to me. I am interested in what's going on with my child.*

The research of Morrow *et al.* (2006) proved that a provided service and model of work has direct relations to the outcomes of children with cerebral palsy. When interaction between doctors and parents is positive, good service delivery, decision support and self-management support, then parents feel their stress is buffered. If doctors would spend more time ensuring optimal communication and understanding, it would give long-term benefits for the family.

It is an especially serious concern if the child really needs to visit a doctor, like if he is taking his *drugs*, so the child has to reach medical consultation on this question. Family case 004:

> *I had better not visit doctors (…) we are taking drugs against epilepsy now (…) but for how long we have to take them we also don't know.*

The second level sub-category of *no trials-searching* was formulated on the representations by families experiencing despair if their intuition was right and they disagree with a doctor or if they agree with a doctor. In both cases the results were evaluated as negative. Family case 007:

> *Our doctor said if he didn't do anything, it would be a norm (…) I don't know how it would have finished if I'd listened her then.*

Some families still experience a deep sense of *failure* and *guilt* as they *did not know* what they could do and they would be thinking *what if I…* for many years. Family case 008:

> *When we went to a sanatorium, our eyes opened… a huge sense of oppressed guilt that we had not been doing so much.*

The second level sub-category of **lack of communication** (4) was based on representations by families concerning intervention which is proceeding only technically. Family case 008:

> *We apply only because of sanitary napkins.* Family case 007: *That doctor is… like if you are going somewhere, so go. She's writing all needed papers and that's it.*

Sometimes lack of communication may lead to *refusal* of using this kind of help altogether. Family case 003:

> *I would not wish any parent to visit doctors at all…* Family case 010: *I have negative feelings about those clinics; we all decided[117] that we haven't received any benefit from there.*

The investigations of Groungaard and Skov (2006, 306) revealed that to receive parental satisfaction and coping abilities with the existing situation is impossible when there is no adequate communication and sharing the information. It is a difficult task, but can improve the quality of life in families with severely disabled children.

Neutral result (4) of interventions is given by about half of the families. A neutral result is more related to a family's point of view that they could not define the result achieved in one or another institution. The first level sub-category *neutral result* was split into two second level sub-categories additionally: **gaming** and **disability acceptance**.

The second level sub-category of **gaming** (2) is related to the representations by families that reflect some unfair games played against doctors. It has a close relationship to untrustworthiness. Family case 006:

> *This was not the first question on which we disagreed…just looking for another opinion.*

From the first sight it may seem as an easy choice for families like *we are looking another opinion.* But if is it really so? Families represent that they hear one opinion and search another without telling their doctor about

117 *All* means family members.

their different opinion. That means families are striving for: another doctor who could support *their* point of view or give *alternatives*. But from the roots saying such holds the position: *we do not trust, but need to withhold connection* therefore, the result turns into constant gaming.

The second level sub-category of ***disability acceptance*** (2) was constructed as a result due to representations that families had already coped with disability and they did not see how different something could be now. Family case 002:

> It is difficult to say[118]… he is a bit different, a bit stronger, can hold his head a bit… understand… we think he understands.

When families see just slight changes, they reacted passively to this question. Family case 001:

> That car accident was absolutely unplanned (…) but it is as it is (…) the same is about blindness (…) it is as it is… nothing can be changed now… it is as it is.

These families seem to have experienced resignation with the existing situation; they take the role of passive actors in the field of constructed reality. The research of Olsen *et al.* (1999) shows that family hardiness in the context of medicine is often evaluated as a family characteristic associated with positive health outcomes, but the hardiness must be also supported by two-way communication.

5.5 Summary on Constructing the Representations of Provided Social Support from the Medical System

In this chapter I will draw some meaningful points overviewing the analysed content. The main question answered here will be how families represent social support that was provided from the medical sphere.

The main schema listed in Figure 1 fully corresponds with the qualitative research to measure whether medics are important for the physical, social and psychological outcomes constructed towards reality.

118 If we are satisfied with medical help.

Analysis was made in four main sub-categories that were constructed by the families during the qualitative interviews: representations towards professionals, representations towards the child, model of work, and result of intervention.

Analysis of representations towards professionals showed that families meeting concrete personalities tend to give the same evaluations on the whole medical system. Therefore, it can sometimes cause a turning off the whole system.

Garret (2007) writes that parents constructing their own life experiences are relating the disposition *go on* as *social agent* that has been derived from life experience. Families describing personalities they met were giving the recipe how to deal with the medic as a cold-blooded, chemical intervenor, opposer, and power dragger. Dealing with the supportive professional no special approach was required. This *habitus* can be seen both as an *internalization* of reality and, in the moment of the practice. Families try one or another method of approach and the most beneficial is to internalize and use later as the best.

Externalization based on personal history as past experience, projected into the future. Unfortunately some of the families reflected negative representations in all levels of the sub-categories of the medical sphere and could not find any positive aspect. Therefore their externalization was projected as avoiding medical workers altogether.

Tew (2006) writes that it is quite typical that in describing medical professionals, families were creating personal identities such as cold-blooded, primitive or anything else. He says that families usually reflect such patterning on the whole medical system. These personal identities are structuring interpersonal interactions that can be a failure, fight or even some kind of violence.

Almost all family cases represented facing a serious problem in the medical system – existing power relations. In all the analysed sub-categories those power-over family interactions were reflected. There was one case when a family faced violence from a doctor when they tried to turn around such an authoritative relationship.

Families see that instead of creating power-together relationships those personal identities (doctors) create interpersonal interactions as authoritative relationships that become their internalization. Non-supportive relations are projected into the future and create a habitus of

attitude demonstrated during the parents' visits and the applied model at work.

Barreto and Ellemers (2000) state that one group's (doctors) representations towards another (children with disability) is also highly related to the power concept. Analysis of representations towards children showed that in almost all cases it relates to the whole family. Representations towards children were labelling, based on the experiments, forming unequal equality situations, and adjusting to some requirements from outside.

For highlighting the higher position doctors tend to use labels in order to spotlight the children with severe disabilities or a whole family's chances to improve their position. Such a situation may cause the situation that Mik-Meyer (2007) calls unresponsive, where a family tends rather to do nothing rather than *demand* positive active participation. In cases where the positive participation is not supported a family may feel discarded.

Constructing particular representation towards children, doctors try to make the family aware of the labelling reality. For example doctors create some personal categories describing a child's character (Yip, 2006) or re-call ancient beliefs (Dembinskas, 2003) that for one such it is healthy to behave in one or another way. Families represent that some of the doctors demonstrated the position that the disabled could choose *right* (health) or *wrong* things (disability), so pain can help a child to define the right position. If parents did not understand their child because of severe disability or choice not to communicate, doctors suggested let the child suffer, as pain may force some positive outcomes (e.g., child could say something).

Pescosolido *et al.* writes (2008) that the demonstration of negative representations and experiences of rejection affect the quality of life for children and their families. Neely-Bames (2008) states that positive representations towards the disabled have a prime relation with inclusion. Inclusion has been associated with increased feelings of dignity and life satisfaction and is considered an indicator of quality of life for people with severe disabilities and their family members. Only then may parents construct positive self-determination, emotional and physical well-being.

These inclusion factors can be described as lost or immature in the Lithuanian context at least in the medical sphere because parents are under pressure not to listen, diagnoses are still made in the corridor or

using irrelevant methods. Also parents who wish more flexible methods of evaluation in commission of disability are held as cheaters.

Demonstrated social exclusion (term used by Roche and Tucker, 2003) of families may occur with problematic behaviour like constant fighting and demands or passive surrendering. Families were telling most often of the use negotiation and arbitration models of communication. None of the families spoke about any experience of mediation. Usually families are faced with the doctor and they are trying to negotiate. Though in some cases where problems occur, families tend to use arbitration and drag in a third party which has power-over doctors. In such a way families expect to solve their issues. However such a situation is not beneficial and not in any way supportive. In Figure 1 such a case a stressed family leads to adjusting of coping behaviour as more inadequate with negative responses. Families represented that each visit to a doctor's cabinet is filled with negative reactions, despair, aggression, disbelief, gaming and dragging power to one side or another. Therefore if a family adapts to the psychosocial consequences as even more overloaded with stress, it means that the family cumulated in stress during the *support* process and came back to the first stage.

Analysis of the applied models in practice showed that even if we speak of the model, parents still tie it to personalities and their professional qualities. Models were shared as supportive, puzzled, limitations, clear medical, and other.

The supportive model was described as having features of trust, acceptance, felt willingness, openness of relationship, striving to help. Kurz *et al.* (2008) similarly describes medical consultation as centred on the patient that leads to the satisfaction of the parents.

Another, puzzled model was defined more on its blame aspect. It seems that a Lithuanian medical check has two actors: bad (*they*) and good (*us*). Families call themselves *us* addressing to the closeness, and *they* are further persons, not belonging to *us*.

The blame is hidden in each sentence where families are explaining what they did not do as they did not know or somebody had to tell them something and that would have changed something. The puzzled model also *identify possibilities to action* (expression used by Graungaard and Skov, 2006) because of the strong feeling of powerlessness that forces parents to act, try to do something, anything, not just to sit and watch.

Therefore, families use terms showing some continuum as if they were always in some process initiated by themselves.

The limitations model had the basic feature parent-professional role as *direct conflict* (term used by Borell *et al.*, 2003) connected to using the resources. Usually conflict was not avoided because families wanted to access some resources but saw that doctors wanted to limit their possibilities. This model also based on *in-direct conflict* related to devaluation of self, when families feel somehow being in a lower place than the doctor. For example some beggar, less estimated or if they have to prove something. In this model prevalence can be explained from the Sheldon's (2001, cited in Lymbery, 2003) defence concept: parents receiving a medical service have the right to expect that practitioners are able to justify the forms of intervention that are carried out. When parents meet irresponsibility from professionals they are trying to soften the feeling of guilt by the constant contemplations such as *what if*.

The clear medical model has positive evaluation when having a direct relationship to the expertise of the service that doctors implement. When the clear medical model was described in commission of disability, it was evaluated negatively. But families mentioned an interesting point that professionals were good, just the model of organization was not satisfactory. Families represented that doctors using the clear medical model must get feedback from them. Otherwise as Howe (2006) writes, occurring defensive mechanisms may form excessive attachment behaviours.

The other group of models used was met by almost all families. For example the Insensitive model was experienced by all the parents and often not just once. Mainly it was related to the clinical correction point of view. The major problem that was highlighted – attaching other disabilities to a central one when doctors do not share the disability itself and other health problems. Families actions were based on the parent activity model in order to represent their child's needs and problems. The most complicated situation was mentioned when families met the bribery model.

Lonkila (1999) explains this model manifestation on the basis of historical-cultural background left over from the dependence on the Soviet Union. In this period a *normal* practice was basing the relationship

on bribery. Usually the point of such relationships was to *buy* something like communication, useful information, favour, or something else.

Constructing satisfaction on the result, parents mentioned positive, negative and neutral aspects.

Kurz *et al.* (2008) writes that families see interventions as a positive result if family-centred consultations are applied. Such consultations seemed to have a direct relationship with parental satisfaction and better physical outcomes for the child. Law *et al.* (2003, 357) writes that satisfaction with a service and physical betterment decrease parental stress.

In the opposite, negative results of intervention were mentioned by the majority of families. Those families were mainly not orientated towards the outcome as a result of treatment but mentioned their feelings recalling from a particular experience in a concrete situation. Negative feelings had a direct impact on the perceived negative result to the child. Neutral result of intervention was perceived when families had already coped with disability and it was hard for them to think how it could be different or when families initiated gaming relationships.

Social support from the medical sphere is mainly focused on the duty of doctors – not to harm. When families were seeking of support they had some expectations on the child's betterment and that for professional care they trust that doctors have a sense of the problem. Even with the represented negative features and experiences, families were still looking for social support variables, like emotional concern, instrumental aid, information and appraisal.

The research showed that those variables are very close related among. The main aspect called *information* is the strongest and the weakest tool of a doctor. The research of Watson *et al.* (2006) shows that the need for information is crucial to parents and generally includes information about a normal child's development, children with special needs, how to help a child at home, and other. For sure families seeking any information about child's present functions and future prognosis is often threatening.

My research overviews showed that the representations by families are basically negative towards the whole medical system and medical professionals. Though it is directly related to the construction of a family-doctor relationship starting with appraisal and listening to what families

want to say. If families were seeing a doctor's emotional concern as empathy they tended to give much more positive descriptions on each level of subcategory. It was absolutely unexpected that *instrumental aid* was the last meaning in the social support pyramid. Also, a negative representation tended to be formed towards the whole system due to personal contact with the doctor. The other unsupportive medical personality met with seems to confirm the family's theory that all of them are so.

6 Representations by Families of Social Support Provided by the Educational System

In this chapter I will overview the shared sub-categories represented by families about the educational sphere: educators, representations towards the child, applied model of work, and the result of intervention. After all the analysis a summary will be given on analysed sub-categories.

6.1 Educators

Analysing social support from the position of the education system, the sub-category of *educators* was split into three additional first level sub-categories based on representations by families: *supportive educators, not-satisfying educators* and educators *as methodologists*.

The Supportive educator first level sub-category was mainly based on the representations describing a professional who is capable of creating a *safety niche* for children. The first level sub-category of supportive educators was additionally split into three second level sub-categories: *meeting needs, realizing themselves*, and *accepting parent-over position*. The *Non-satisfying educator* first level sub-category was mainly based on representations by educators on the child as a burden and the second level of sub-categories were: *based on unfriendly environment, on complaints*, and *on labelling*. The first level sub-category of *methodologists* was split into: *know how* (to reach a child), *open to parents* (flexible).

When families were speaking about a concrete educator they usually mentioned either the possessiveness of contact or methods of work. The main difference existing between the medical and educational systems is the much more positive meaning put into the relation between parents and educator. It is very meaningful; because families perceive the educator-parents relationship as having more longitudinal supervision patterns than that of doctor-parents.

The first level of sub-category is called *supportive educators* (8). This first level sub-category contains three second level sub-categories that describe the content of the safety niche: meeting needs, realizing themselves and accepting the parent-over position.

Families feel secure when those three second level sub-categories or components are met in an educational environment. Families think that meeting the needs of children is one of the main goals of the educator.

An educator who is ***meeting needs*** (4) is perceived as having the necessary qualities to handle the job, create secure surroundings for the child and gain the trust of parents. Family case 005:

> *The educator handles her well.* Family case 003: *We had a very good specialist once. She came, calmed down the child, and created a safety environment (…) only after getting feedback did she start work with the child: counting fingers…* Family case 008: *They have lots of work to do, especially during bad days.* Family case 005: *They do not complain that it is very difficult for them.*

Families in a disability situation know how it is complicated to work with a child therefore if they feel that the child is happy in this environment, they value it. Also when a family sees how professionally an educator perceives a child, they see that the educator is energetic, works with enthusiasm they take-off the sense of guilt that they are already too tired to work so much with the child. In this way families tend to construct trustful contact with educators.

The second level sub-category of educators as ***realizing themselves*** (8) was mentioned by almost all families. Communication is the basis for providing educational support. All families mentioned good personnel. Good means of observing their children, giving all the information concerning a child's being in the educational surroundings. It creates a feeling of development for the child and security for the parents. Usually knowing the details of the salary of these educators, families make the conclusion that educators do not work because of the salary, they work because of self-realization. Family case 008:

> *We are very happy about the personnel (…) they are all working for the satisfaction of children, for feeling happy and secure. And you feel this atmosphere there.* Family case 004: I *think they are working not because of salary.* Family case 009: *The director is very good-natured.* Family case 005: *I think our child is (…) heavy, he tires educators (…) so she can mount on their heads.*

The main difference here in comparison to evaluation of medics, families were describing as if all educators are open-minded professionals that are a

part of the *perfect* place created just for their disabled children. Educators are: good from their nature, ready to tackle problems, ready to accept and love different child, always ready to speak about that special child.

A very interesting position was revealed during this research in comparing educationalists and medics. A shift in the power-over relationship was found. If medical relationship was mostly constructed as power-over-parents, educators were forced to accept power-lower position.

The second level sub-category of accepting **parent-over position** (3) is based on the need to construct longitudinal relationships; families represent that because of that educators are open for collaboration. One family mentioned that they tend to show power-over relationships rather than construct power together. Family case 009:

> *I always call educators and speak with them. (…) If I disagree I say so, as only I know my child best.*

It shows us a construction of authoritative relationships. The meaning of being hurt and ready for defence is hidden there, as nobody was arguing about obvious things. But the family stressed exactly those words *to justify the surrounding* that they are *ready to fight* for their beloved son in case it is needed, therefore better *not to hurt*. Such readiness to fight behaviour was interiorized in other surroundings and habitualized as the most proper solution found. Family case 010:

> *Educators seemed normal, humane. I was afraid to leave my child in a group. (…) But later I saw that they took good care of my child (…) and they are not so bad (…) but he got tired very soon.*

The reason for measuring relationships exactly this way is hidden in a few possibilities: first possible – family's sensitiveness in facing new things. This family had negative preconceptions about educators, maybe they looked for features that would prove her thinking. The mother mentioned *they are not so bad*[119]. Also, the family had had negative experiences from the medical system, therefore parent-secure turns into attachment to the child and willingness to protect him. The same family was telling:

> *When he started kindergarten, he liked (…) later started crying, so I decided not to leave him there (…) and specialists there…like a speech therapist… she did not have any qualification even.*

119 As she was thinking.

This case shows how fragile the process of constructing social support is. The perception of negative experience of a child brings mistrust in further systems for the family; therefore, each occurred issue is evaluated as a great problem. In this case the family decided to take the child away from the kindergarten. Two serious reasons to keep a child at home were mentioned: the speech therapist was without qualification and the child did not like his group anymore. Wheeler (2001, cited in Lloyd and Dallos, 2006, 369) states that attachment has connections with altered negative perceptions and blame. The blame sense can be perceived by the mother if nobody shares this sense with her (Ho and Keiley, 2003, 244). In this case the decision was to take child out of kindergarten and the reasons were given by mother exactly.

An absolutely different situation is found if the educator is represented as *non-satisfying* (4). In this sphere there were only three cases telling of dissatisfaction, while evaluating the medical sphere the number was more than double that. The first level sub-category of non-satisfying educators was split into three second level sub-categories: ***based on not friendly environment, based on complaints,*** and ***on labelling***.

While families were telling of non-satisfying educational surrounding because of a ***not friendly environment*** (3), they addressed criticism not to the exact educator, but to the outside issues. Family case 003: *The situation with educators is very problematic.* This family described problems of not finding a proper educator for a very severely handicapped child, as educators are not prepared to deal with occurring problems. Family case 008:

> *The local government suggested we go to school (…) but we are created in extreme circumstances and the school could not accept us because of the unadapted environment (…) how could a government not know about this.*

Unadapted environment[120] and unready professionals are the main ideas families wanted to express showing their dissatisfaction. Sometimes families seem to be satisfied with educators, but problems occur in the system. Family case 006:

> *Contact was good with the educators (…) the problem was learning sign language.*

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120 It is contradictory that a special school for special needs children is not adapted to special needs children.

It appears that if families have a child who has to learn sign language, he can do it later or never, despite the fact that all laws guarantee this learning opportunity.

Hall (2002, 149) writing about inclusive education mentions two major things: the accessibility of the education service and indigenous workers (allied professionals). Negative evaluations about doctors were much more often addressed as *personal* antisocial thinking; educators were not blamed for the problems, usually: *situation*, *government*.

The second level of the sub-category **based on complaints** (1) was presented as very negative family experience. It was very rare for a family shared their negative feelings about a concrete person in the facility. Family case 002:

> *I am not very satisfied with educators… not with the educator, but with the nurse (…) she always complains that the child dirtied his nappies and they don't have time to change them.*

The second level of sub-category based **on labelling** (3) also reflects problems experienced with educators. The same families who were dissatisfied with relationships in the medical sphere because of labelling repeated the same in educational. This dissatisfaction varies with the severity of the situation of the child. In all three cases children were the most severely handicapped of all who participated in the research. The statuses of their children were presented as being much more close to *invalidity* than *normality* not only from the functional but also from the social point of view. By this I mean that the families had many times been neglected in the medical sphere, they carried a sense that Goffman would call *associated stigma* and medical stigma appears in the social context – school, kindergarten.

Families represent that differently from medics, educators cannot construct authoritative relations, so in meeting such circumstances they feel puzzled. Puzzlement changes to desperation or anger as families speak it is not so easy to find an educational institution – such an *invalid* child is not needed; he is too severe to handle. Then families tend to take the *habitualized* method as in the medical sphere – communicate only in *technical* questions like whether the child eats. Family case 002:

> *I don't like them (…) they do not communicate with my child (…) teachers are reclusive.*

Reason (1999) explains such a phenomenon as a two-sided incorporation. Parents strive to get as much intervention as possible for the child's sake. But seeking intervention in education they reach professionals that are explaining the failure of the system regarding child's severe disability. Therefore, such representations distract both parts from the main issue - meeting the child's needs.

Educators as *methodologists* (4) described by nearly half of the parents. If in the medical sphere information was the main supportive mechanism, so in the educational sphere information on methodology was the least important thing for families the same as the goals of child. This first level sub-category was split into two second level sub-categories: *know how* and *open to parents*.

The second level sub-category *know how* (2) is related to personal characteristics of the specialist. Generally it can be called *emotional concern*. Family case 007:

> *When we go to the kindergarten, the child makes a reach for the teacher.* Family case 001: *When she started to go to an educational institution (…) we lived together with her (…) she rejected all strangers (…) now it's the second year and she is able to live there for a week.*

The second level sub-category of *openness to parents* (3) is based on the acceptance of parents and flexibility in work. Family case 003:

> *I go there, communicate, stay (…) show teachers how I calm her down, persuade her into activity, and show teachers what activity could be organized for her.*

Parents are not afraid to show educators *what to do if*. The education sphere is *safer* as the educator is working on the child's development which can be reached in long periods of life. If the educator is communicative and wants to share information with parents, also trying to collaborate and ask parents' opinion they feel very highly valued. Family case 001:

> *Educators tell us everything about how she is doing (…) one is especially good, with her we can speak about everything (…) asks us what would be our goals, what would we like to do.* Family case 004: *Educators have prepared a separated programme for him (…) they are showing these programmes to us and telling us what results they expect.*

Families put the meaning in the sentences that educators share information with them and show them the things that have been learned, they consult with parents. Families represented that the main social support constituent in an educational institution is *emotional concern* for parents to feel secure about their child and *instrumental aid* assuring a child's development. Information is given for showing emotional concern and appraisal, but in reality it was represented by families as enough to know that the educators' work was satisfactory and for the child's sake. When we later spoke with families concerning the concrete methods, such as how educators are working now, they all said (4): *well, you know they have methods there, I don't know actually.*

Nelson *et al.* (2004, 162) writes that the relationship between educators and families is very important, as they form a partnership to meet the needs of the child and educator and they can be in a relationship where the educator provides support for intensive emotional challenges that the family is facing. Therefore, education as a *later* branch of social support is seen rather as a substitute for a child's life in the family than as a possibility to change the diagnosis.

The analysed cases allowed me to see *what really matters for parents.* One of the main aspects represented by families was that educational institutions and educators were perceived as practically helpful sources (instrumental aid). Families expect to get the same safety niche in an educational institution as if it were a substitute for home. And it is perceived so because of the tiredness of families from the constant stress and issue. Also families represented that seeing a child in an institution form activity content: celebrations, rituals (summer holidays, Christmas holidays, and other calendar events).

6.2 Representations towards the Child

The sub-category *representations towards the child* was split into three first level sub-categories: *orientated towards the child's strength, orientated towards the child's weakness,* and *burden.*

The first level sub-category *orientated towards the child's strength* was split into two second level sub-categories: *growth-orientated* and *normal.* The first level sub-category *orientated towards the child's weakness* was

split into two second level sub-categories: *disgraced* and *segregated*. The first level sub-category when educators demonstrate representations of *burden* towards the child was not additionally divided.

Representations towards the child as social support are very strong in the educational sphere. Representations towards the child practically forms emotional concern and appraisal showed towards the whole family. Families have a wish for educators to accept their severely disabled children and continue a process of socialization.

Despite each child having severe disability if educators use the ***orientated towards the child's strength representation*** (5) families tend to *forget* about the diagnosis, limitations and stress the strongest sides of the child. The second level sub-category of ***growth-orientated*** (2) mainly occurred mentioned strengths of children such as mental capabilities, socialization signs, or just the child's happiness. Family case 005:

> *They say she is reasonable.* Family case 007: *They tell me about my child, that he is orientated, communicative (…) interested in environment, people. Other children like him very much (…). Teachers said in the beginning that it's a view that he has been attending this kindergarten for a few years already. No problem, no tears.*

This second level sub-category was evaluated as very important for building longitudinal relationships by families. Families hear appraisal in the words of educators: *see what a socialized child you are raising, everybody likes him.* The biggest fear for parents is to see the child alone, neglected. They are always under the fear of who is going to take care of him if they would not be around one day. Therefore, when educators are giving the evaluation that a child's status despite disability is closer to *normality* than to *invalidity*, parents feel relief and the activity in the process – the child is developing.

Carpenter (2005, 180) writes when educators meet with stressful parents a need for new co-operative strategies for sustaining and upholding them appears. Inclusive strategies and involving family members (brothers, sisters, grandparents, parents, significant others) in the education process helps to feel acknowledged and valued.

The second level sub-category of ***normal*** (4) representation towards the child is an even bigger reinforcement for constructing alliance with

families. When families see development in other disabled children they construct the same expectancies for their child's achievements. Those achievements give the family the perspective of possible development of the child. Families get the chance to move towards something and perceive their child as capable of advance. Family case 007:

> *They told me what they are working on and I thought, oh my God how much patience and effort they need (…) I saw how other children were drawing and was surprised that it is possible to teach so.*

When parents see *the drawings* of other children that had similar problems they imagine themselves in this situation – maybe one day their child visiting this institution will achieve the same.

The comparison aspect is also very important in perceiving the child on a normality scale. Families seeing other children with disability tend to compare whether their child is *worse* or *better*. Family case 001:

> *I am so happy my child has cerebral palsy, not autism. When I saw parents of autistic children I felt sorry.*

These ideas are usually shared with the educators and withholding is expected.

Representations towards disabled children as *normal* can be demonstrated not only from educators, but also other children. Seeing how *healthy* children interact with disabled child, families shift the scale to *normality* rather than *invalidity*. Family case 004:

> *I was surprised about the children (…) nowadays healthy children are habituating to such children, in our times such invalids were second-rate.*

This family said that the child is perceived not as second-rated as expected but equal in the group of friends.

Despite the overviewed positive representations towards children, there appeared also the opposite – ***orientated towards the child's weakness*** (4) that is often met the same way as orientated towards the child's strength. This first level sub-category was split into two second level sub-categories: ***disgraced*** and ***segregated*** representations.

The second level sub-category of ***disgraced*** representations towards child occurred only in one case. This family evidenced the educators'

behaviour according to the correction model and demonstrated dissatisfaction with the child's condition. Family case 003:

> *Teachers told me he is too severely sick and they work with easier children.*

Instead of supporting the family and organizing an individual education programme fitting this child's capabilities, educators *take responsibility to share* what best could be done in their situation. Family case 003:

> *The head of the kindergarten suggested I withdraw the child.*

The family knowing the position of the head said that they would still keep their strength to take the child to that kindergarten because there was no other choice. Describing their feelings about this suggestion the family mentioned that they felt as if they were living in an ancient civilization. Family case 003:

> *I thought that such civilizations that used to throw sick people from the mountains or bring old parents to the forest have already gone.*

Lutz and Bowers (2005) say that similar situations may appear in discriminating and prejudicial societies. The change of such a situation is seen as eliminating discrimination and prejudice, removal barriers of access to services.

When representation towards the child is *segregative* (3) families were mentioning facts of physical separation of their child from other children. Families were saying that they were shocked seeing a child separated from other children, they felt as if their child was not a human. Family case 002:

> *I come to take my child and see him separated sitting next to other tables.*

Families were dissatisfied on such decisions of educators who can use general resources and who can sit children alone, separated from others.

Finkelhor (1984, cited in Kelly *et al.*, 2000, 115) states that such situations show that when a child is powerless, dependant and inferior, there are all the conditions for him to become a target of oppression or even abuse. He (ibid, 115) also states that children with severe disabilities have double the risk to suffer jeopardy owning to their further vulnerability, dependency and inequality.

Very similar to one of the medical positions that disabled people are different and they don't need what *normal* people do was represented by the same family. Family case 002:

> *He is the most severe patient in the whole kindergarten (…) when it was warm outside the educator did not take the children outside.*

The first level sub-category when child is a ***burden*** (3) was mentioned by one third of families. Family case 003:

> *They got the jitters from my daughter as she is too severe…* Family case 008: *He is a severe case (…) nobody can handle only the nurse from his school.* Family case 002: *They always ask me to come and take him home earlier.*

McLaughlin *et al.* (2006) writes about such a labelling process existing in many countries in the educational sphere. The most important that labelling unfortunately leads to attaching negative stereotypes, expectations and exclusion.

Representations towards children with disabilities are perceived as one of the main important factors in constructing relationships with families. No methodic can change anything if families know how much the educators are aggrieved by their child and how they are unhappy each day seeing him. Families instead of receiving social support through emotional concern, instrumental aid, information and appraisal are made the suggestion that they remove a child. Such complicated relationships cumulate in parental stress. And in case such parents have weak internal resources, they can feel absolutely frustrated.

6.3 Applied Model of Work

Questions concerning the model of work in educational institutions have been raised and discussed by various scientists and politicians. These questions reached their peak when integration of disabled children into secondary schools started. The most interesting question here is to know what model of applications they met and how they evaluate them.

Due to representations given by families, I apportioned only one first level sub-category as the ***individual*** work model. This first level sub-

category was split into the second level sub-categories: as *inclusion* and *as segregation*.

Only one model of work called *individual* (9) was faced by almost all families. Family case 005:

> *The teacher says that she needs an individual model.*

Kluth *et al.* (2007) presents her research about inclusive education. She writes that quite often inclusive education is faced with a range of obstacles, including educational segregation, inappropriate curricula, lack of appropriate support and services, and social rejections.

Due to family's' representations, the individual model of *segregation* (3) is applied in those educational institutions where disabilities are opposed over strengths and capabilities. Despite this fact, disability may dictate some peculiarities constricting the functions. Family case 006:

> *The government allowed teaching her sign language after my writing (…) so I can say we started to communicate with the child only when she started to go to school.*

The family speaks of the situation of having the only deaf child in a small city means the child needs an individual learning programme in order to communicate in everyday life. The problem is that there is no such specialist who can teach a child and other family members and that means that for until seven or eight years the family had to invent their *communication* signs.

Families speak that each case of a child with severe disability should matter and the environment has to be adapted to their requirements, because there is such a small number of such children. Family case 003:

> *In that school it would be impossible to speak about education: too many children, too noisy.*

If there is not an organized individual model in a particular educational facility, families and educators form their relationships through stress experience and confrontations. The same family case:

> *For the moment they accept my child but they call it a trial period. Everything will depend on the child's adaptation, if she is not going to cry and disturb other children.*

The family sees that educators are trying to protect themselves and express their segregative model of work showing that the child will probably not suit the environment.

Therefore, the educational facility is perceived as being happy to suggest a better for *them* way of learning, also based on segregation ideas. Family case 003:

> *She suggested a take home learning programme and that we remained at home. But I wanted her to be in collective with other children and come back home each day.*

Families faced with such a situation spoke of the situation in Lithuania a few decades ago, when many hidden institutions for disabled children were established. The only work model this time was – none or group model as a nursery. Nobody cared about social life, integration, and inclusion. This family sees problems in segregative thinking:

> *The programme is not bad, but I see nobody is working with her (…) in two months they made only stamps with finger on the list (…) but they gave me a huge list of means I have to buy and I took millions of Plasticine, books, scissors…*

The mother tells of her strivings to motivate educators in seeking the slightest changes in the child's condition and adaptation in the environment, though she says desperately that *nobody is working*.

The model is dictated by the same representation towards the child. The child was perceived as a *burden* and an *individual* who cannot fit the *general* norms so teachers don't see any purpose in working with a hopeless individual that soon will perhaps stay at home as they are all trying to create such conditions. Faced with such a model applied to the child, families represent their behaviour as communicating with educators as little as possible, sometimes even refusing to communicate. Family case 002:

> *There is nothing to talk about with them. They all are incommunicative.*

The individual model **as inclusion** (6) is met positively by families. This model is perceived as orientated towards the strengths of children. Family case 008: *He is a voluntary student there (…) positive and negative emotions*

show he is learning. A child being severely disabled is accepted as student with an individual learning programme and individual evaluation of the process he attends are expressed with positive or negative emotions. Family case 009:

> *They suggested to me an integrated group with healthy children (…) I was afraid, so the first year he went with disabled (…) the next year I already wanted him to be in an integrated group (…) now he is there successfully.*

This family case shows that the education process is fully corresponding with their understanding of social support: educational facilities are welcoming disabled child in *normal* surrounding, but if a family is not ready, they suggest another options – one year trial.

Families share not only positive methods in the education process but also speak about the applied punishment methods that it is suggested educators implement (1). Family case 005:

> *I ask them to treat my child stricter (…) and I will not be angry about that (…) we tell educators about our punishments at home (…) but educators say it's not allowed to apply them in the kindergarten.*

I was concerned about the methods, so asked them to tell me about them, and it appeared that punishment can be actually described as *methodological means*. The main idea of punishment – to give benefit to the condition of the child, therefore, methods like *gathering of beans* are used in order to give positive outcomes. The family thinks that by using such methods on a child is working on his attention span and improves small motorics.

Families telling of an individual model as inclusion mentioned that the system is still segregative (4). Families gave valuable information in their statements concerning the model of work with disabled children that is dictated from the government.

Family case 008: *It was a circus.* Family case 007: *Our kindergarten is 15 km away from home.* Family case 001: *School is 200 km away from home.* Families call existing situation as *circus*, because they feel as if everything is arranged in order to put parents into a clumsier situation. Families are raising the question if they have to drive 200 km away from home to reach their child's school, then why is this system called integrated? A

child is taken from home for weeks; has to change its life absolutely, as *normal* children live at home.

Kluth *et al.* (2007) writes about similar situations when educators inform parents that there is no possibility to get education in an inclusive classroom; therefore, the only chance of receiving such support is seen as conveying the child to school miles away from the family or a move to another location for the whole family.

The same physical segregations can be organized in integrative schools. Family case 006:

> *Her school is on the 4th floor (…) as she is the only child with cerebral palsy at school they are not going to adjust the building (…) in order not to fall she has to cross some spaces where are no handrails.*

Families were speaking of the needs of their children with various disabilities, such as adjusting the environment, individual model of work, more help while studying. But experienced of unsupportiveness described by families is demonstrated in reality by the model of cold-bloodiness of and lack of financial resources in the government: child with severe disability must *extend some periods, learn language at school,* as earlier the child did not need to communicate, *stay at school as a permanent inhabitant.* The majority of families represented the individual model as perceived as inclusion. Such a model is very valued by families because it is corresponding to the social support needs of families.

6.4 Results of Intervention

The sub-category result of intervention was split into two first level sub-categories: ***development*** and ***limited representation***. When the result is perceived as constant development, families feel satisfaction with educators and the institution. When the result was developed on a limited representation towards the disabled, it cumulated in more stress for families and created a sense of dissatisfaction.

The result of longitudinal interventions by educators is very important in a system of social support.

When seeing result as ***development*** (4) families mention a few of the main aspects: inclusion, increased the child's abilities, and self-sufficiency. Family case 004:

> *Children are playing with him, shares toys (…) participate in concerts (…) celebrate a day of disabled.* Family case 001: *Now it is easier with that school… easier when you feel the development.*

Families perceive that integration leading to inclusion can somehow make progress for their child, as he will strive to reach them instead of being *at the same level* with the disabled. Family case 004:

> *I see the last year that he spent in normal school; he was one among healthy children so the unbelievable jump forward is clearly seen.* Family case 005: *In another kindergarten she spoke less.*

For some of the families inclusion is really the highest evaluation. Family case 004:

> *I don't have any complaints at all, but my major joy is seeing my child together with healthy children.*

When a child attends school with *normal* children he can experience many problems, which are turned into positive thinking of the family. Family case 001:

> *They try to lead her holding her hand (…) it is hard for her, she gets angry… well, and it is still complicated for her.*

The family sees that process is being complicated, as their daughter is not so physically strong, though they evaluate it as a positive change and striving towards self-sufficiency.

Families speak of the results of visiting an educational institution as the sum of many compounds: the same social support variables, as concern, aid, information and appraisal demonstrated in any form clearly reflect on the result of the child's development.

When the result is perceived as ***limited representation*** (3) to the disabled it is a closing all doors for development which was faced by one third families. Families mention that in visiting educational institutions such cases are expected to fail. Family case 003:

At the age of seven she had to go to school. The situation is dramatic and complicated.

This family doesn't have the possibility to take the child to a school 200 kilometres away from home, therefore seeking education they call *complicated* and *dramatic*.

Another case is meeting with limited representations not from the system as previously, but the personal educator. A feeling of guilt and unfriendliness is experienced when a mother asks a particular kindergarten to accept her daughter. Family case 003:

They did not want to take us into that kindergarten but I was under constraint… so now I feel as a constrainer.

The used words *they* and *I* creates a sense of confrontation when two sides that should work for the same goal seem to be in a silent fight.

Families speak of situations where educators perceive a child as a limited organism, the result is the same – a full stop is put to development. The family visits the same educational institution only because of good nursing. Family case 003:

Educators lack competence in working with my child. But I am very satisfied with the job of nurses. They take good care of my child; they feed her, look after…

In this case the family demonstrated a sense of *bitterness* because the educational process was not organized, only care. Family case 003:

I read if you do the same action a hundred times, the paths will be formed in the brain that allow her to got further on her own, but only if you work with her.

These are the three cases mentioned of families who represent seeing visiting educational institutions as failure. When the result is raised by limited attitudes the problem is hidden by improper educational specialists. Then families say that they *do not see any point in kindergarten*.

Families spoke of periods of their life when having a child with severe disability was perceived as a very negative experience with a need to find confirmations or as a future challenge that the family is constantly re-

living. Family case 001 tells that their expectations about their daughter are just in the beginning and the biggest future strivings would be if:

> *She learns reading… somehow before 18 years… it would be very good. If she reads she could reach all the information.*

Such a saying shows that this family evaluates information access as the most valuable thing for their child equal to self-sufficiency.

6.5 Summary on the Representations of Provided Social Support from the Educational System

In summary of the overviewed educational system as a possible social support, I will overview the main ideas that were represented by the families.

In comparison to the medical system, the educational system was represented much more positively by families. When families were speaking of educators, eight families were even satisfied with the educators. The three first level sub-categories were split: supportive educators, unsatisfying educators and educators as methodologists.

Supportive educators were usually described as specialists having abilities to create a safety niche for the disabled child. It seems that families were describing a substitute for parental care in educators and the home environment in kindergarten.

Bronfenbrenner (1992, cited in Lindsay and Dockrell, 2004, 226) called this phenomenon the *environmental niche*. Poor development in the same way as positive development cannot be explained only on a child's deficiencies or the environment. All the systems are complex and transactional, the same way as a child and a system affect each other. Therefore *environmental niches* can be explained as particular regions in the environment that are especially favourable or unfavourable to the development of a child. One of the main points in this theory is – affection of the third part – parents. Parental involvement through support can enhance the match between a child's status and the environment.

Some of the parents expressed a strong attachment with the severely disabled child because of the urge to protect the child from the

environmental systems. Howes *et al.* (1994, cited in Tuompo-Johannson, 2001, 14) writes that mothers having secure attachment with a child tend to choose appropriate educational institutions for their children and indirectly affect the child's development there.

Families describe the personal features of the educator in a particular way: representing their good qualities they mostly concentrate on the surrounding and atmosphere while mentioning negative qualities always concentrate on personal qualities. For example, families say that an educator is good because he creates a calm atmosphere. And an educator is problematic, because he is not communicating, complains about the child or something else.

Selber *et al.* (2007, 51) writes that families using the educational service feel that they are consumers where they hope children will be met with respect and dignity. On this basis families hope to participate equally with care providers regarding their children's needs and treatment.

Educators were evaluated very positively if the child had rejected all strangers but due to some features liked the educator. Families represent this as if the child had made a choice. Howe (2006, 100) notices when parents raise children with severe disabilities they may experience an increased risk of insecurity. Therefore, such caution is reasonable in this situation.

Dellve *et al.* (2006) writes that such contact may be seen as achieved support from the environment (service providers). The supportiveness based on communication through parental involvement.

Individual representation towards children (created a personal programme) creates a sense of worth in the child himself and parents, as the process is discussed with the parents. Mitchell and Sloper, (2002) write that educators have to think in what way and manner to disseminate any information concerning the child, as parents must feel they are of the most practical value and worth. Mitchell and Sloper, (2002) mention that each parent is unique and they all need a different depth of information. The same shows in my research, that parents evaluating educators for special methodic and good results can barely say exactly what the child is working on.

Another sub-category evaluating the educational net as a social support provider was drawn to the *representations towards the child*. Families shared three types of representations towards their child met in educational

surrounding: orientated towards the child's strength, orientated towards the child's weakness, and as a burden.

When families meet positive representations towards their child, the most mentioned perceptions were as if the educational process is directed to some activity in change. In such a way educators create for a family a sense of being proud of their child. Clare and Mevik, (2008) state that research shows that children are often not credited as competent social agents in any process of their development, rather like passive recipients in their best interest. Therefore, giving the perception to parents that the child is part of a system. Involvement in a small community of other children is important because here parents find their child in a shifting role: from passive and vulnerable to an active player in the area of human endeavour (Badley, 2008).

Families appreciate educators seeing the possibility for their children to grow and even reach some results (like paint a picture). The importance of seeing inclusive representation towards the disabled child is hidden in seeing the needed support and supplementary aids from the education facility for assuring the child's success – academic, behavioural and social – and preparing the child to participating as a full and contributing member of society.

Negative representations towards the child met by families were perceived as labelling, such as to withdraw the child, physical segregation, discrimination.

These features are rather labelling than as Gibson (1991, cited in Nilsson, 2003) writes maintaining an anchor within the families. The labelling process allows educators personally to demonstrate a negative representation towards the idea of inclusion and helps to differentiate *disabled* children from the *normal* (Smith, 2007, 469). Goffman (1963, cited in Burcu, 2007) write that if children are discredited, this labelling weakens the ties not only within the group of children but also in the family itself.

Representation towards children with disabilities that are demonstrated by the educators is one of the main streams to express social supportiveness of rejection of the family. Families say that in demonstrating negative representations educators close the door toward the implementation of inclusion in practice. The same researches that were presented in the

theoretical part (Ruškus and Mažeikis, 2007, Ališauskienė, 2005) proved that Lithuania has almost the same inclusion problems as there were in 1999, because social attitudes towards disabled people have not changed even in the educational sphere. Instead of changing the attitudes, some of the educators tend to seek an ancient understanding of disability and feel comfortable in suggesting parents to remove the child, as if it was not a human being, *something* like *terrata* (term used by Ruškus, 2002).

The analysis of the applied model of work was surprising, as all the interviews revealed that families represented that all their children needed an individual model and an individual approach. Though despite families' understandings that a child needs an individual model of work, representations towards the child show that educators demonstrate either a very successful implementation or dereliction of their duties saying that they don't have the additional time for children.

Oliver (1983, cited in Barnes and Mercer, 2005, 531) writes that when an individual model was successfully implemented, it could be understood as an individual-social model. In such a model clear relations between children's functional limitations and the barriers to social inclusion are seen: if no barriers for inclusion are created, the child is seen as wider than a limited organism.

Barnes and Mercer, (2005) write that as opposed to the social or holistic model, many barriers may be mentioned by parents for the inaccessibility of education. Representations by families showed that educational institutions are perceived as lacking financial and human resources in order to implement inclusive education. Families mentioned the main problems: there are no possibilities to learn sign language, the environment is not fit for wheelchairs, schools for the disabled are established on the fourth floor without an elevator, some of the barely walking children need to miss some periods as there is nothing to hold on to, or the educational institution is 15–200 km away from home.

Analysing the result of intervention, representations by families show that the best result is interconnected with inclusion. A scale of measurement of disability-normality is very important. If the educational institution involves the child in a group of *healthy* children or work with the child in order to move towards *normality*, then the result is perceived as positive or very satisfactory. When the situation is different, families

tend to mention again personal features of the educators; such as nobody is working or nobody has the qualifications to work.

Castaneto and Willemsen (2006) raises an interesting idea that educators evaluating children with disabilities tend to have *their own* attitude towards them depending on their disability, for example, the deaf are more favoured than the paralyzed, while the paralyzed are more favoured than the developmentally delayed.

Families speaking about the educational system represent their expectations of finding longitudinal social support. The main point noticed in all cases is that families are full of two-sided emotions when seeking this support. Families seem to be more sensitive in seeking educational support, because they already have had negative experiences in the medical sphere. The main difference is that families were coming with a habitualized behaviour of protection. In some cases just because of this habitualization power-together relationships were not represented as being possible to be constructed, rather they can be called as parent-over relationships. Two families raising the most severe children had very negative experiences in the medical sphere and the educational sphere which were accepted as desperation. They are in constant conflict with educators.

The most important role of an educational institution for families in the social support schema is socialization. Families see an educational institution as a continuum for the disabled child – secondary socialization through an inclusive environment.

7 Representations by Families of Social Support Provided by the Social System

This chapter was constructed with the same logic as previous two. The main category of the social system was also split into four sub-categories: social workers, representations towards the child, model of work, and result of intervention. In contradistinction to previous analyses, this chapter is constructed not only on representations by families, but also some analyses are made on their given ideas and images on the research topic.

7.1 Social Workers

Before starting to observe the sphere of social support and social worker's roles in it, I have to mention that this part of the research was absolutely not acceptable in its results. Families raising children with severe disability should meet a social worker during the 5–14 years of seeking help. I experienced a great surprise when during the interviews almost all families said that they never met with a social worker. Some of the families could not explain what sphere of specialist he should be (3), and it was astonishing to hear that a social worker is a *specialist* who is entertaining (3) parents with some activities when that is *nothing to do*.

The sub-category of social workers was split into the following first level sub-categories: *misunderstanding* (but helping), *title*, and *professional*. When the social worker is only a *title* this first level sub-category was split into the second level sub-categories *absent*, *general specialist* and *theoretical image*. The first level sub-category of professional social worker was split into the second level sub-categories: *informators*, *appraisers*, and *bureaucrats*.

The first level sub-category of *misunderstanding* (3) was formed due to representations by families who were confused in giving a picture of social workers they had met.

Constructing the social worker's image, some of the families definitely did not know what a social worker was, therefore, were often confused describing the social workers, and the descriptions really showed that

families are speaking about a *social worker* who is definitely not a social worker. Family case 001:

> We attend NGO, so there was a parental support group, so the leader of that group was exactly a sociologist.

Families don't see any difference between sociologist and social worker, or social worker and physiotherapist. Family case 002:

> Good workers. They help me if it is too heavy for me in massage, they help me to hold the child (…) they come to do massage from the third floor to the first (…) really devoted. Family case 001: *Social worker we met only in sanatorium. (…) He works more for… what for… like… somebody… makes massages for the feet, and somebody-what…*

When families did not know how to describe the social worker, they started to recount general ideas, like a social worker *does something*, but we *don't know what*, like physiotherapist who does foot massage, the same social worker *constructs his help somehow*.

The first level sub-category describing the social worker as only a ***title*** (8) due to the representations by families describes the situation that they had never met a social worker, or met but could not say for what this specialist was needed. Hearing the last representation, I asked families to created ideas of what the social worker could do. This first level sub-category was split into the second level sub-categories ***absent, general specialist*** and ***theoretical image***.

The second level sub-category where the social worker is ***absent*** (5) was met by half of the families. Some of the families met educators with social workers' professional qualifications. Family case 006, 008:

> We did not meet real social workers. We met educators that have a social work diploma and work (…) in my child's school there is no such position.

Another interesting finding I met with in this research is that half of the families mentioned that they had never met a social worker, and later speaking of sanatoriums some of them were describing the social worker. That means families do not hold this meeting as social support or it was not meaningful. These ideas are proved by the given representations by families. They did not see the social worker as social support provider.

On this basis the second level sub-category was given a category which describes the social worker as a ***general specialist*** (7).

Half of the families were representing ideas that they did not know what support could be gained from social workers. Family case 009:

> *I don't know what her functions (…) are… just found an advertisement on my sanatorium door 'please come to have a talk when you have time'. So, you just go there and talk if something is not clear for you and what new laws…*

Two family cases gave representations of an unprofessional social worker which appeared to be crossing professional boundaries. Family case 006:

> *For example I get along with one social worker in the sanatorium… But what help I could get from her… I am absolutely without thoughts (…) even information I can not always get (…) Well… it's a person… really have to do something.* Family case 009: *When there is nothing to do, we go to the social worker and drink coffee.*

Families perceive the social worker's role simplified to coffee drinking or *chatting*. Therefore families think that the social worker is some kind of general specialist, a person with whom you can spend your spare time in the sanatorium and nothing more. Families do not even expect any social support compounding prevalence. Such ideas seem for families impossible. The social worker is perceived too simply for creating just friendship relationships, and therefore, he is seen as too weak professionally, as such relationships don't lead to solving any problems. Such lost professionalism could barely be rebuilt when the same family came to the sanatorium. It is also possible that the social worker can feel professionally weak therefore, consciously construct relationships with families based not on information and instrumental aid, but on emotional concern growing into identifying.

The second level sub-category when the social worker is a ***theoretical image*** (3) was described by one third of families.

Using their imagination families tried to describe social workers as specialists. Family case 008: *Those social workers…how to say…They are various…* *Various* term shows that families have no clear image what this specialist should do and how he could be useful in their situation. Some of the families were asking for a description of this specialist. Family case 003:

This term[121] is not a bit clear. Where could we meet them? (…) I heard that the kindergarten has a social educator… what for?

The theoretical image of the social worker for some families seemed possible as an objective arbitral with mediator's functions in the commission of disability. Family case 004:

We don't know about social workers (…) Maybe he could be a specialist in disability commission like from the side, objective. He could observe the child for a longer period and his word could be determinant.

This family had a previous negative experience which they called a *unilateral* decision from medics investigating the child's self-sufficiency, therefore, the social worker as a *decision maker* seems beneficial in their situation.

Asking families to say their opinion of the possible functions of mediator of the social work, usually they did not understand. Family case 003: *Such functions are not understandable at all for me.* Later this family gave some ideas about the social worker:

I think disabled people are not so many (…) and there are lots of social workers that do nothing. So, maybe some of them should call to explain what is new, what new laws, give some information, could attend, observe. (…) We tried to look ourselves but it's…

This family represented the functions of the social worker as some kind of information provider or person who could clarify new legislations. The family represented their wish for a social security guarantee by providing new information, instead of allowing the process to flow.

The overviewed excerpts show that social workers are very rare specialists in the social support system according to families' representations. My initial idea was to reveal more of the social work context, but during the interviews I had to add additionally more to the social system as support. It happened because speaking of only social workers gave the same result as: *don't know, we did not receive, not understandable.* The families could hardly construct a theoretical idea about any possible *positive* joint that could exist.

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121 Social worker.

While analysing the first level sub-category of the social sphere workers *professionals* (10) that some were social workers and some called specialists taking care of disability affairs in governmental or nongovernmental institutions, three second level sub-categories were defined: *informators*, *appraisers*, and *bureaucrats*.

Social workers as *appraisers* (8) were usually met in sanatoriums and NGOs. Families described such workers as emphatic persons. Family case 001:

> *That social worker in the NGO how to say… kind-hearted lady, so what she could, she told from her side (…) now she is no longer a social worker, but very good and sacrificing.* Family case 010: *She was very warm person (…) I recovered there; she was very understanding, emphatic.* The same family case: *she was very nice (…), encouraged me a lot… advised me where to seek help, so we got a wheelchair and seat…*

The social worker from the position of families is perceived as a specialist close to consultant, as providing emotional concern, appraisal and listening functions. Those social workers were represented as very *warm, and understanding*. One family mentioned the social worker's *responsibility* as *scarifying*.

Families describing social worker as *informators* (8) mention that these specialists provided or should be providing information services. The mentioned cases show that where families lack information they can join mutual groups in NGOs, because it is easier to reach *at least information*. Pearson (1990, 13) thinks that creating mutual social support groups is a democratic sign of participation in a natural system. However representations by families show a different situation. It is rather a striving to chink the gaps opened by *governmental spheres*. Social support as a way of providing information or appraisal is still based on the most important aspect perceived by families – communication. All families mentioned that their mutual groups are important because of this compounding. Communication is the basic element produced in relations among systems and environment (Ritzer, 2000, 322–325).

Social specialists as *bureaucrats* (9) mentioned by almost all the families. All those specialists were described as having been met in governmental institutions. The commonly represented features were:

lack of communication, and unwillingness to help. All descriptions by families were almost identical. Family case 001:

> Those social… in that social care, they always sit sulky. (…) And if you need to talk about subsidized apparatii… they are not nice… and if you don't know something, it's your problem.

Those workers whom the families met were the representatives of governmental organizations, therefore, later, speaking generally about the social system as whole, families mentioned the general representation that the system does not take care of *such* families.

7.2 Representations towards the Child

This sub-chapter was organized a little differently from the others, as in the majority of cases, parents could not report on social workers' representations towards children for the simple fact – they had not met social workers. Though, I will mostly give my attention to the analysis: representations towards the child met in the social system.

Three first level sub-categories in the sub-category of *representations towards the child* were split due to the given representations by families: *emphatic*, *burden*, *expecting poor*. In all the social supporting systems the same representations towards the child as a burden was repeatedly indicated.

Two families mentioned examples that were categorized into the *emphatic* (2) representations towards the child. One family mentioned that emphatic representation was shared not only with the child, but supportively to the whole family. Family case 007:

> The social worker taught me how to love from the heart, have a wish, burrow into myself and not to leave[122]. Just fight, fight and everything will be okay.

The mentioned cases are based on demonstrated emotional concern and appraisal for families. The emphatic representation is perceived when the social worker *understands* how difficult the situation is and consults professionally showing representation towards the child – *not to leave*.

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122 The disabled child.

No crossings of professional boarders were mentioned as a necessity. Satisfaction was achieved because of professionalism, not personalization.

The same family made a comparison to another social worker met in another centre. The family pointed out that they did not like that social worker because she concentrated only on *general information concerning some benefits, no empathy, and no further communication.* Family case 001:

> *The educator is working well with her (…) everything we arrange, with her help. The social worker doesn't know any of the children.*

The direct functions of the social worker as written in the law do not included knowing all the children in the educational institution, but it is mentioned that the social worker has to know families and construct relationships with them. This case shows that the *educator* partly fulfils the social worker's functions at school.

Therefore, families see it as easier to solve all social sphere problems via the educator than built new relationships. In this case the educator shows an emphatic representation towards the whole family. The social worker uses inflexible representation towards families, based on parents' activities.

The representation when a child is perceived as a **burden** (9) was met by almost all the families. It has a direct relationship with the next representation when not only the child, but rather the whole family is perceived as expecting poor results.

Usually families indicated such representations as being met in governmental institutions. A child is held to be a burden putting its family into a beggar's position. Family case 002:

> *We had a wheelchair with a table, but it did not fit, he would fall out of it (…) also he had special bed, but we consigned it to storage as we all live in one room, there was no place for it.* Family case 010: *I cannot buy[123] a good apparatus. He is long now; the car seat is too small for him. I asked if I could get one, the answer was that they exist but I couldn't have one. If I had money, I'd better go and buy it instead of begging.* Family case 008: *All wheelchairs are not suitable for him. So we are waiting for wheelchairs from aboard… but cannot get them (…) Lithuanians working in this field are doing so only for 'laundering money', as even a seat in a car has to be re-adjusted by the father.*

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123 Afford.

Families represent the situation where a child with severe disability has to satisfy the basic needs to be eligible for funding for an apparatus that would preserve at least some dignity and self-sufficiency. The three mentioned cases showed that wheelchairs are not adapted for special needs therefore; families feel as if they are having to expect charity from aboard or construct them themselves. One family said it cannot use apparatii at home because of their flat being too small. And this family has still been on the waiting list for getting bigger flat for many years.

The acts of the Ministry of Social Security and Labour, which were overviewed in the theoretical part say that parents receive about two times higher benefit if a child is nursed at home by the father or mother and less if nursing is provided by professionals. So, the main representation towards the whole family is more one of excluding. Such acts force family members give up work and stay at home with the disabled child. The prevalence of such a phenomenon is also supported in the educational sphere.

A child is perceived as a burden in some governmental institutions, because of the representation that they waste the money of the budget. Family case 003:

> I heard about 40 Litas benefit was available for transport, so asked in social care. They glanced at each other and said: we will get into jail for giving all those benefits… Alright, we'll assign it to you… So I felt as if they had done a great favour.

Authors Mitchell, and Sloper (2002, 74) write that recent research shows families with chronically ill children are often confused about what services are available, what different professionals can do. Therefore they need more supervision and more social support. Cases show that instead of demonstrating empathy and additionally asking if families are receiving benefits to which they are entitled; families feel that governmental institutions are more likely to withhold this information instead of sharing it.

Families coming to clear matters about benefits meet with the representation that if *those beggars have come again; let's hope they did not find any additional information concerning the benefits*. Because of such representations families tell of having to habitualize and use the most beneficial behaviour models. These can be various, from fight and begging

to severe quarrels in order to get what is needed for basic existence. In almost all cases families indicated having used negotiation, confrontation or *swallowing*. One family mentioned that they had used arbitration to solve their problems. This family complained to Ministry of Social Security and Labour about problems in the lower sectors. Family case 010:

> *If the wheelchair was to be given through the district authority, there was a chance that we would not get one because of the shortage. So I asked the authorities in Vilnius directly to get a nominal.*

The faultiness of the existing social system creates a representation towards disabled children as if they are only some ballast, therefore a conscious hiding of information and negative representations are perceived as being demonstrated in the governmental institutions. It is interesting from the Goffman'ian position that families faced with such an unsupportive system speak of changes in their inner personal qualities and adapting even *illegal* methods of *communication* and search for methods of paltering to get the things they need that are efficient for meeting the basic needs of the child.

Representation towards the whole family as ***expecting poor results*** (7) was also met in governmental institutions. Family case 001:

> *We got twice as much money when she stayed at home with me. Now she's started to go to school, so they cut half because I don't keep her at home.*

Such examples show that *mothers* are given the *non-discussed* choice – stay at home with the child. Families call such two-sided social politics as giving with one hand and taking it back with another. Family case 003:

> *The same support about everything. We had to buy a house, so when we took a loan, the government had to fund 20% of the house price, but as our credit was more than 240 thousands, that means no funds at all.*

The representations by families show that the lack of money for the social sphere creates a rule that it is expected of all disabled to live poorly. Families mention a *miraculous circle* of social support. Family case 010:

> *It is too small what he gets as a benefit (…) so I have to go to X facility and beg there for more. If they have any money left – I can buy additionally massages.*

Families talk about cases of having prescriptions for more instrumental aid from governmental institution they also have to visit another governmental institution begging for help. When all the families depend of such begging because of a lack of personal money, they speak as if they feel locked in the same *circle*.

One family mentioned that its severely disabled children could not receive the essential medical support and addressed this unsolved situation as gap in the social system. Family case 002:

> *If we had more money we would have an operation on the cochlea. The neurologist said he needs this operation.* Families reflect that *nobody cares about us.* Family case 008: *Money is enough for our family (…) but if there was more of it, we could do many more things that our son likes, like going to the concert, as now it is expensive.*

Families see their children as not only having basic needs – physical, but also social participation – live *normal* social life, like attending concerts. Representations by families indicate that it is only possible in rare cases, as the financial situation does not allow them to go more often.

The last cases reveal representations expecting poor results for the family in rather an extraordinary way. Families tell of cases of bribery in getting compensated apparatus. That means when families ask for equipment, they do not get it for free, but easily get when it is paid for.

Representation of it being normal to rob families and leave them poor was mentioned in two cases. Family case 007:

> *I bought those shoes, but I think sorry, my child is sick and they're taking advantage of him so… it is enough that we meet the same in hospitals, everywhere our money is needed. That attitude is not new to me… it's a normality.*

The family was telling about the compensation for shoes. When presenting all the needed papers to get shoes for free it was said that it was impossible to get that size. After the parents said they will buy them, the worker brought the shoes in the same minute. The family compared such a social system to the medical system in the sphere of bribery. The same case:

> *I think it is awful. It is guaranteed for a child to get benefits but the system takes the last things that belong to him… attitude towards a human being – no empathy.*

No empathy means *bribery, and malapert* to take the last money from a family's budget in order to get something.

Another case reveals that in order to get something because of the severe financial situation, families have to use their children. Family case 008:

> *We are participators in NGO. A head of that facility asked us to join. She said I need such children with severe disability as she wanted to write projects to get funding.*

Therefore, some families are formally the members of mutual groups with concrete goal – to get some benefits.

Representation towards the child in the social sphere is rather unsupportive than helpful. The majority of families indicated different situations when social support was essential but instead of gaining help, they faced as if they were again raising additional problems by asking for some benefits. Two cases of families represented met empathic understanding, where empathy is seen as appraisal, information and emotional concern in one.

7.3 Applied Model of Work

It is not surprising that after making the previous analysis of the interviews with families, analysing the applied model of work is mostly puzzling, as it was already seen that the social sphere was perceived by families as full of problems and fragmentation. Previous analysis showed that families felt rather as being the enemies of the system than consumers, not speaking of being partners. Only a few families could mention social support provided by a concrete social worker in a concrete centre. The sub-category applied model of work split into four first level sub-categories: *red taping, informational, none,* and *you need*.

The first model of work is called *red taping* (2). This model contains representations by families describing some documents that the social worker was constantly filling in. Families thought that such red tape caused delays for the expected social support because the social worker needed more information about the child. But in the end it appeared

that social workers were using their position for some surveys or anything else, but definitely not for constructing support on the basis of gathered information. Family case 002:

> *Social workers gave me lots of questionnaires to fill in; they wanted to know more about his illnesses.* Family case 006: *We met the social worker in X centre… But I don't know what her role… was… She was just constantly filling in something.*

These two examples show that the social worker's model of work is somewhat different, surely not family-centred. Despite the families' thought that the *social worker wanted to know more about the child*, the whole context rather indicates a meaning that the social worker filled in something and questioned the family without giving any information of what the reason was for that and how it could help family with their issue.

The ***informational model*** (5) was mentioned by all the families who said they had met a social worker in seeking social support. Family case 005:

> *Their job - providing information about rights in the sanatorium.* Family case 004: *We think the social worker is needed for giving information.* Family case 010: *A social worker consulted me, I could get all answers to my questions, but I did not know what to ask, what benefits we are entitled to.*

Families represented that the information model can not only hold positive aspects, but negative as well. In some cases families were describing the social worker as a passive agent giving answers and showing no initiative himself. Families were representing it as if something was unclear and they did not know what to ask, therefore they were left without information.

Families represent that there are different ways to provide information, especially if the comparison aspect appears. Family case 007:

> *We did not like the social worker in X centre. She just gave the information that we have the right to get 3 tools for the child per year. And when we went to get those things it emerged that we could get more, and we already had bought a ball for him that cost 100 Litas.*

The family is giving a sense of the absurd existing in the social system. Such puzzled information created a sense for the family that all the joints

of social support belong to different systems. Families tell of joints of the same support system lacking communication between them. Therefore, families see this system as a place where it is possible to get lost easily in those gaps of misunderstanding.

Families represent the most problematic aspect in social support are that they have to face issue solving without any coherence among separately working fragments when dealing with serious life questions (1). Family case 003:

> About house benefits we new in the bank, so went to the social care department and they said everything has been changed (…) then by chance I heard that there is compensation to adapt a house for the disabled, but again nobody there confirmed that to be so…

The family was speaking about their despair in the social system; it leads to neglecting the whole system and unused social resources. The same family holds very negative representations on the medical and educational systems.

Sometimes families in mutual help groups organize an *informational* model for themselves. This case is not really this model application and has features of the *you need* model which will be described later. The family is telling of their membership in NGO. Family case 001:

> The social worker invited somebody from SODR'a[124], and sometimes from that social… social care.

A fascinating opening in this research was to find out that families tend to change and look for information among other families instead of asking a professional social worker. Families tend to implement the informational role of social workers (4). Family case 010: *The main information I get from other parents.*

If we follow the logic of families, the main role of the social worker is to provide help for those who need it. One family mentioned (case 001) that *if the social sector were strong, perhaps parents wouldn't communicate so often*. It shows that the family thinks that the weakness of the social support system forced them to meet parents in NGO's and deal with

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124 SODR'a is a governmental institution in Lithuania belonging to the Ministry of Social Security and Labour, responsible for providing social benefits.

their questions together. Though, analysing the results, it is clear that families meet to solve informational and instrumental problems. In cases where those functions were implemented by governmental institutions, it is possible that families would focus on the more emotional aspects of support. The research results showed that mutual groups of families are formed more than power-together alliances against the governmental support.

Sometimes the informational model turns into an over-informational model, when families lose the sense of understanding, because the information is too much. Family case 001:

> When we were in X clinics, social workers gave so much information that I had to 'digest' it.

Family wanted to represent the problem of the informational mixture they had received. The same social worker explained the diagnosis of the child and at the same time gave information in detail of what benefits the family had a right to.

Another first level sub-category of the used model is none (8). Families say they could not meet social workers when needed. Other professionals take over the responsibilities of the social worker. Usually functions implement an educator or doctor. Family case 001:

> All social benefits were arranged by our neurologist (…) as when I go to that social care department, they do not say anything. If you 'dig out' some information, you can ask, otherwise nobody will suggest anything to you.

Sometimes a model of social work as *none* can be inspired by the family itself because of the physical environment. Family case 003:

> It is awful to come to that invalidity centre that gives the papers. The premises are smoke-filled… Scary to bring my child there.

The model: **you need** (9) was represented by the majority of families, even if they did not meet the social workers. Family case 002:

> I think those who need to, go to her office. I don't go; I know everything that belongs to me, all laws.

No social worker is going to representing himself as a social supporter, but families have to find this specialist if they need one, as social workers don't need families.

The *you need* model makes families feel as if they are always begging for something or are always in debt. Families mention the most problematic aspect that they visit many clumsy institutions and it would be easier to have *their* social worker (personality). Family case 001 (3):

> It would be really great to have some person who would say that you have rights for this and this (…) otherwise you don't know.

Research results show that the *you need* model employs them for seeking information from all possible sources. Families feel deprived in their situation and have to spend all their spare time in the analysis of new laws. The mentioned model *you need* can oppress families and increase stress (2): Family case 003:

> We are not lawyers, when we see law, then it's correction and then we don't even understand what that law is about. So, the main conclusion – nobody cares about you.

The general understanding *nobody cares* should be a serious worry, as families met only negative contacts in the social system, including medical and educational.

Clifford and Burke (2004, 317) write that it is obvious that families seeking social support should draw upon the knowledge of those who are experts, like doctors, educators, and etc. And it is universally accepted that professionals should work together for the benefit of the child, especially in longitudinal care.

Representations by families show that the social workers are not recognized as having any *expertise* in making social assessments, and they are not in a strong position to contribute on an equal basis with other professionals. Representations on social support analysing the model of intervention show that families see the model of organized help only on the basis of parental activity. Families speak of situations where when in need of getting social support they have to mediate between the social system and the child or even other institutions.

7.4 Results of Intervention

In connection to the analyses represented in previous chapters, the results of intervention were not surprising. Unlike the medical sphere, the result in the social sphere has a direct relation to the model of work and evaluation of professionals. The sub-category *result of intervention* was split into three first level sub-categories: *word of mouth, not-satisfactory* and *rare meetings*. The not-satisfactory result was additionally split into three second level sub-categories: *bribery relationships, lack of financial support, leading own case*.

The first level sub-category result of *word of mouth* (9) was mentioned by almost all families. It means that despite almost all families having seen the main role of the social worker as a provider of information, families said they gained all the needed information from other parents and then checked it in social care departments. Family case 001:

> *The social worker gives general information, but that information we know from word of mouth.* Family case 003: *You know, if concerning benefits what could we get… we know from word of mouth but in general we don't know anything… we live in the countryside, so this information is not reachable at all.* Family case 008: *All the information we get from other parents…not from the government.*

Families represent that mutual groups are mainly responsible for *filling in the gaps* of socially desolate families.

Families see the most important stream of giving useful information as other families who have older children and have struggled with the same challenges (3). Family case 010:

> *We get everything mostly from other mothers that raise older children… psychological support also.*

Another first level sub-category was formulated as *unsatisfactory* (10) result. Dissatisfaction is based on three second level sub-categories: *bribery-based relationships, lack of financial support, leading own case*.

One family said they faced social support as bribery-based relationships in the X institution for receiving instrumental aid. Family case 007:

They said they didn't have such a size. So, I paid money and the same minute they gave me them[125]. (…) In winter we will need the new ones, so I am sure I will have to buy them (…) it's a disaster…our system.

Three families faced with the final results of social support relate that they have a **lack of finances** essential for basic needs (3). Family case 004:

All tools needed for such children are very expensive. So we cannot buy them. Some of the tools are available to use only in kindergartens. Family case 002*: Money is too little. He needs nappies, drugs, clothes and everything costs a lot.* Family case 006: *There is not enough money … we had to buy digital devices, it cost 6000 Litas (…), the government provides two pairs of shoes per year, and we need six (…) transport is not financed, as my child cannot use the buses.*

Families see that the general supporting schema of benefits creates an unequal situation for each child. Children are very different and there cannot be a *general formula* for making them equal.

The spectrum of benefits overviewed in the theoretical part is wide. But almost all families were telling of their children being unable to make use of all benefits. Therefore they say it could be more beneficial to decide the financial aspect that could be spent on each child per month for meeting needs.

This research reveals that general services are perceived as too general not echoing individual cases of children with particular severe disabilities. Some of the children neither use guaranteed resources nor have the possibility to get individual service.

The second level sub-category where the result is **leading own case** (6) is interconnected with the previous first and second level sub-categories. It was mentioned before that some families spoke of other professionals covering social work functions. Though, the majority of families mentioned that more often the result of their support – being left alone in their struggle. Family case 009:

I would say that social care could send a brochure as they know about us… if the law was changed. For example only recently I heard of the possibility to have one additional day off per month if raising child with disability. Nobody tells you that. The same is about transport. If you find it out by yourself so that

125 Needed size.

is what you know. The problems of *un-leading cases* are constant struggles in *fighting, finding, and accessing.* Family case 006: *So now if we need something, we go and fight…everywhere you have to push your way on.*

The first level sub-category describing the results as ***rare meetings*** (6) somehow covers the already overviewed issues that appear for families. Rare meetings are supported by families, specialists or circumstances.

When circumstances are not beneficial, families represent losing support from a social worker who is on holiday. Family case 001:

> *This year when we went to the sanatorium I had some questions for the social worker, but did not succeed as she was on holiday.*

Some of the families say they are satisfied with rare meetings with the social worker (2). Family case 001:

> *We meet only on the 1ˢᵗ of September if there is some general information.*

Families tell that rare meetings can be substituted by internet access, as it is easier than finding the social worker. For some families this stream of information source is invaluable (3). Families reflect that they feel more self-sufficient not being dependant on the government's grace (3). Family case 001:

> *We don't know many things, don't have access to the Internet. As others tell me that they found information about this or that on the Internet.*

The most interesting part of the results was discovered when families gave information about access to resources (4). Rare meetings can be an initial problem and occur as result of problematic relationships. Even knowing the diagnosis from birth does not guarantee results – benefits, because families do not meet any social worker. Family case 001:

> *The benefits started to be paid when the child was 1 year and a half… or maybe more (…) the diagnosis we knew from the birth.* Family case 010: *When the child was five months old the doctor said she would suggest giving invalidity status to my child. Then in three months we got the benefits.*

Despite a diagnosis being known from the birth, families speak of only gaining access to benefits later. And the second case represents that it

takes around three months to prepare the documents for getting support from the government.

Nothing can compare with the experiences related by Family case 006:

> *When our child was seven years old our physiotherapist was very much surprised that we did not get any benefits as we did not know. Nobody had given us such information.*

For seven years the parents were raising a child with severe disability and could not receive benefits, no compensatory techniques, everything was bought on their savings. During these seven years they had visited many professionals, as the child had had many health problems, also they had visited kindergarten but never met a social worker, so nobody had provided information. The meetings were *too rare* with social workers. It is the best example of socially desolated family.

A similar situation was experienced by the Family case 008:

> *It is ridiculous that I knew nothing about transport compensation… this law had come into force already 10 years earlier, I could use it, but I did not know.*

Laws can exist for many years, but if nobody knows of their existence, the result is that nobody uses them. Families say that such a situation shows that laws are made just for their existence, because families cannot reach the information and use them.

Such rare meetings with social workers as illustrated leave space again for other professionals. Family case 003:

> *Our physiotherapist in kindergarten said to me that I have the right to get this or that. If she had not we would not have got any wheelchair at all.*

Such cases show that the results directly depend on the surrounding specialists and if they only do their job or know a bit more.

After seeing all the sub-categories families represent the idea that social work in Lithuania is seen as short-term information providing. There is no longitudinal supervision planned, not to mention of case managing. Social workers seem as essential specialists that should implement many functions of social support, but the meetings are so rare that for some families it is challenging to remember these specialists.

7.5 Summary on the Representations of Social Support Provided by the Social System

The representations given by families of social support provided in the social system could be called the most fragile in comparison to all three systems guaranteed by the government. The majority of families raising children with severe problems never met a social worker. Therefore, my idea to find the social worker's role as constructed by the families almost failed.

When speaking of social workers as professionals, this sub-category was split into the following first level sub-categories: *misunderstanding* (but helping), *title*, and *professional*. When the social worker is only a *title* this first level sub-category was split into *absent, general specialist* and *theoretical image* second level sub-categories. The first level sub-category of professional social worker was split into the second level sub-categories: *informators*, *appraisers*, and *bureaucrats*.

In comparison to other systems, families at least met doctors and educators and could describe their roles at work. But social work was quite often mixed with the fields of other professionals or known by title without any content. Another aspect, showing the fragile role of the social worker is the representations by families speaking of re-qualifying social workers in order to get a job. Families represented that the majority of social work functions are mediated through educators. Education is one of the nearest branches to social work for re-qualifying. The majority of social workers were met by families in sanatoriums, but there exist many barriers to getting professional consultation. Some of the families said they had never had a meeting with a social worker because they did not identify this specialist with social support. Another point, that some of the families met this specialist but constructed a relationship that is based more on personal relationship than professional consultation.

Participation in and activity of mutual groups is very important for families in the social support sphere. Families say that they have to represent their issues by themselves.

Families shape an understanding that mutual groups are a source created against the governmental sector. There were very negative representations towards the medical system and a few negative representations towards

educators – more negative representations towards the educational system[126]. Critically negative representations towards the so-called social work professionals of the governmental sector forces families to join into mutual groups in order to obtain social support.

The problem of such mutuality exists with a contrary meaning in Pearson's (1990) idea that a third sector is based on democratic participation. Families say that they are forced to join NGO's because of the badly implemented functions of governmental institutions, also information or benefits are more easily achieved when dealing with other parents. Families said that the social system is especially weak, bribery is rife, it is inflexible, and unsupportive. Families give their meaning that workers of the social system tend to hide information from parents and because of that they only learn about existing laws after many years from their coming into being.

While analysing the functions of the social worker, only one family directly mentioned the possible role of the social worker as a mediator. This family perceived such a role as very beneficial during a disability commission. They represented this process as very declarative.

Families analysing representations towards the child split them into three first level sub-categories: *emphatic, burden, expecting poor*. In all the external resources providing social support the same representation towards the child as burden was repeated.

When families mentioned an emphatic social worker, they represented a professional giving information on their issues together with feelings in the conversation. It is interesting that families made some comparisons of different facilities and despite professional information concerning benefits it was the same, the negative representation was given about such professional who did not show empathy. That means not only was information meaningful, but emotion was put in the consultation.

Ruškus and Mažeikis (2007) describing various research results write of some showing that a child with severe disability tends to be perceived as a burden. Seeing the problemacy of a severely disabled child is not helpful in creating a supportive environment. Families are made to feel guilty that they are raising those children. They faced such experiences in the medical sphere when support was needed. A few families met such

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126 I mean unadapted buildings, discriminative attitudes, uninclusive environment.

representations even more dramatically when looking for an educational facility. And when such a family meets obstacles when approaching the social system, they feel like constant beggars for *bread*. Families tell of how they are living in strange circles of this system. Norms of possible support are set by law, but not all families can use the resources. Families speak of situations in which they check time after time whether some money or funding is left and maybe something additionally could be shared.

One family said that we should not perceive that a child with severe disability has only basic needs, but also requires social participation. This aspect has never been discussed so far[127]. The family said that the majority of concerts and performances are divided into those for *healthy* people and those for the *disabled*, but their child also loves the concerts and has his favourite music groups.

Families talk of their personal behaviours, beliefs, inner qualities, and values that tend to change in order to reach the resources, when meeting unsupportiveness in the social system.

While making analysis of the applied model of work it was split into four main models of the social system: *red taping, informational, none,* and *you need*.

The *red taping* model was perceived as a very declarative model of social work. It seemed as just gathering information from the family about the child and its situation for some kind of report but not for constructed support for parents. The *informational* model represented a puzzled system in Lithuania. Families were representing examples showing that each specialist follows different laws, therefore; it creates additional expenses for the families. When families faced the *none* model of the social sphere they were representing the positive qualities of other professionals, like doctors or educators who helped the family with their social issues. That means these specialists were covering social work functions. Almost all families met the *you need* model which is based on parental activity. No social support is directed towards the family. All *support* is perceived as gained by the family itself.

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127 I mean it was not discussed about children having severe disability. About the needs of the disabled and especially social participation in general has been written about in the majority of articles and books by Ruškus (1997ab, 2001, 2002), Ruškus and Mažeikis (2007).

Unlike the medical system, families representing the result of intervention by the social system as having the same negative qualities of all previous representations.

The result of intervention was split into three first level sub-categories: *word of mouth, unsatisfactory* and *rare meeting*s. The unsatisfactory result was additionally split into three second level sub-categories: *bribery-based relationships, lack of financial support, leading own case.*

A very popular method among the representations by families was gathering information from other parents when seeing them in kindergarten or school. Getting this information often leads to checking it on the Internet and then in the social department. The puzzled relationship between professionals opens gaps for existing bribery-based relationships. Families perceive such a situation as a repeated affirmation that benefits guaranteed by law are only declarative. Families represent that they had lost their trust in this system. Another problem mentioned by families is that knowing the diagnosis of their child does not guarantee the possibility of receiving benefits. Sometimes it takes from a few months to seven years for getting support.

8 Representations by Families of Social Support Provided by Dolphin Assisted Therapy in Connection with Other Systems

Dolphin Assisted Therapy was used as a window to reflect the additionally overviewed systems and draw a deeper analysis into the lack of social support experienced in one or another social net compounding. Therefore, when analysing the DAT sphere four sub-categories were reflected: the *medical*, *social* and *education* systems dealing with DAT. Additionally the first and second level sub-categories were split due to the research results.

8.1 The Medical System Dealing with Dolphin Assisted Therapy

The sub-category *medical sphere* dealing with DAT was split into six first level sub-categories: *missing joint, functional benefit, recommendation of doctor, doctor's indulgence, natural stimulant* (miracle), *child's chance for expression.*

Watson *et al.* (2006, 647) writing about cerebral palsy has assigned this term to *developmental disability* since the late 1960s is a description of clinical conditions that cause disability, beginning early in life and requiring supportive services. This term focuses on a broad range of diagnostic descriptions such as mental and physical impairments, adaptive behaviour skills (mentioned by Cotton & Spirrison, 1991, ibid, 647), and aetiologies (mentioned by Baumeister & Baumeister, 2000, ibid, 647). Neely-Bames *et al.* (2008, 56) writes that severe disability of a child creates a sense of desperation and psychological attenuation for the parents, therefore interventions are expected.

Dolphin Assisted Therapy for families is seen as a *missing joint* (9) in the medical sphere. Benefits were expected and were not reached in the traditional helping net which gives new expectations of their fulfilment in an alternative sphere – DAT. Families tend to think that human beings have mysterious positive relationships with dolphins (4):

The positive relationship to dolphins has been known from the ancient times.

Also families tend to create such theoretical understandings on positive relationships in order to construct their explanation of the positive effect. Family case 005:

Dolphins are clever animals (…) therefore we have to use them for health.

It was mentioned in the medical sphere that families think of some medics as chemical interventors. Therefore, DAT fills in the missing joint sought by families as an alternative treatment. Family case 004:

Traditional medicine is where chemical interventions are used. And the impact is better for those who use DAT.

Families represent their belief in existing treatments for the child, but not achieved up to now using the traditional helping net. Therefore, DAT is represented as a joint which was missing.

Previous analysis has been directly related to another sub-category of the first level – ***natural stimulant*** (8). Families represent that dolphins are somehow miraculous doctors knowing the secret recipe for treatment. The most beneficial in this situation is in meeting parental expectations – *treatment* is absolutely natural and does not harm their child.

Families construct their representations that natural stimulations will have physiological changes (8), or more exactly neurological (7) and communicational – emotional (1). Family case 004:

We hope dolphins will awaken something in his brain. Family case 009: *It's emotional treatment. Dolphins emit sounds to children's brains and they react.* Family case 007: *Dolphin's scream of course, children react somehow… the signal goes to nerves… to brains.* Family case 006: *DAT is a treatment… it's neurology…because some signals are going through brains...* Family case 010: *We hope that the cells of nerves would be set back (…) so maybe he could speak.*

Dolphins are perceived as miraculous stimulants that have the ability to make those improvements that it was not possible to achieve with chemical interventions.

Families see DAT as some ***functional benefit*** (4) for their children. Those functional benefits are achieved during some of the exercises with dolphins. When families see the functional benefits that it is possible to achieve by exercises (2), they tend to construct the representation that possibly some medics are working here (4). Family case 001:

> *I think there are neurologists working in DAT.* Family case 001: *DAT is a physical activities, so she liked those activities in the past.* Family case 008*: I expect that there will be changes in spontaneous movements… and maybe eating better.*

Usually these functional benefits were expected to occur with the help of doctors. But the research showed that it appeared that families expected more than real results. One family participating in the research (001) said that after waiting for six years on the list they would not call and ask for DAT, as their situation was solved as much as they expected in medical sphere.

One of the most interesting first level sub-categories was ***doctor's indulgence*** (7) which has a direct relationship to the sub-category of *power draggers, labelling representations* and *puzzled model*. Families having mentioned negative experiences tend to construct the negative representation towards DAT as an ordinary doctor's indulgence. Family case 002:

> *The family doctor could not say anything about DAT. (…) The neurologist was knocking his pen on the table for half an hour and could not say anything (…) then told us not to go as there was no chance for people like us.* Family case 006: *The neurologist said to us: well, what can I say…if you don't have where to put your money… DAT may raise the mood…* Family case 007: *Vicarious doctor (…) looked at me as if I was insane and gave me the papers for going to DAT. But it is not surprising… all the time they had thought of me this way, the same impression is left from them.*

The last representations of family reveal an interesting idea for discussion. From one side DAT seems to be categorized as in the medical sphere, but only instrumentally. I mean that families expect that DAT heals children though sounds and some neurological signals. Additionally the cases of families 002 and 007 put DAT into a very important place on the emotional concern and appraisal scale. They represent as if DAT

already deserved trust. It is because medics labelled the children as if they were different, but to the contrary families perceive that the children had a need for DAT. The same as DAT accepts children when medics use the *puzzled* model instead of suggesting something and even try to demonstrate their power.

If families had already visited one DAT centre they probably would like to return there. Such willingness is more related not to the result on the child, but the result on the parents (3). Family case 005:

> *When I saw weaker children in X DAT centre, I thought we are healthy, but after a visit to the doctor – again I bent my neck.*

It is especially supportive that experiencing positive emotions are linked to the support of a doctor. Family case 005:

> *The doctor in X DAT centre gave us a very good prognosis (…) but the continuous job has to be done and for long, nobody expects full recovery after two-three years…*

Willingness and hope was found in X DAT centre that had been lacking in the medical sphere for long time. The family expecting better results and believing in the child's future somehow opposed DAT and the medical sphere. The same case:

> *When we said in clinic Y that we were going to Dolphinarium X, the doctors told us they didn't believe in such methods.*

Some of the families gave their representations showing that medics tried to show competitive relationships because of DAT (2). Family case 006:

> *Everybody was so happy we are going to attend DAT. Even the questions releasing us from work… as our employers knew where we had been invited, immediately said just go and use everything you can (…) except our neurologist… this time I did not go to him, as I'd already predicted his uncommon reaction.*

All *actors* in a micro network are supporting families' willingness to visit the DAT programme except doctors with whom families had already been at variance. Supporting such opposing, families' even represent that

it would be beneficial for doctors to know more about such alternative treatments. Family case 004:

> *It would be beneficial for medics to observe DAT, in the sense that they are people in the same sphere… to know more about this treatment.*

More often families supporting DAT do not understand DAT as additional, rather a competitive sphere of intervention. They construct their representations on the argument that the child is not recognizing a specialist in external resources in contradiction to DAT (1). Family case 005:

> *What can a doctor do? She does not distinguish a doctor from a builder, a dolphin she recognizes immediately.*

As far as families could choose of their free will whom to cooperate with in order to bring medical documents to DAT, almost all families meeting with a negative position from one medic seemed to be seeking approval from others. The first level of sub-category **recommendation by doctor** (9) was constructed on almost all the representations by families. But the main point is that really positive and supportive representation was demonstrated only by three doctors, others tended to be more neutral. Family case 007:

> *Our neurologist said that dolphin sounds exceed the hearing limit for humans and that sound has power on producing some hormones (…) and that there were people that had heard that DAT helps and teaches to communicate.* Family case 006: *Our family doctor supports any of our searches.* Family case 008: T*he family doctor's point of view towards DAT was extremely positive. She is very affirmative orientated, she led us with her best wishes.*

The majority of representations by families were given as more neutral than positive. Family case 010:

> *The neurologist said she hadn't read any researches about DAT.*

One of the main hardships for families raising a child with severe disability is represented as not having a possibility to communicate. This situation is especially essential when medical problems occur. Families do not understand which medical interventions are required by the child's

situation. Therefore families represent their expectations that after DAT the **child** will have a **chance of expression** (3). Family case 002:

> *Maybe he could take a toy at least (…) maybe spell a word (…) so if he cries we do not know why.* Family case 007: *I firstly think that he would start talking. Could be any communication then…*

Summarizing the representations by families it is fascinating how families construct the social support needs for different social net agents. Families tend to represent the medical system more negatively because of a lack of information about treatment and emotional concern. Though, in comparison to the DAT programme, that was medicalized by the majority of families all representations were related to instrumental aid (10). Family case 004:

> *There is no chemical treatment for our child's disease (…) DAT is a very good choice… stimulus and miracle...*

Stimulus and miracle – that's how families project their representations of DAT, that means a child's betterment in development.

When families have not understood their children for many years, their biggest expectations are associated with the child's expression (3). Dolphins are perceived as miraculous creatures that have the ability to help children express themselves. Family case 003:

> *I will give a chance for my daughter to communicate emotionally as she cannot do that any other way.*

The meaning here is locked not in finding a miraculous treatment but in finding a means of expression for the child, as according to the representations by families *our* way of expression is not possible for them.

Other representations were directly tied to betterments in the child's condition (10). Family case 005:

> *We hope that she will recover. (…) Maybe it's an experiment (…) but the drowning man will clutch at a straw…*

Families represent being ready to accept experiments as the last possibility to see a child's betterment at least the slightest one. The child's health is seen as the major concern for the family. Family case 005:

Maybe DAT will open one room; maybe enlighten one corner of her brain.

Saying that DAT maybe open a room, the family does not have any clear ideas exactly how DAT could be beneficial in their situation. Neglecting the doctor's negative representations, they construct meaningfulness in DAT with just grounding: if drugs are not helpful DAT is needed. Family case 004:

For such patients drugs are not helpful but they need some stimulants for their brains.

Asking families about the result of such *treatment*, they tend to construct a medical explanation for the prospective failure, which is playing a role of self-preservation (2). Family case 007:

If it does not help… that means it has to be so…I am not going to panic… just go again and again (…). We will go to medics to physiotherapists; it would be the same as before.

Families tend not to verbalize the expected representations in order not to *document* what is expected. But they all express in other words how much they really expect a miracle. Family case 007:

Each child is individual and the treatment comes differently.

Families construct the result on the child's exceptionality and choice whether he accepts *treatment* or not. The last point – the address towards the government that there should be attention towards alternative treatment methods (1). Family case 004:

There should be more governmental attitude, more money for such kind of treatment.

This case again shows mutuality with DAT and seeing it as in the same support level as parental support groups rather than the governmental sector that the families oppose.

In a summary, representations towards DAT by families from the perspective of social support content are tightly related to the medical system. The majority of representations by families show their medicalized

position for DAT. It seems that in those aspects of instrumental social support were not achieved by the medical resource, DAT is a second chance to do that. The majority of families contrast DAT to the medical sphere criticizing the latter because of its drug-treatment strategy.

8.2 The Educational System Dealing with Dolphin Assisted Therapy

The sub-category *educational* sphere dealing with DAT was split into the first level sub-categories: *inspiring, sceptic, putting the same power, progress* and *winning*. The first level sub-category *winning* has of sense when two people fight and a third wins, therefore, more negative than positive connotation was attributed to it.

The analysis of the educational sphere dealing with DAT has two sides of comparison: professionals' representations (supportiveness) towards DAT and the result (already displayed or projected).

The first level sub-category of educators *inspiring* (10) visits to the DAT programme were made by all the families. The families represented that specialists from the educational sphere were not only supporting this seeking by the family, but put in even more meaning increasing the expectations of the result. Family case 009:

> *Everybody was happy, said that it would be great in there (…) everybody had good emotions.* Family case 002: *The speech therapist said she is glad we were going, but she did not know anything about DAT.* Family case 005: *Our speech therapist is waiting for us to come back as her relatives have always wished to participate in this programme.*

Families represented that working specialists from the educational institutions were not as radical as medics, some of them (case 002) even said they were waiting for parents to come back and share with others the experiences they had had, as they also have an interest in the same programme.

There can be processed positive representations towards the DAT formatting episode: families were invited after many years of waiting on a list to participate in DAT research, they were happy because of this

fact. Then, their positive emotions were neglected by some doctors as was expected, so the families tended to take those warnings as *ordinary examples of the indulgences of the doctor*. From another side this search is extremely well supported by educational resources. Even more, families felt exceptional as *everybody is waiting for their coming back and sharing their experiences*.

The only **sceptic** (1) educator was represented by a family which has been in a constant battle with whole educational and medical systems. Family case 003:

> *The educator was sceptical. She said one child after DAT became worse. She'll become aggressive[128].*

Earlier it was overviewed that families tended to compare DAT and the medical spheres expecting better results and looking for the missing joint for constructing help. Though, it was very interesting to find out that despite such similarities to the medical sphere, families clearly represented which position they were going to take in the DAT programme, they projected parent-over power relations.

Therefore, families tend to **put the same power** (3) in the beginning of constructed relationships with DAT specialists; they stress the meaningfulness of parent-over position. Family case 008:

> *It would be good to be advised… like we speak with our physiotherapist at school.*

An already known method of communication that creates a sense of assurance for a family is interiorized and perceived as *habitus* for the next construction. In this way a family putting the same power in possible relationships creates a safety niche not only for the child but more for the whole family.

Dolphin assisted therapy in relation with the educational system is represented as an activity, some **progress** (2). Families in DAT find a change and progress of the child which they lack in the educational sphere. Family case 005:

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128 The educator told parents that a 14 year old boy started masturbation as he came back from DAT the act being called *aggression*.

Dolphins made a huge impact for her… she was not afraid, though the dolphin is big (…) even for me it was uncomfortable. And she had already thought of something… she raises her eyes up and this is seen that the child was thinking.

Breitenbach *et al.* (2009) latest research in DAT shows that even if educators do not see any change in a child's status, there is an obvious change in parent-child interactions. The child has better communicative abilities and social-emotional behaviour[129].

One family case represented a sense of parental achievement in the description of DAT. Family case 002:

Maybe he could say a word (…) the speech therapist in kindergarten forced him to spell 'mother', 'grandma', but I cannot do that.

The mother had never heard the child say a word but in the kindergarten the child spells those words, so it would be important for her to hear the first words from her child. A family creating parent-over relationships perceives the spellings of the child in educational institutions as losing some war. Instead of creating power-together, they tend to seek DAT like some second chance to win.

The same case 005 describes rapid changes of the child after few DAT sessions in another facility. Family case 005:

For example there were two cars the same in colour, not everybody would distinguish between those two identical cars next to one another, but she did that – she said its mum's car. It was strange… so pleasantly strange.

This educational jump is highly bonded with the effect of dolphins that could not be reached in the ordinary educational sphere. The emotional support from the closest net appraises parents and creates a sense of true way that they are doing for the child. Family case 005:

She changed into better side by no means after DAT. (…) All friends say so.

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129 According to their parents, measures were made for children with severe disabilities.

The family receives support for their behavioural way as the betterment seen by everybody, therefore, the striving to attend DAT is also growing, as after DAT *parents raises their heads*, they see betterment for the child and it is confirmed in the social network.

The first level sub-category is constructed on representations by the family showing the competitive relationships where some ***winning*** (1) exists. Family case 005:

> *Educators say she needs some drugs for calming down (…) When we were in the Dolphinarium… so she fell asleep (…) dolphins act as an anodyne.*

The family represents the educator-doctor disagreement where the educator expresses an opinion on the prescription of tranquilizing drugs to the child and the doctor rejects this opinion. The family in this collusion of opinions takes on the mediator's role. The family (case 005) represented that the answer of the doctor was: *she does not need any drugs, they would suspend her development*. Therefore, the family sees solving this conflict as winning the third part, this case it was DAT that could possibly calm down the child.

One point about this situation is that the family sees the possibility for the child to calm down with the aid of dolphins and much more strive for this programme as to ***natural drugs***. Another point is the relationship between doctor and educator, as the phrase gives a sense of creation of competitive relationships or doctors over educators. Salmon *et al.* (2006, 67) gives an interesting comment that can be used in this theme that when we are speaking about different specialists in external resources, we perceive how different professionals from different institutions deals with each other. Therefore natural misunderstandings always arise about the diagnosis, revisiting the previously discussed power struggles between doctors and educators or other specialists regarding labelling and other issues.

In summary, DAT in connection with the educational sphere is represented positively, inspired by the personnel of educational system. Families in connection to educational sphere represented more features of personal behaviour than social support for the child or family. They rather gave representations that projected the same interaction between them and DAT specialists that was implemented for the educational system.

8.3 The Social System
Dealing with Dolphin Assisted Therapy

The sub-category of the social sphere dealing with DAT was also split into the first level sub-categories: *constant neglecting, acceptance, human neglecting-animal acceptance, being in the process*, and *hope for betterment*. The last sub-category of the first level was split into two sub-categories of the second level: *child perspective* and *family perspective*.

Families were not able to have any consultations about visiting DAT with any social worker but the main ideas put into the analysis reveals the main compounds that parents always represent as lacking in the whole social support system.

Families represented that they were tired, vulnerable, and they very much experienced a lack of professional communication. Families saw Dolphin Assisted Therapy as a very strong social support not only because of the possible changes to the child, but more as a stress-buffering for the family.

The same ideas are raised by Pelchat *et al.* (2003, 243). Her (ibid, 243) research showed that caring for a disabled child and numerous appointments with specialists, obviously takes up much more time than under normal circumstances. It is especially reflected when evaluating the situation by gender. The distribution of all the functions, of daily household duties falls largely on the mothers and increase their workload. Therefore, mutual support and relationship with professionals are important not only as a way of providing support, but to give converge for mothers and fathers in a family.

Families that represented the model of *you need* in the social sphere; met the same criterion in DAT. Families represent the same *constant neglecting* (6) when trying to get into the DAT programme as they experienced in the social sphere. Families represented this sense as if they felt denied when applying for DAT. Family case 005:

> My wife wrote a letter of application… I did not know even (…) Later I called and saw that it is not possible to get here by force or bribes, so we understood that we are not only sick.

Families feeling constant neglecting from all institutions of the social system are choosing the easier way for survival. Mothers write a letter without telling their spouse so as not to give additional hope. Then, families tell of their bungled trial to get there by force or bribes that made clear that some order exists. Family case 008:

> *I saw about DAT on TV (…) we talked about this with my mother (…) thought that it's only for autistic children and my cousin's wife said she had registered us. It was many years ago when son was getting worse.*

This case represents that close relatives taking care of family tries to help in all ways and seeing the hesitation of parents take as denying possibility for themselves. These cases are important not because of revealing families' difficult situations in getting into the DAT programme, but because families speak of the fear of being *again neglected*. Such feelings they represent that they are experiencing each day.

In the very opposite emotional content to the previous first level subcategory, an ***acceptance*** (8) was formed because of the representations by families. For who families experienced acceptance it was very meaningful. Families represented some kind of scale of neglecting-acceptance during the interview. It seems that some kind of feeling of cumulated frustration was removed after they were invited to DAT. Family case 008:

> *I had not been expecting a call already (…) it was an illusion... but thought maybe there would come such a time when children with cerebral palsy would be accepted.*

The words *I have had not been expecting* and *but* show that there was always a hope for getting into the programme as an untried social support branch. The family constructed a secure feeling in order not to become frustrated again and did not experience a feeling of neglect.

Families waiting on the list for DAT for three-six years said they were trying not to *feed* their hopes and illusions. Family case 003:

> *Coming to DAT… somebody called us and asked us if we would like to participate.*

The main importance for families was mentioned interest: somebody was interested in this family's situation, somebody asked how the family

was living and for somebody the child is not a burden but valued and somebody wants to see the child in some project. When this family was telling of the social sphere they were very dissatisfied that *nobody* took care of their family and child. And only in DAT did they feel for the first time accepted and needed. This family experienced that a child being a burden in the medical, social and educational nets was accepted in DAT.

Another first level sub-category **human neglecting-animal acceptance** (6) is very closely related to the previous one. The main difference families stressed here is that a child perceived as a burden in other systems is accepted in the animal system. Family case 005: *We hoped to talk to a dolphin*. Family case 010:

> *Always with a smile, happy and kind-hearted[130]*. Family case 005: *In any case communication with a dolphin gives lots of emotions and it is good already.* Family case 008: *I think dolphins feel…how a human is feeling and even what he's thinking about (…) they feel some impulses.*

Hewitt-Taylor (2005) analysing the situation of families raising children with severe disability, states that parents in their everyday life feel many tensions. Therefore many factors may disrupt family life and functioning. Unlike professionals families have no time off duty; their homes are usually disrupted by medical equipment, and sleep is disturbed. Families must learn the medical and technical aspects of care to make any difficult adjustments to their everyday life and accommodate the child's needs within the numerous aspects of family life and relationships. Therefore, besides the functional improvements families represent seeing the joy, pleasure, positive emotions, and talk of them as the features they lacked so many years.

Families construct the meaning of support based not only on the child, but include a sense of the whole family's involvement in DAT (2). Family case 005:

> *I think the betterment of the child depends on the whole surrounding. If the mood is good for the whole family, DAT is organized via some games… There is no longer a wall between parents and specialists…*

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130   About dolphins.

Families mention that there exists some kind of wall between them and specialists which is related to the general mood of the family. Family case 007:

> I think changes can depend on the conviction also (…) if parents believe – changes will occur.

The family represents having preconceptions of happiness and they come to any programme with the best expectations, together they experience new and positive emotions, the child with severe disability definitely reflects the whole family content in addition. An interesting idea was generated by another family. Family case 010:

> Communicate with a person and you get relief, with dolphins you get more dreams.

This family represents that they need dreams and expectations; otherwise they would have to resign to their destiny and the understanding that there is no chance for their child to get better – *belief* is an act of seeing the activity in life.

The same can be said about another first level sub-category **being in the process** (7). Families project their representations of working specialists (4), and of desperation (7). Family case 006:

> I think changes may occur because of working specialists…the specialist may determine that for one there are huge changes and for other none. Family case 004: *Think that everything depends on the working specialists… if they are enthusiasts.*

Devotedness to work was the most important feature families wanted to express, as they all mentioned why it was so important: *I do not know how to call a dolphin to us.* That definitely means families are afraid of being neglected by dolphins.

Being in the process for families is perceived via participation in the DAT programme. Families hope to find in DAT enthusiastic workers who know something more than other support systems. Dolphins are the most important actors for the process of implementation. Therefore, a specialist is very important for calling a dolphin.

Another important finding was related to trials and attempts to seek DAT. Almost all families represented that they had sought DAT while being in harsh psychoemotional status when critical intervention (7) and support was needed. Desperation created the wish of being in any process just to feel some activity. Families sought DAT at the same time as all other systems. Some of the families registered their children just after knowing the diagnosis, when their children were only about five – seven months. Family case 006:

> When we decided to register for DAT our child… it was a very complicated year… many operations… bones were cut that year (…) she was in pain… nerves were touched during the operation.

Families represented that in extremely stressful periods of life they tried to get social support from any external resource, the same situation was repeated when serious problems occurred again.

Seeking support from any source including DAT is a perception of parental activity. Families think they have to do something. Therefore, faced with the unchanging situation of the child and unsupportive net they try to catch any straw.

The last first level sub-category where families construct **hope for betterment** (8) was constructed on the representations of projected results. This sub-category was constructed by the majority of families, but not all. It was unexpected that one family said they would not call and ask for therapy as they had already found the support they looked for in other spheres.

Projected betterment representations were constructed on **child perspective** (6). Families represented that in further social life their children would have to live somehow. As far as families now do not see a developed system of care and inclusion, therefore they strive for the self-sufficiency of the child. Family case 005:

> We do not want to desolate and strand our child. She is growing and she will need to live somehow with our support or alone… somehow… hard to believe… but…

The second level sub-category of **family perspective** (2) was built mainly by mothers who spent almost all their time with the children. Families

reflected their fragile situation and lack of social support in the system. Family case 004:

> We mothers are seasoned… we seek everything we can whether it is dolphins, penguins… just to help… if it does not do harm that means it heightens.

The main idea – generally expressed *mothers… seasoned* that means they require positive changes and relaxation.

Summarizing the relationship between DAT and social sphere, the main importance should be drawn towards the social factor. All families mention the acceptance, process and hope. However the majority of families represented the DAT programme as betterment for the child and the whole family. In relation to the social sphere, families said more sensitive and emotional aspects could be reached in DAT. Families were speaking of being tired and also needed to have some kind of re-charging programme.

8.4 Dolphin Assisted Therapy as Providing Social Support: The Expectations of Families

The last sub-category *expectations of family* as a future projection was split into the first level sub-categories: *happiness, relief & relaxation, instrumental aid, last hope, safety niche for the child.*

The first sub-category of the first level where family represented *happiness* (5) was constructed according to the families' primary meaning; I have in mind when they directly said that DAT for them is happiness.

Dolphin Assisted Therapy for families raising children with severe disability was achieved after many years of hope and waiting on the list. Almost all families experienced happiness even before coming. Planned DAT already influenced this feeling for the whole family even if they have no ideas how this therapy is going to be organized. Family case 002:

> *I cannot even imagine DAT sessions (…) I am just very happy.* Family case 001: *It's something new and exciting for our family.* Family case 004: *We are very happy in participating in this programme. (…) those two weeks would be particular as we will all be joined of this participation.*

Families feel *happy* participating in the DAT programme, they all came with positive representations even not having an image of how the sessions would take place and how the child would react. Families had already constructed preconceptions that it was going to be a new beneficial experience having meaning for the whole family.

The majority of families represented DAT as expected *relief & relaxation* (7) for the whole family. Even when families say that if there was no result, they would still be enjoying the process as relief and relaxation. Families tend to see relief because they know that they have already tried everything. Restlessness is a major problem for all families; therefore DAT as a relaxation programme is very meaningful for them. Family case 007:

> *We are all very happy (…) It will be relaxation and unwind from the problems (…) relax for real.*

Such a situation can be seen also from the position of Wong and Heriot (2008, 352). Their studies showed that when parents have more hope they experience less self-blame for the child's illness. And if they blame themselves for the child's disability they disengage from pursuing the goals of their child and have a high level of despair, they are at risk of experiencing high emotional distress, depression and anxiety. Families represented a willingness to receive a higher level of emotional support and that would encourage and give hope and also lower the level of stress. Family case 006:

> *If nothing changes we will still have spent a good time.* Family case 004: *DAT gives impulse (…) you know we still are very tired of children such as ours.*

Dolphin Assisted Therapy is meaningful for families as unwinding the problems and relief from overcharged problems. Substantial happiness and positive emotions are seen as another life impulse for the family that had been waited for many years. A positive injection can be created for family social development features (Bannon and Bodker, 1991; Foot, 2001, 10).

The first level sub-category of expected concrete *instrumental aid* (7) has already been mentioned in all the previous chapters. It has a direct relationship with the social, educational and medical streams of help.

Some of the families represented the projected concrete changes in the children therefore the sense of DAT is locked in instrumental aid. Family case 006:

> *We decided to call and register for DAT because we know one girl who had visited DAT and after that she had good results…even too good.*

The family is comparing the effect of DAT on another child they know even with a sense of jealousy that the other child has *too good results* after therapy.

Families represent that the reliability of the DAT method lies in its popularity and inaccessibility (6). Family case 007:

> *Crowds of people go to DAT because it helps.* Family case 010: *If people go, that means it helps… I believe that those animals can give something – at least the slightest move forward.*

Representations given by families show that conformist thinking is related to the construction of a specific reality. Families construct their belief that DAT is a method of treatment and dolphins emit some miraculous sounds with which they improve a child's health. Families know that this programme is barely accessible and because of that create more aspirations because *everybody tries*.

The first level sub-category of expectations of **last hope** (8) was constructed by the majority of families. Families had registered their children many years before and expected to participate in this programme. Though, their experience was such that they had had to try many traditional methods before coming to DAT. And because of that families did not put their faith in the medical, educational and social systems; the only stream left is perceived – DAT. Family case 006, 005:

> *We waited for DAT for five years (…) we understand that there are other children… thought that there was just little hope left[131]. Family case 008: Physical disability is nothing in comparison to emotional load… That you cannot change… you will not get inside… I believe dolphins are the only ones that can change… Family case 009: He was one year and a half, so 6 years ago, I registered him to DAT (…) Then my son was still not sitting… not talking about walking… Family case 007: It was always like inspiration*

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131 To get there.

(…) from four months (…) I always knew one day we would come here (…) and when I read in the newspaper… it seemed that something from inside had burst.

Families representing the situation that years have been passing and they saw a non-changing situation that created a sense of despair. DAT was perceived as the expected last chance for the majority of families to change their child's status. This additional hope was very much needed in creating a sense of life activity. Bredehoft (2001, 138) analysing a family's complicated situation writes that each professional meeting a family in their way is a *family life educator*. Therefore, each professional is important in understanding the needs of the family at their developmental stage, as well as their complexity. Family case 002:

I would have been the happiest woman in the world if my child were healthy.

The family said that when no hope was left in other external resources and internal resources were weak, DAT gave them hope and positive emotions like an injection for the family to renew. Family case 005:

We were in X DAT centre, so there she swam alone… it was in some way fantastic for us.

Some of the families projected representations as seeking changes in *speech*, *walk*, or something similar. A family represented the changed features of child as development towards self-sufficiency and evaluated as an activity in their life, some steps forward that the family evaluate as *fantastic*. Both cases of families who tried DAT at other centers represent the change of their child were noticed in communication with dolphins. Family case 005, 003:

We felt that the child was improving in health (…) now again we feel she is worsening…

Bronfenbrenner's (1997, cited in Bowes *et al.*, 2001) idea about a **safety niche for the child** (10) was borrowed and used for the construction of the general first level sub-category. All families mentioned features projected to DAT, but all the features belonged to the same construction of a safety niche for the child. Families projected an understanding that the child

would find something useful in dolphins, and the whole family would stop suffering. Almost all families (9) represented expecting more from the process of DAT than the actual result. Family case 004:

> *We would like him to experience some calmness… Maybe dolphins…* Family case 002: *I hoped my child would be able to communicate.*

Families represented that they actually did not understand their child as much as they wanted. Therefore, DAT was seen as a possibility to make inner changes in the child that would probably not be seen by others, but still beneficial. Family case 009:

> *Maybe we will not see but something will change in his inner (…) we will do anything that would make the child better.*

One family said that they would despair if their child did not get better after DAT. Family case 002:

> *It will be a pity if nothing were to happen, but we still hope that something will change (…) if not, we will suffer further and live.*

The words *suffer further* reflect their current situation – they are also suffering now in everyday life. Therefore, this family represents DAT as process and expected result are projected as a safety niche not only for the child but some kind of salvation for the whole family.

Families expect to create a safety niche for their children in DAT. Surprisingly families expect so much not knowing anything about DAT (10). Family case 008:

> *I don't know anything about the specialists in DAT, we just rely on them (…) Can it be different? Are there any parents that allow them to raise any requirements? Think that there is not. Is it?*

Families tend to rely on specialists in DAT not knowing anything about them. Perhaps, such a saying contains many senses. Families in general tended to construct positive representations based on belief, taking care, and ideas about natural drugs, stimulant, and others. Families determined their own constructs as features for a safe environment for their child. In any case such a vision is seen as the basis for open collaboration and two-way communication.

Families think that a child who was somehow not suitable for the DAT programme earlier and after the suggestion to participate, families represented as a newly opened expectation to achieve a resource to which all the families had strived. Family case 005:

> *While waiting for five years I felt that we were not suitable enough to come here (…) so it's like a grain for a blind chicken.*

Therefore, meeting questions about the working model and parental participation, families re-asked *if there were any parents that allowed*. Despite that families tended to see their authoritative position in the construction of a relationship to DAT. Later, when all conversations became deeper and based on concrete parental suggestions, all families reflected that the safety niche should be based on working professionals. Family case 002:

> *I am without thoughts at all concerning DAT. It would be best if the specialist would decide (…) we will help but the specialist must do his job.*

Families tend to un-tie the hands of working specialists in DAT about whom they do not know anything (10) just in order to give the child a safety niche which is unseen from others sides. Family case 005: *The child needs positive shakes*. Family case 008:

> *I think that closeness to dolphins was always felt and that in some way we belong to them (…) they are very close to the disabled, they can reach an invalid's mind… and thoughts.*

Hearing about other children's achievement can support the hope of getting help and solve the problems of the child and family. Families represent the DAT programme as their last hope and chance for the child and family's recovery. Some interesting aspects were also given, like seeing DAT as a very helpful branch of support and delegating full support content in it, they are under inside discussion: strictly determine the authoritative position in DAT and after conversation they say that they trust DAT specialists absolutely.

Therefore, social support in DAT is expected as an emotional concern, appraisal, information and instrumental aid in order to construct supportiveness in order that the family may improve their coping behaviour with positive physical, psychological and social consequences.

8.5 Summary on the Representations by Families of the Social Support Provided by Dolphin Assisted Therapy in Connection with Other Systems

The place of Dolphin Assisted Therapy as a window for seeing social support in other systems was very beneficial for this research. When analysing the DAT sphere four sub-categories were reflected: *medical, social* and *education* systems dealing with DAT, and *representations by family*.

The sub-category *medical sphere* dealing with DAT was split into six first level sub-categories: *missing joint, functional benefit, recommendation of doctor, doctor's indulgence, natural stimulant* (miracle), *child's chance to expression*.

Families represented that raising a child with severe disability is equal to a constant stress experience because of the unpredictability of their everyday life. Families spoke of questions that were constantly raised in the medical sphere. However when the medical system seemed not to be able to fulfil the dream of the family, they construct their future projections on alternative methods, such as DAT, because the families needed to have faith in the future and perceive activity. Families tend to medicalize DAT and assign functions because of a belief in the mysterious positive relationships with dolphins.

The majority of families represented DAT as a possible functional benefit for the child. Representations of families showed that the medical sphere and DAT were put on almost equal levels for providing social support. One family noticed that they did not need DAT because their issues had been solved in the medical sphere and they were coping with the disability of their child.

Research was constructed in such a way that families had to get some medical documents from their doctors. Therefore, families could represent not only earlier experiences in the medical sphere, but also the experiences of recent meetings. Almost half of the families represented a critical opinion being given about DAT by doctors. Families accepted the negative opinions of doctors as possible to ignore because they perceived it as the usual behaviour of this doctor. The same way as families represented compete existing relationship between the medical system

and the DAT sphere. Only a few doctors gave positive recommendations for families to visit the DAT programme or were open and said that they did not know anything about it.

Families projected their expectations of DAT as an instrumental aid with concrete results and the way that this aid should be provided they named as a miracle and natural stimulation. Families tend to construct their expectations on some miraculous theories that they do not have knowledge about. Marino and Lilienfeld's (2006; 2007ab) articles broadly discussed the same phenomena existing in many countries. They pointed out that families are misled by information given by working specialists. Though, my research showed that families raising a child with severe disability tend to believe theories about DAT based on the impact of the brain-waves (Brakes and Williamson, 2007) and sound impact theories (Brensing, 2004). All families represented the main problem of the child that he/she is not able to express him/herself in our society. Therefore, the belief in sound theories is perceived as the closest to their situation, because quite often the only expression of a child is also based on emitting sounds.

The same point can be set on representations by families that the results of DAT depend on the choice of the child. It was expressed not only in connection to the medical system, but also the educational. Families represented that the child did not like the educator or doctor because of the possibility to choose. Therefore, a child can choose if it accepts dolphins and how deep to allow such contact to happen.

In analysis of the *educational* sphere dealing with DAT, the first level sub-categories were split: *inspiring, sceptic, putting the same power, progress* and *winning*.

Almost all families got very strong support from the educational system to visit DAT and almost all families were expressing that everybody is waiting for them to come back and tell them about DAT. Only one mentioned that the educator was sceptical.

The most interesting observation in this research was based on seeing representations by families of power relationships dealing with different specialists in external resources while searching for social support. If families speak of a *power-over parents* relationship in the medical sphere, the educational sphere was perceived differently. Families tend to

represent *parent over educator* relationships. In case it was not possible, the problems arose in collaboration.

The same context was put forward in explaining about DAT. On one hand families said that they were ready for all experiments and were ready to trust working specialists. But on the other hand, they noticed that they were the best parents and only they knew what the best was for their child; therefore, the specialist should consult and listen to their words. That means families showed openness to collaboration but in reality asserted their power-over position.

Almost all families expected a possible development of the child as a result of DAT. Very similar features were presented when they spoke of the medical system. In comparison to the educational system, families expected achievements that they were not sought in the educational system or to solve some problems that were raised by this system.

A very critical point that was represented by families was competition among professionals. But the main idea which was revealed by families, that when families do not find positive communication and clarity of behavioural models in a concrete situation, they tend to leave disputing parties and drag in a third one which wins. In this case it was DAT. Such a way of constructed communication is closest to a simplified form of litigation (term used by Parsons, 1991). Conflicting parties are not dragged into constructive conversation.

During analysis of the social sphere dealing with DAT the first level sub-categories were split: *constant neglecting, acceptance, human neglecting-animal acceptance, being in the process,* and *hope for betterment.* The last sub-category of the first level was split into two sub-categories of the second level: *child perspective* and *family perspective.*

The main similarity between the social system and the DAT sphere was the experience of neglect for families. However, families tend to give different representations concerning this point. The social sphere was evaluated very negatively, and DAT more with understanding and mutuality. Neglect felt from all spheres increased a family's fear of experiencing frustration, therefore, instead of calling and registering for the DAT programme they chose other options. Those other options are when mothers send letter and register without telling their husbands or close relatives make this step.

However, almost all families after being registered to DAT experienced this period as some kind of activity, as there is still some *straw* left in social support. Like a last chance or last hope.

While analysing the social system's connections with DAT there was found to be an interesting representation by families. Almost all families oppose two experiences: human neglect from social support systems and animal acceptance. All expectations are built on the belief that dolphins would accept the child who is a burden to human beings' systems. Families represent that there is a wall between them and the specialists, but in DAT they see how such walls vanish.

The last sub-category *representations of the family* with future projection were analysed and categorized into the first level sub-categories: *happiness, relief & relaxation, instrumental aid, last hope, safety niche for child.*

Some representations as expectations of families in comparison to the medical, educational, and social systems have already been overviewed. When families were representing their ideas about DAT, almost all mentioned that from this programme they expected happiness for whole family in any way. Mothers mentioned relief & relaxation and said that they were really tired of their children being *such*. Therefore, they see DAT as some kind of re-charge for the emotional context of all the family.

Usually when comparing to other systems, families were representing their expectations as a concrete instrumental aid. In some of the cases families told that participation in DAT is their last hope for betterment.

The perception of DAT as safety niche for the child was represented as an expectation by families raising the most physically severe children, if described from a diagnostic perspective. The same families showed most negative representations on social support from external resources. The main features for this safety niche were represented as the following: possibility for the child to express himself, motivated personnel, dolphins that are able to accept the child, and positive emotions.

9 Representations by Families of Social Support Provided from External Resources: Conclusions of Research

This chapter with the main conclusions of the research consists of two sub-chapters. I will make conclusions of representations by families based on the Scandinavian activity theory (Engeström, 2007). Engeström's schema (see Figure 3) of social work activity was very beneficial in making the final research findings and answering the second research question.

I adapted this schema to the Lithuanian context on the basis of representations by families. The next sub-chapter will draw the main findings of the research in an Eco-map perspective (due to the perspective of Vodde, Giddings, 2000; Flashman, 1991). This sub-chapter is answering the first and third research questions.

I combined all research findings in one system as some kind of organism. From this schema it is very clear that representations of social support and problematically functioning parts seen by families in the Lithuanian context. Due to representations by families of social support it was possible to make some practical implications from the research results.

9.1 Constructing Activity in the System of Social Support

After I finished my research I decided to come back again to the Scandinavian activity theory and see the practical connection of this theory and the research results. This theory I chose for answering the first research question, summing up the representations into a schematic perspective. Also these final conclusions define the social work position in external resources due to the perceptions of families, therefore, the second research question also has been answered.

At first glance I thought that perhaps the Scandinavian activity theory could not be applicable in its traditional form and it that really did not reflect the context of functioning systems in Lithuania. However, later, when combining the research results I saw that Engeström's (2007)

schema of the theory is more than beneficial in revealing the research results. This theory is open for expansion. Therefore, understanding the fact that this schema is impossible to apply in the Lithuanian context in its original version, I made my corrections due to the research results.

Huotari (2008, 85) described this schema as an active process where the social worker as a subject is actively catalyzing the processes in the system in order to help clients with multiple problems. The research results showed that all cases of families are those objects dealing with many problems. In this case, the Scandinavian activity theory is very helpful in designating a place for each actor of the social support system.

Figure 5 represents the activity schema which I made based on research results. Howarth *et al.* (2006) writes that the need to improve coordination between professionals and prevent ineffective collaboration is clear. Social workers as *case managers* could coordinate and lead those services. However the representations of social support by families showed that they did not meet the social workers or met too rarely. Therefore, families were reflecting a situation where it is much more often seen as managing their own cases in social support providing.
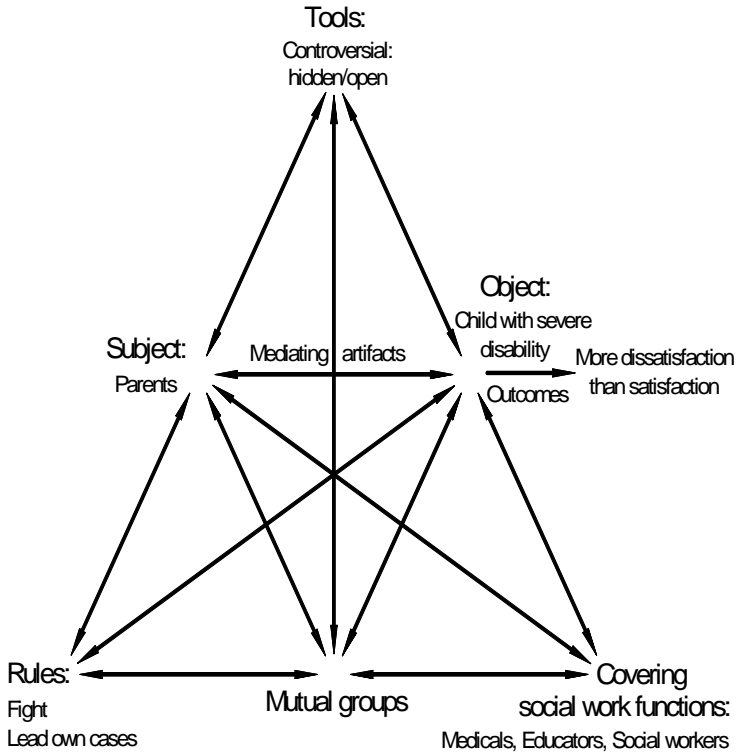
Figure 5. Activity schema developed on representations by families in the Lithuanian context.

The original Engeström (2007) schema shows the social worker in the Subject place and Object is defined as clients. My schema shows that according to representations by families the family is split into: child and parents as they belong to different poles in the schema. Engeström (2007) withholds Rules (effective care) and Tools (care relationships), but orientated towards benefits for the client. My schema shows Rules (fight, lead own cases) and Tools (controversial: hidden/open) that were developed and represented by the families who were in the social support searching process. The original Engeström (2007) schema shows Community that I changed to Mutual groups, and Division of labour:

between professionals that due to representations by families was changed into Covering social work functions: Medics, Educationalists, and Social workers. Engeström (2007) showed the schema as an active process towards a particular goal – The Outcomes: (intended: improvements in client's situations; unintended: possible dissatisfactions, low continuity in care) that due to the representations of social support were changed into Outcomes (more dissatisfaction than satisfaction).

The analysis of the representations of social support showed that barely any of the families had met a social worker mediator. There were only two cases of families that could give broader information about this profession. And only one family mentioned the possibility of mediation functions in dealing with the medical system. The families represented the process of social support seeking as common in their practice dividing it into: Subject and Object. The families represented that Parents are the most active catalyst in the activity schema, leading towards the result. Instead of being in Object place, social support is constructed so that the family is split into: Parents (as Subject), Child with disability (as Object). Siblings seem not to be included at all, as they do not figure. Representations by families show that the social support system in external resources requires Parents to represent the issues of their children themselves. The families represented that otherwise they would not receive any social support at all.

The families were did not mention any Community contribution, but the majority of them mentioned the invaluable contact and support they found in Mutual groups. Huotari (2008) calls this phenomenon seeking to make improvements in the situation. Though it was mentioned earlier Parsons's (1991) idea of creating such mutual groups and how they differ in the Lithuanian context. Mutual groups here take the place of the Community. The problem arises that these mutual groups are created in order to access resources more easily and their functions seem to be opposing an unfriendly governmental level of support rather than complement it.

It was very hard to find the right place for DAT in this schema, because of the main engaging of DAT into a window place for revealing social support from external resources found its reasoning in the broader explanation. The Eco-map shown in the next sub-chapter depicts the answer to the first research question showing general understanding from

the perspective of families on social support. This sub-chapter elaborates the second research question focusing on social support from the social worker understood in the context of other professionals and specifies the answer to the third research question in connection to DAT.

Due to the representations by families, the place of DAT should be close to Mutual groups or covering the functions of other professionals, however the families did not pictured DAT in a way so clear that we may detect its real place in the schema. Therefore because of the unclear place of DAT, I decided not to make my decision of putting it into this schema. All families mentioned lacks of medical, social and educational support which they expected to be fulfilled in DAT.

When speaking of the medical system, DAT was noticed as a system of positive experience with positive emotions. In contrast, the medical system was full of negative representations because of meeting concrete medics with negative attitudes. The general point noticed in this research is that families when first facing one or a few professionals tend to generalize and give the same meaning to the whole system. Therefore, faced with negative representations in the medical sphere they seek to have their *own* one doctor to attach to. In dealing with other professionals in this sphere families' experiences were always led by negative feelings. I mean negative, in that families are having some preconceptions and have some rules, tools of communication that are *interiorized* as the best dealing with the mechanism of this system. Representations by families showed that the medics they met had very weak skills in interaction. Consultations and communication could be described as not being sufficiently developed.

Power relationships also play a very important role in this interaction. The families represent the need to find such a medic who would not criticize their choices and would accept their opinion, discuss the situation, and provide all needed information. Some of the families represented that they had experienced fear before meeting a new medical professional. This situation is based on not having medical knowledge. Families feel as if each new meeting is some kind of arena for a fight or an examination of parental knowledge about the child, where each medic has the right to show his medical knowledge and reveal shortcomings in parenting.

Another aspect of the power question represented by families was a way of approach towards a particular medic. Such representations show a clear limitations model, when the whole family are seen as having the associated stigma. An interesting point of this research was opened that despite criticisms towards the clear medical model, families were mostly happy meeting such a model when the result was perceived as beneficial. When constructing expectations towards DAT, the families mentioned a way of work that corresponds with this clear medical model. The families were describing many stressful life situations where they had needed urgent medical interventions and decisions. The families were telling of these periods of life that were the most stressful and the application of diagnostic model worked as a stress-buffering mechanism for all families. If the situation was not solved or the status of the child was getting worse, wrong interventions due to families' opinions raised the family's stress level.

Before constructing this research I had my understandings that educational system would probably be the most supportive for families. Even though, three families were not satisfied with educational context. The main problems of this system were pointed towards poor representation for the child. Families experienced stress faced with a demonstration by some educators that the child was a burden. All families represented the educational system as the child's possibility for active socialization in the wider context. The most satisfied families were those whose children were attending integrated classrooms together with healthy children. As well as those whose children attended integrated classrooms and the educators were giving positive evaluation of this process to the family.

The majority of representations by families showed that they were satisfied with the personnel of educational system. The biggest problems families mentioned occurred in finding a proper educational facility with an inclusive environment. Four families even represented an unfriendly educative environment for their children. The failings were mentioned as follows: schools did not have elevators, no handrails in the corridors, no sign language teachers in the whole city, schools were located in remote regions, and therefore children were forced to experience early separation from their families.

The most important aspect of the educational system by mentioned families was its motivated personnel. Families represented personnel

as the most supportive and meaningful factor in subduing unfriendly environmental factors. Families see personnel as most the important factor in the construction of a safety niche for the child. Power relations were also mentioned. In comparison to the medical and social systems, the educational system is the most open to constructive power sharing relationships with parents.

This openness can be caused by the fact that educators create longitudinal relationships with families. Though, families tend to accept such openness as the possibility to show their power over relationship and even try to compete. Representations by families show that they have some family defence mechanism which is used in times of doubt.

Representations by families showed that Dolphin Assisted Therapy could take the same place as Mutual groups in this schema. The most interesting thing is that such mutuality is based more on opposition to institutions that implement Covering functions. Therefore, DAT is strongly seen as some Mutual support that can be gained instead of other external resources. Another factor for the perceived mutuality – the same feeling of begging and fighting. Families gave many explanations for why DAT had not been accessible to them for so many years. These explanations were directly pointed at the unsuitable attitude of the government towards such alternative streams of social support.

The representations by families showed that support from the social system is narrowed into the social work functions in the schema. Instead of Division of labour between the professionals, the research results show that in the Lithuanian model families met those who were Covering for social work functions. The representations by families show that the social worker takes a place of misunderstanding, as just an existing title and sometimes as a professional giving information. The research results showed that the majority of families said they had never met a social worker. Some of the families in later interviews remembered that they had met this specialist, but could not describe their functions. Therefore, the majority of ideas on social work were constructed on the theoretical concept: *what if there were a social worker*.

When the families were representing their experiences in the social system, there was a constant feeling that it is very hard to see the whole picture of provided help. Later, when I was making my analysis of those

representations it appeared that all families were describing the *puzzled* system. One of the main problems mentioned by families was the lack of a person leading the family's case. The social worker could take such a place and change the Parent's place in the schema.

The other great problem that was mentioned was unprofessional social workers. Usually social workers were met in sanatoriums and special disability facilities were based more on personal friendship rather than professional consultation or declarative information giving. The main support that families expect from social workers was mentioned as gaining information. But it is very important to give this information in a clear way for the client and with empathy. One family was telling of a social worker who overloaded them with information and it was impossible to remember everything. This case shows that rare consultations giving all the information at one meeting are not the proper form and are not helpful for families, as they cannot remember everything.

Two cases were exceptional when telling about social support in the social sphere. One family did not know that they needed to apply for the benefits till the child reached seven years. The other was telling of a law they had recently found out about that they wanted to invoke and it appeared it had already been in existence for the last ten years.

Covering the point of social work is shared by the social worker himself, educator and medic. Families were describing medics as power-draggers, passive neglecters and other negative functionalists. Though, few mentioned positive examples and the creation of supportive professionals allowed sharing this point with medics who think *outside the box* and implement some of the social work functions. While educators were mentioned in a more positive aspect: families view them as supportive and methodologists. The majority of families delegated their issues to educators to solve with the social workers in educational institutions.

The listed schema shows that the most popular social work model is when parents interact among themselves and gain information by word of mouth (9). It is seen as an activity of the already mentioned mutual groups, when families discuss their issues and share information. In general for all of the families social work seemed unsatisfactory in its results. In the activity of Covering functions between professionals and Mutual groups there exists and interesting relationship. It is shown as a two-way process, but the research results showed that Mutual groups

are more orientated towards the creation of contact with professionals Covering other functions than the other way round.

According to the representations by families, all member of the family have to play some kind of role in this activation process. And roles, the same as tools, are based on representations about a particular system of social support.

The tools used for maintaining connections within this schema are described as Controversial relationships. It is impossible to make general representation on the Tools point, because all the families had had various experiences. However those representations were very close when speaking of the division spheres. When Parents are looking for support from Mutual groups, the Tools used for contact can be described as Open. Families described these relationships as communal work rather than an experience in deeper emotional levels, they were representing meetings where they had shared information, and written projects for accessing instrumental resources. Only one family mentioned that this group was important for interaction rather than because of its benefits. Un-official mutual groups where parents meet each other in educational institutions also look like a *quick exchange of information* but not as a means of emotional support.

Representations by families showed that when Parents dealt with professionals covering social work functions, they also encountered Open relationships and Hidden relationships. When families were speaking of short-term intervention relationships were more often hidden and destructive. Long-term intervention is more often constructed on a basis of open relationships. Representations by families showed that the initiators of such open relationships are professionals. The families reflected that the main problem is that it is a few family doctors, but mostly all educators that are following this model.

The rules used for activating the model of work were harsh according to the representations by families and can be described as fighting. The main points on understanding the construction of the internal and external activities are given to the empathizing of mental process in order to make a complex view. The research results showed that these two constituents are much related. Families have to use the rules of fighting or pushing their way for getting something. The research results reveal an interesting phenomenon that families do not always use such rules because they

feel strong-for, but because they feel begging-for. Goffman (1963) and Jones *et al.* (1984 both cited in Carter and Feld, 2004) called such a phenomenon as the negative side of social regard. Families represented their long ways of searching for social support and how the social system had forced them to accept the role of *beggar* or *fighter* and even change parents' inner qualities.

The listed methods of Parsons (1991) to solve a conflict also helped to reveal some very interesting points of research. Families seemed to be divided into distinct agents playing different roles. The child can be in a burden role or in the role of a family member, in the role of Object etc. Siblings in almost all cases are faced with grown up issues as soon as this is possible and take the role of caregiver. The father of such a family is in the role of money earner and passive Subject. The mother is in the role of official caregiver and active Subject.

Families represented the conflicts they experienced with the system beginning with negotiation. For some of the families such method of conflict lasted for many years, as they did not have any other option. While conflicting in the medical sphere negotiation is usually used. When negotiation was not helping, all families told of a *jump* towards arbitration. Usually arbitration leads to a change of doctor for all the families.

Contrary to the medical system, the social system in dealing with conflicts often starts with negotiation when one party (family) is disappointed and another party is neglecting. In this case a family tends to *jump* to some kind of litigation process. It is not a very clear litigation process, but more like complaint to the highest institutions that have power to decide over some questions.

The educational system when in conflict holds a very clear negotiation model. Sometimes a disagreement leads towards direct conflict on both sides. Other developmental stages were not mentioned by the families.

In summary of the conflict solving methods, I noticed that all families in any system tended to jump over the mediation choice, because they did not see such a possibility or a possible mediator in the situation of conflict. Because of such a situation families are forced to change their inner qualities and use fighting relationships for obtaining resources.

Speaking of the outcomes and results, families often used the expression *nobody cares about us*. It expresses a general dissatisfaction with the

outcomes. It is very important that dissatisfaction in the outcomes does not always occur because the result somehow dissatisfies, but because the process leading to the result was too exhausting. Families were meeting lots of barriers for accessing the resources.

The analysis of the social sphere as a possible means of support gave the clear result that according to the representations by families there is a great lack of system within a system. I mean that families spoke of puzzlement existing in coordination and resource access. Social work is not perceived as in any way supportive except as an information provider, however even access to information was also evaluated negatively. Probably some ideas from the report[132] of the Controller of children's rights, written in September of 2009, about the social system will make some clear insights into this situation.

There are 551 administrative wards (*seniūnija*) in the Republic of Lithuania. There work 593[133] social workers (or this is the number of staff), in general it takes 1 social worker for each ward. Social workers are responsible for the providing of social services for all inhabitants of the ward; therefore, it is unrealistic to expect that there is enough time for everybody. Quite often this work is implemented episodically. Perhaps these circumstances may give us some understanding about professional dissatisfactions usually demonstrated on the clients that were mentioned by families. Out of all the staff, the staffs of 7 have representatives for children rights (10 workers), the staffs of 16.5 have representatives for social work with families and children, the others are representatives of social work for all groups of people.

Some of the wards of cities (Šiaulių, Palangos, Druskininkų, Visagino, Ignalinos, Jurbarko, Kelmės, Kretingos, Mažeikių, Plungės, Prienų, Radviliškio, Tauragės, Ukmergės) don't have social workers, therefore, the work is carried on by specialists of the Child's rights. They are responsible for sharing this job in collaboration with other specialists, like workers of social care, medics, social workers of day centres, social educators, police officers, etc.

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132 Report was made by Rimantė Šalaševičiūtė, the main controller of the children's rights. *Apibendrinimas dėl socialinių darbuotojų, atsakingų už vaiko teisių apsaugą seniūnijose.* www.3lrs.lt, access 2009/01/07.

133 This report is gives the numbers of social workers in administrative wards. Additionally social workers are financed in the cities by the local (municipality) budget.

In some regions there are working groups of *social workers* on the public basis. It is constantly felt that there is a shortage of social workers in whole country for constructing more effective social work. Those few social workers that implement work cannot fully cover their functions and implement the work on time and qualitatively. The same results were showed when families were describing the model of work they were faced with. The majority of families were telling of the social worker who is always writing something or of his requests to fill in mountains of paperwork.

In the already mentioned report, we can find that even in some wards, like Naujoji Akmenė the staff of the social worker is established but the budget for it is not.

In the same situation we can find convergences with families' perceived portraits of the social worker. The report gives information that the people who implement social work can have various *titles*: senior specialist for care and worship, inspector, social worker, organizer of social work. For example in the Šilalės district social work is assigned to and implemented by accountants of the ward, in Melnragė's ward (Klaipėda) social work is implemented by the organizer of cultural events. Such a situation definitely shows that the social worker cannot in any case construct social support professionally. Governmental decisions show that social work is so *simplified that it can be implemented by any field specialist, for example an accountant*. However, the law of the Ministry of Social Security and Labour[134] says that social work can be implemented by the staff: social worker, organizer of social work in the community, the assistant to the social worker, and the worker of visiting care.

In the theoretical part I mentioned the idea that the social worker in Lithuania has legal knowledge, interpersonal qualities, and a professional understanding about the mediating process, but unfortunately practical implications are in the developing stages. My research results found an agreement in that.

The representations by families showed that they had rarely or never met social workers, some of the families were describing other professionals naming them social workers. Some of social workers that were met were represented as friends rather than professionals. Representations by families show that there is a need for mediation, leading, representing

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134 2005 m. rugpjūčio 3d. įsakymas Nr.A1-223.

issues but this role is most often taken by the mother. The representations by families of social support presupposed a feeling that families would tend not to believe this situation could ever change.

Speaking of the social worker families did not give any special prominence to this specialist, but they were speaking of the main issues that the families faced. First of all, the social worker is perceived as needed for longitudinal supervision. Families need only long-lasting interactions with specialists, therefore the social worker is considered as a person taking care of the family, visiting and checking the child's achievements.

Secondly the social worker was seen as a mediator only by one family, but all the families viewed the social worker as a mediator between the law and themselves. All the families delegated informational support only to social workers. The representations by families showed a disappointment in not being able to understand new legislations or sometimes ways to find them. Families were feeling deprivated from the external resources.

The newly formed schema shows that the need for mediation exists, but changes have to be implemented in practice. Dissatisfactions of the families were led not only because of the failings of some professionals, but also because of a too general social support schema for severely disabled children. The families were not only accessing information on law changes but also experienced that in their unique situation they are treated as a generality. The dissatisfaction seemed to be in the growing process when step by step families' were faced with bureaucratic obstacles towards the resources.

The representations by families showed that social support in stressful periods of life was not achieved as a stress-buffering model. It was rather scattered, unorganized, based of parental efforts. Families represented that social support was found from or attached to a concrete specialist that was chosen after many attempts to meet professionals.

9.2 Construction of the Representations of Social Support: Eco-Map Perspective of Families

I decided to construct the conclusions from the perspective of an Eco-map, because as Mattaini (1993, 22 cited in Vodde, Giddings, 2000)

writes, it is the best method for conceptualizing a client system *holistically and for organizing a large amount of data in a nonlinear, contextual fashion*. Answering the first research question and specifying the third I found it mostly beneficial to picture the interconnections by which families were represented among the DAT, medical, social and educational systems.

Flashman (1991, 55) writes about the protocol of using the so-called traditional Hartman Eco-map presentation. Such a map contains inter- and intra-relations (Vodde, Giddings, 2000, 45). Hartman and Laird conceptualize that the Eco-map is a concrete tool in assessing, developing and coordinating resources for families (Flashman, 1991).

Using the theoretical understanding of the Hartman Eco-map, I still base my Eco-map construction on the Mattaini (cited in Vodde, Giddings, 2000) idea that there can be creative variations. These variations are needed because my research was organized so as to analyse three main systems of social support: medical, social, and educational via DAT. This Eco-map holds the Hartman Eco-map protocol where a clear line means a strong relationship; the direction is shown by arrows: one-way support or two-way interconnection. A dotted line means the relationship has weak tension. If the line is without an arrow that means it is impossible to say who initiates such a relation. Usually life circumstances create a social reality where both sides are acting. Curved arrows show the direction to which the representation is directed. Communication among the different systems is showed in direct connections or indirect connections, where representation by a family was creating this relationship. Dotted circles represent areas of possible conflict.

Firstly I had the idea to project families of all cities on the real map interconnecting them with the provided social support in a concrete district. I rejected this idea because almost all the families were telling of a concrete supportive personality with whom they have a strong relationship in their own cities. But the representations given about spheres in general quite often covered other cities and districts, as families were having the experience of facing different specialists all over Lithuania. Therefore, the Eco-map concentrates on the main representations of the concrete sphere in relation to DAT, not city or district.

The research results do not allow me to apply the initial Hartman Eco-map approach, because no concrete men or women are presented

in the research. The findings are based on the family's system of dealing with the support systems in the context of the DAT system. Family inner relationships and characteristics were also not analysed. Therefore, I have used my own approach in constructing the meaning of the schema, such as a square represents the medical system, a triangle represents the social system, a soft-angled square represents the educational system, and DAT is represented by a circle. The family in a circle was decided to be given central position in the middle of schema. The most supportive branches are depicted in close contact with the family system, the less or not easily approachable – further away.

Another aspect is that the research results do not allow me to develop and coordinate resources. It is more O'Brien's (2006/2007) position of use of the Eco-map in which I can reveal the opportunity to better comprehend the families' perspective of the support system. Therefore, my Eco-map will be used for assessment and answering the first research question about the representations of social support from external resources and specifies the answer to the third research question showing interconnection of other systems with DAT.

Figure 6 illustrates the main research results schematically. The ideas for the usage keys were taken from Agbényinga and Ahmedani's (2008) research.
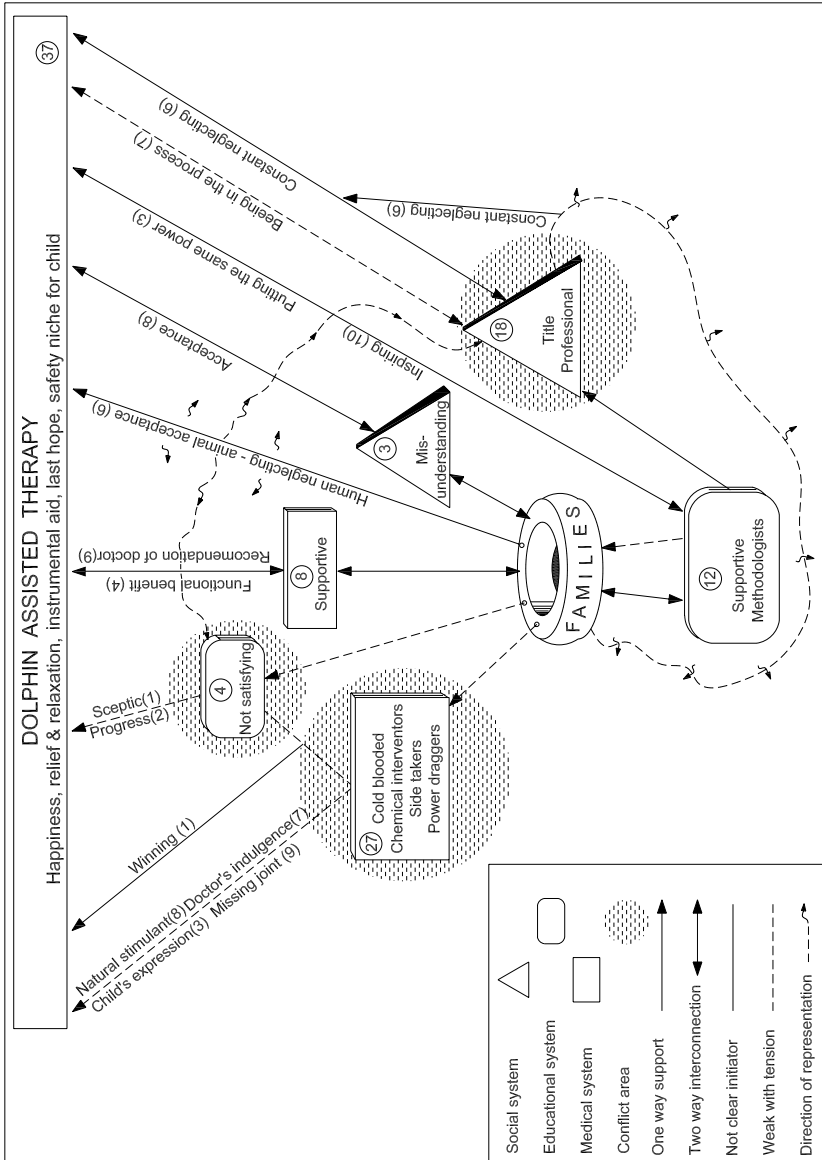
Constructed by Kreivienė.

Figure 6.   Eco-map of families raising severely disabled children in Lithuania.

Figure 6 shows that the most supportive branch for families is perceived as the educational sphere. The closest contact families tend to hold is with educators, from first level sub-categories as *supportive* and *methodologists*.

The results are not surprising because educational support is always directed towards holding a longitudinal relationship. The majority of families represented that specialists are orientated to create collaborative rather than tensed relationships.

The most interesting point is the one-way support direction coming from educational specialists towards families. Such a situation is depicted in which families tend to trust the professionalism of educators and that they create a safety niche for the children so that no further relationship is held anymore. From the representations by families it seems that educators are motivated to give information about children and seek contact with parents. They use letters, notes, and calls. But the parents themselves initiate the termination of the relation because of only being able to take their children home at weekends and there being no physical possibilities to meet each other.

In connection to DAT, all mentioned educators supported the families attending DAT. The cumulated positive expectations by the family were additionally supported in educational institutions, therefore DAT was perceived beforehand as a safety niche for the child. Though, three families tended to apply the same parent-over power model in DAT as was used in educational sphere. The model which was learned and interiorized as the most beneficial in seeking social support is delegated in additionally received resources.

The second most supportive stream is perceived as the medical sphere. The majority of families spoke of supportive medical professionals with whom the families also held strong relationships. Though, the second supportive stream means that two families did not have any support at all from medical professionals. And other families had only one concrete medic who is taking care of their issues.

Families mentioned that the problem arises that severe disability often requires intervention from further medical professionals. Therefore, in dealing with the other problems, families still faced unsupportive medics. Unsupportiveness was described as not giving information about the issues of children, no instrumental aid during high stress periods and the more commonly mentioned – no emotional concern or any

compassion for the problems of the child. Families speaking of their supportive medics mentioned a closer contact to DAT. They orientate or recommend participation in DAT as a possible benefit in locomotion. Therefore, families construct their expectations towards DAT as a concrete instrumental aid belonging to the medical sphere.

Also families giving positive representations and speaking of their expectations from DAT revealed important aspects that had not been achieved by the other systems, the same as in medical: betterment of the child, the child's expression, relaxation for the family.

The least supportive connection for families was seen in the social sphere. The results could be a lack of supportiveness. The activity schema adapted to Lithuania depicts how representations by families change Engerström's (2007) initial schema. Families represented that the instrumental aid, information and social support content is constructed rather by the parents themselves or mutual groups. Only four supportive social workers were represented by families. Three of them were mistaken for professionals belonging to some other spheres. Such a result shows that families do not have a clear image of the social worker as a specialist. They do not understand the difference between social work and sociology or physiology. Families were basically focusing on the need for instrumental aid, acceptance and meeting their different needs, which was measured as social work.

This kind of support has a very close relationship with DAT, as the accepting of research and DAT are perceived by families as in the same social work dimension. They also accepted but did not have clear idea of who would be working and what methods would be used. Acceptance is the main aspect, as it guarantees being in the process.

The most beneficial and interesting research results were based on the negative evaluations and seeing interconnectedness between the spheres.

Families represented that meeting negatively evaluated medics and educators created a strong relation between them which really did not exist. But both professional parts are very closely interrelated in using the same representations, working methods, even labels. The families represent those medics and educators almost equally.

The most fascinating result of the research was revealing that when a family meets an unsupportive medic as well as an educator, it leads to a third party *winning*. This winning aspect is not based on suggested

social support, rather on desperation. Therefore, it is supposed from the research results that the theoretical idea that given the probability of meeting unsupportive medics and educators, families would tend to initiate third-party intervention. In this case the third-party was DAT, but it is possible that other families construct third-parties with other agencies or private supporters.

These results of the analysed representations show that the families initially needed some amount of social support from the external systems during stressful periods, which could not be provided from within the family.

Medics evaluated negatively by families were represented as criticizing the idea of taking the child to DAT because of the perception of a demonstration of having power-over. Therefore such statements support even more families to visit the DAT programme. The result is controversial. Families perceive that doctors feel somehow being in competition with dolphins that could cure better. Families tend to give priority to DAT in comparison to the medical sphere, because of the aspect of nature and the initially perceived belonging more to the animal sphere than to human beings. However, this priority represented by families has to be perceived as *truth of situation*. I say so, because the families were speaking of medical help having experience in this system and more often negatively. But initially they firstly were seeking medical support and only then other alternatives. That means from the social support schema families need medics in the very first moment after learning about the disability.

An even more interesting result was given by families about negatively evaluated specialists in the social sphere, so-called professionals. Constant neglect is common to DAT and the social support sphere. Feeling neglected in the social sphere has been the same in DAT for many years and forms strange relationships. Families represent the very negative experiences of neglect in the social sphere for many years but are very positive towards DAT although also having been neglected. Speaking of DAT, families find their own explanations as to why they were not accepted for so many years into this programme. The negative aspects on the social sphere are concentrated only on a personal basis: personalities, equipment, representations and premises.

While speaking of the problem of not being accepted for years into the DAT programme families construct an additional negative field

for the governmental sector. Families represent that the *government* is guilty for not adapting the environment and for not giving finances to the Lithuanian Sea Museum for expanding DAT. Such representations put DAT into the activity schema (see Figure 5) together with mutual groups that are formed *against* the *government*. Mutuality comes from the sense of substitution of anger and despair with sorrow which this thought tended to share.

Another unexpected relationship between neglect in DAT and the social sphere is shared in the first level sub-category of *being in the process.* While families represent the negative points that nobody cares about them having in mind longitudinal care, this care is perceived as *provided* in DAT. Practically DAT does not provide any longitudinal supervision, but families registering children in this programme are in the process of waiting, and accept neglect as a natural component of the process. Some of the families find their explanation that they are waiting on the list because their child is not *sick enough*; there are much more seriously sick children to whom priority is given.

While the educational and medical spheres seem connected, the social sphere seems to be outside of the system. Representations by families show that social work is more often covered by other professions that truly implement it. Social work functions are delegated to medics and the most often to educators, whom families trust. Initial social support that should have been provided by the social worker in nine cases of families was represented as provided by other professionals, mostly medics.

The representations showed that educators usually have a strong, one-sided relationship with professional social workers (educators) to whom they usually transfer the task of asking of parents. But the medical system does not touch the social work sphere. The representations by families did not show any signs for representing it on the schema. Some of the families were telling of social workers in the institutions of early intervention. However, families represented their work as some kind individual family investigation for unknown reasons rather than as social support.

And the last interesting joint in the picture is the family striving towards DAT because of the perceived animal acceptance paradigm. More than half of the families spoke of neglect of the child and the whole family by the social support system. It seems that after many years families had

tried almost all methods and faced different experiences and the last hope left: try animal acceptance and natural stimulant. This idea was reflected as some kind of self-esteem reconstruction for the family that would mean *somebody needs us*.

Unfortunately these representations took on the shape of opposing relationships in building connections of family-professionals to DAT. Six families said that the social support system had neglected their child and dolphins *understand more* about such children.

It is possible to make a conclusion from the representations by families that the majority of them were happy to be on the list of DAT for so many years because they felt themselves to be in the process and were very stressed after accepting, because there was the question of their constructed expectations that dolphins are needed by their child or that the expected results would occur.

10 Evaluation of the Research Process

This final chapter is my evaluation of the whole research process. I draw my analysis on the construction of the theoretical and empirical parts, as well as write of the practical implications of the research results.

10.1 Evaluation of Theoretical Commitments

After writing this thesis I understood that many questions that had been touched upon could be the basis for a future thesis, as more research could be done giving more attention to existing problems that each of us can draw. I have to acknowledge that it was very hard to analyse the problems I raised for myself and some of the results were absolutely unexpected by me.

Lithuania can be called a young country in its searches for which political, social and economical models to follow. I had two main *new* objects that are presented throughout the analysis: social work and families raising children with severe disability. I say new because these two objects were founded at approximately the same time in Lithuania, together with the gaining of independence.

Families represented that social support during their stressful periods of life was not provided effectively, the system was perceived as a field of a social fight arena. Families felt they were being treated too generally among other social groups when they described their situation as worse than others. The Lithuanian activity schema on the representations by families revealed many problems in all the branches of social support. Research showed that families do not feel supported enough; the situation of their reflected social work arena can be called critical. One of the most important aspects of the social support content mentioned by families is that finances were not the main problem.

My theoretical observations and research are based on three main theories that helped to collect the puzzled system.

The social support concept was defined as my working term from the authors Wilton and Plane, (2006), Parrot and Madoc-Jones, (2008), Hunt *et al.* (2004), Hill (2002), Olsen *et al.* (1999), Mulvaney and Kendrick, (2006), Anderson *et al.* (2002), and Howe (2006). The main

idea was based on Urek's (2005) understanding that social support is constructed in everyday interaction processes. Families and professionals negotiate it and construct their interpretation.

There are two main strategies for explaining the social support mechanism: either processing support in a stable network or analyse it on stress prevalence. My theoretical direction was organized according to the second strategy where social support is seen as a stress-buffering. Analysis of the representations by families could give the answer to their individually perceived qualitative support factors.

Cohen *et al.* (2000, cited in Davidson and Demaray, 2007, 385) notes that the buffering effect can materialize in two ways. First, if a person believes that support will be available in times of crisis, this belief improves that person's coping ability to handle such a crisis. Second, if a major stressor does occur, social support can reduce the harmful consequences of such a stressor, including the effects on the person's health and/or behaviour.

Research construction putting DAT in a window place to analyse social support from the social, medical and educational systems helped to unite two historical periods of families: from the calling to DAT (identifying situation) to coming (projecting situation from current position). In such a way families represented their perception of social support when a major stressor occurred and could reflect (as belief) what social support is available in a crisis.

The developed general concept for all external resources social support covered: emotional concern, instrumental aid, information and appraisal. The thesis was based on seeing convergences in social support terms of the understanding between the social, medical, and educational systems as it is exactly those systems that are the main social supporters guaranteed by the Republic of Lithuania (Valstybės žinios, 2004, Nr. 83–2983). In such a way I could speak the same conceptual language for different professional branches having peculiarities within the content.

Generalized terms helped to see what professionals are able to cover on the side of other professionals in the provision of social support. Instead of creating clear boundaries I dissolved them. Such a decision was based on the idea of Bidgood *et al.* (2003) that when seeking betterment, professionals who are able to think *outside the box* may help. Families representing social support were speaking of my idea giving real

examples based on their practice. All the families speaking of supportive representations, professionals and a supportive model of work included a concrete personality standing over this result.

The Scandinavian activity theory was used for showing social work as an active process where object deals with subject – family in order to have satisfactory effect – social support that is the basis for the family with stress to accept coping behaviour with positive psychological, social and physical outcomes the for family. The main ideas and were taken on the basis of Engeström works (2007; 2008, cited in Huotari, 2008). Paavola *et al.* (2004, 560) writes that:

> *Human beings do not live in a vacuum but are embedded in their sociocultural context, and their behaviour cannot be understood independently of that context (Engeström, 1987; Engeström, Miettinen & Punamäki, 1999).*

This idea gave me the possibility to make insights into some historical – cultural background for understanding the discourse of disability and social work.

Research showed that ideas about the social worker as a mediator drawn from Soar (2005), Flynn (2005), Barsky (1999), Kiselica (2004), and Petraitienė (2006) appeared to be meaningful on the theoretical level, as families were not representing social workers as mediators among other professionals' roles. They were noting about a possible mediator between: doctor and family and family and information providing. Representations of research showed that there was no single case where a social worker had mediated in any situation, even more – the majority of families had never met a social worker and few asked during the interview *what does it mean social worker?*

All family cases represented many trials of negotiation rather than real negotiation in seeking social support during their stressful periods of life. All cases of families represented tension in relationships with external resources and the basis for the conflict was reflected by a constant construction of relationships (from both sides) with *power*[135] involvement.

The systems theory was used according to authors Weiß (2001), and Bronfenbrenner's (1979, 1997 cited in Bowes *et al.*, 2001) ideas that the social worker could be a professional mediator in the support process.

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135 Main ideas of Barnes and Mercer, 2005; Hugman, 1991; and Tew, 2006.

Research showed that these conceptual ideas are very important, as the need for social support exist. Families represented a rather puzzling understanding of the functioning system than one of collaborating, but they reflected the great need for professional social support. Systems theory was valuable in opening the interconnections between the systems in micro, mezzo and macro networks and detecting the possibilities for the social worker's intervention. Also the systemic approach allows a view that is more open to the existing phenomena.

Berger and Coopersmith (1984, both cited in Ho and Keiley, 2003, 247) wrote that such interventional sight is always more effective than treating one individual in the system.

Analysis of social support in three main streams – the social, medical, and educational systems as external resources was enriched by engaging Dolphin Assisted Therapy in the approach of a window to the analysis. This decision focused the research on a particular historical period of analysis of social support for families having a future projection. It was only through the DAT sphere that it was possible to obtain the essential data about social support and answers to the following questions: when the social support is needed for family; what parts of social support are lacking in the medical, educational, social systems; what social support families hope to reach through DAT in connection to support from other external resources; if the stress-buffering model is working in Lithuania; what meaning is constructed by the family itself about the participation in DAT; and how it is connected to traditional external resources.

10.2 Evaluation of Methodological Commitments

It would have been hard to measure and draw a clear line when I started my research. Perhaps it would be honest to say that a question of social support in connecting the social, medical and educational systems with DAT was in my head for more than five years. My research ideas were first aroused as practical orientation and only then did I start to complement them by searching for a theoretical background. However, understanding that practice can be a very valuable generator of research ideas I had to be cautious of not getting into fusion with my research participants.

This worry raised many questions. The worry was about putting a limit between my understanding and the understandings of the families in the research. Being a researcher I wanted to represent the results as close to the true situations of the families as possible. Though, I understood that this research constructs a family-via-research truth. Such a truth is new. Bannister and Fransell (1971, cited in Geelan, 1997) write that from a constructivistic perspective we do not have direct access to the construct system of another, to the extent that where one person construes the construction processes of another he may play a role in a social process involving the other person.

My research was an attempt to understand the representations of social support by families raising children with severe cerebral palsy, but I understood that I was involved in a construction process, one of construing the families' constructions.

In solving this issue I took the role of voice giver for the families and together we constructed the primary categories of research. In such a way I could represent the representations of the initial source as close to primary understanding as possible. When reading the texts of the families there was a constant sense that the representations of one family complemented those of the others. Therefore, even when reading the research part a sense that it had already been mentioned sometimes appeared. That shows that the families were picked for research being very close in experiential background.

I was thinking how I could gather such an identical group of research participants with almost the same life stories, experiences and even representations. And analysing those thoughts I came to the conclusion that I had a beneficial research arena. On the first research stage I clearly decided on the patterns of possible respondents. All those families had registered for DAT, they had waited on the list for a few years, therefore the motives, problems, way of thinking, and even life situations could be closer than between families who had never registered for the DAT programme. Another aspect was common facing the same social support system in Lithuania. I hoped to get more different representations from families raising children of different ages. However my research revealed that a time span of few years does not reflect considerable differences in representations of social support by families raising children with severe disability.

Another ethical question was raised in the analysis of the Dolphin Assisted Therapy theme. Though my research was not based on revealing the impact or any opposition to one sphere to another, it was therefore, ethical to use it in the context of connection analysis.

When I was consulting families coming to DAT, I constantly questioned myself: how will families see what is wrong with the external resources? My idea to make this research from the initial background was based on the understanding that DAT is a rather emotional family supporter and never should be the main, as help gained through DAT should not repeat the functions of governmental support provision.

It was meaningful that the Lithuanian Sea Museum is not a private or fund-raising organization that would need *clients* for a therapy programme and my research could *promote* this programme. The Lithuanian Sea Museum is a governmental institution belonging to Ministry of Culture of the Republic of Lithuania, therefore the whole collected revenue throughout the year goes to the budget of the Republic of Lithuania and then is shared to all Lithuanian museums. Dolphin Assisted Therapy is a very small piece of the activities provided in the museum. Nowadays the situation allows the museum to accept only 50–70 participants per year. The price paid for therapy barely covers the expenses and many children are the participants of research, therefore no fee is paid.

Content analysis was applied for finding research results. The gathered texts were taken for analysis when more than year had passed after the research. After long interviews, discussions with families on the primary categories I had to take some time letting to simmer both the texts and my thoughts.

Only after such a period of time was I ready to take the texts and redo them again going into analysis. However some of the research results confused me as a researcher. For example, I could imagine that social work is not a so commonly spread profession because of the natural historical approach that can be understood and the same concerning social support proving for families. I must say I even expected that there would be one or two families that had never directly met a social worker, but may form an image of his roles. But the result that majority of families had never met a social worker and that few families met social workers whose job is directed towards entertainment and parents visit them only

when there is nothing to do. I cannot hide that these results were a great disappointment for me.

During the whole pre-research period as a researcher I experienced many tensions that were based on the whole research process and the participants. Many people were involved in this research, like dolphin trainers, photographer, law consultant, doctors, public relations specialist, vet, and director. They helped to construct and implement the research as it was shaped. After my phone conversations with possible research participants, the back-phones started. I felt very bad evoking families' hopes and expectations that after so many years there is finally a chance to reach dolphin assisted therapy. During the process of forming a list of respondents I had to face with one swindle and one bribery attempt that aroused many thoughts for me as a researcher. Unfortunately some of the families that were not taken in the research are still only on the list and they will maybe never be invited to participate in DAT. After completing the research and reading through the research results I again face the same feeling of discomfort because I know from representations by families what it does mean to be rejected.

Peled and Leichtentritt (2002) wrote that one of the main points of research ethics that has to be kept is confidentiality. I hold confidentiality allowing only people directly involved in the research access to the research information. All cases were coded, no names or other particular features were described that would allow the recognition of the respondents. Material related to each case and interview data are kept in the archive of the Lithuanian Sea Museum and cannot be accessed without the permission of the director.

In comparison to my previous qualitative research these research participants were different. Instead of willingness to stay confidential, they were proud of participating in the research and allowed me to use their true names. Despite that, I did not use them. One family gave an interview about this research for a national newspaper; a few of the families gave interviews for TV programmes.

For me as a researcher it was very meaningful to built a friendly environment without any tension during the interview, therefore, I tried to ask general questions and only later entered into more depth. Caring for families (mentioned in Campbell *et al.*, 2002) was one of the

main interests during the interviews. As far as I got the message from two families that the mothers themselves were struggling with terminal illnesses, for some period I felt a compassion for the families as I was not emotionally ready as a researcher get so much sorrowful information and honest openness.

I was glad that after finishing the interviews families said that the interview itself was seen as more therapeutic than only an interview and sometimes had revealed new meanings for them. I may say that my personal experience of these interviews is invaluable because the interview as a process had surely been moved beyond its traditional understanding. Some families said that they even enjoyed the interview and said that they really hoped my research findings and their contribution to the research would be meaningful for other families in making improvements to the system that serves families' interests and not the opposite. All the families said they expect my research would change something in Lithuania.

While applying content analysis my main engagement was related to the issue of definitions of social phenomena. Though, I draw attention to the critics of Riessman *et al.* (2005). He (ibid) writes that quite often the researchers try to summarize the content and put only frequency counts of text such that the picture of the issue may disappear. Therefore, I decided to put in broader texts of the analysed issue to leave the picture that had been drawn by the families and show the representations of their constructed understanding of social support from the medical, social and educational systems in connection to Dolphin Assisted Therapy.

The main research results have been overviewed in the previous chapter. One of the main ideas reflected by families that instead of coherence in social support they faced a puzzled system. Families were not sure who among the professionals are able to provide the needed social support at the moment of crisis, therefore, due to the understanding of the families practical changes must be applied for social support as a means of stress-buffering. Families strive to come to Dolphin Assisted Therapy because of a lack of social support and in very stressful life situations.

The biggest caution for me as a researcher was finding that families do not receive social support from the different branches of system, but from a concrete specialist they are attached to. That means social support from external resources is perceived by families not systemically, but rather

fragmentally orientating towards the same social support providers each time when stress occurs.

Families represented that in highly stressful periods of life they desperately sought any accessible social support stream as a stress-buffer. Families saw many elements of perceived social support in DAT in connection to the social, medical, and educational systems. Additionally families represented that DAT is perceived as a supportive programme not only for the children but also for their families, especially mothers to *relax* and gain *new experiences* being *overloaded* by the issues of severe disability.

The representations by families repeated the idea of Bidgood *et al.* (2003) that the path to open relationships begins when each professional thinks *outside the box*. However, families were also speaking of features that did not lead to open relationships and collaboration.

Speaking of the concept of general social support with the content of emotional concern, instrumental aid, information and appraisal, representations by families revealed that quality depends on the concrete personality of a professional they had met and some additional environmental factors. Families represented some of their sensitive experiences where professionalism had been put aside, highlighting personal representations, and ambitions. Such representations by families reduce their possible external resources into a very few social support providers.

10.3   Practical Implications of the Research Results

The main research findings were presented in the previous chapter. In this section I will draw the practical implications of the research results.

The theoretical and empirical analyses of social support for families raising children with severe disability allow me to draw practical implications on the research results that can be implemented in order to improve at the governmental level according to the understanding of families. These implications will hold the social support components: emotional concern, appraisal, information, and instrumental aid. The research results showed that emotional concern and appraisal can be put

into one level as they have a lot of similarities. Practical implications are shared by the levels.

At the level of emotional concern and appraisal

The research revealed that the majority of families tend to give medics descriptions such as not having social skills of not showing empathy which is perceived as neglecting. Medics as professionals were taught in clearly professional matters and not how to deal with a severely disabled client and his whole family, therefore according to representations of social support it was shown that the most satisfied element of content was the evaluated result of intervention having features of a clear diagnostic model. Families were depicting medics in a situation of high stress for family as not reacting properly. Instead of emotional concern and appraisal they were perceived as hiding, neglecting or quarrelling. Another dissatisfying point represented by families was honesty, as families felt that medics pretended to know about the diagnosis of the child when they were professionally not sure about that diagnosis and its treatment. Families were speaking of such unfairness to them constructed under stress on both sides where the doctor is perceived as playing some sort of games with families and treating them as if they were not important at all.

The educational level was perceived as more supportive, though two families could not establish any contact with educators. The main aspect mentioned by families lies in longitudinal supervision. Families represented social support being most meaningful in this branch as constituents of the content of full social support. Instrumental aid was perceived as a framework of supervision of the child. Families were satisfied with an individual plan for the child, the methodic and the shown representations towards the child. Appraisal and emotional concern was tied to inclusive education. When educators emphasized the positive aspects of the personality of the child and the success of interactions with other children, families represented that they did not need anything more. The emotional aspects were usually put above the unfriendly environment.

Families represent educators as a substitute for parents creating a safety niche for the children. The most important is attention showed to the individuality of each child and professionalism. However, the representations by families showed that parents tend not to prolong close relationships with educators as they feel safe, see that child is willing to visit a particular institution.

Something close to emotional concern was represented as being met in sanatoriums when speaking of the social sphere. The functions and practical contribution of those social workers met there were represented as being of no value; however, families did not give prominence or problematize having merely friendly relationships.

In the connection to DAT emotional level and appraisal as a component of social support was always opposed to the above mentioned systems. The medical sphere was especially seen as very emotionally unsupportive. Representations by families were directed towards the comparison that the medical and social spheres are cold and uncaring and that DAT they see as full of positive emotions and welcoming. A very sensitive situation was faced by two families in the educational system. They perceived personnel of external resources as demonstrating very negative representations towards a severely disabled child. Representations by families towards DAT are that it seems to be some kind of salvation from the negative responses received at governmental levels.

The social system was severely criticized by families on the point of emotional concern and appraisal. Families represented institutions they met with that are directly responsible for providing service, as having critically negative attitudes towards the disabled and their families. All families tended to give prominence to their special situation because of the severe disability of the child. Families represented that there must be a strict change in the representations of specialists. Families said that the most negative representations were met in the social care departments where specialists taking care of the issues of the disabled treated families as not clients of the service but as beggars.

Families represented that specialists working in a social care department do not seem responsible for the quality of the service provided, the empathy showed to the individual issue and the information they provide or hide. Families gave examples where solving critical issues of life, information given by different sources was split because of the lack of

clear information provided by the social care department. Families point at the unwelcoming atmosphere in social care departments; professionals they described as displeasing who are not meeting the needs of the family or answering any question by the family so that the next time the family feels discomfort in coming back.

The research results showed that parents are experiencing the greatest happiness in seeing their child in communication with healthy children. Families represented an unclear model of practical inclusion for each child. The dissatisfying representations towards the educational system were based on unwelcoming educators and heads of facilities that had been met. Families felt hopeless when they met a position in which it was not clear who was directly responsible for the inclusion of a concrete child. Almost all families were describing social educators in an educational facility. Families expressed that they tended to be more likely to solve the issues concerning social support through an educator than to approach a social educator. The social educator according to the descriptions of families is a more neutral specialist met once a year at the beginning of the child's school year.

However, the social educator is a specialist who could form a group of people responsible for the concrete inclusion of each child. It would be welcoming if this team contained not only working personnel but also parents of disabled children and healthy children, the same way as a disabled child could have a healthy child curator at school. Such a way would allow the social educator to coordinate the process of inclusion at school. This facility would create a welcoming environment for each child with disabilities.

Healthy children and their parents would also feel responsible for creating an inclusive environment. The social educator could build a contact with parents of the disabled child and educators would no longer need to mediate between them. The practical implementation of this model at the educational level would involve all members into the shaping of an inclusive environment. Naturally such a supportive educational surrounding could change the rules and tools used by parents, as they would not need to be defensive of this environment inserting a power-over relationship. It would be possible to construct a real power-together relationship.

Some of the representations by families were extremely sensitive on the emotional level. I am speaking of given representations of a few concrete professionals: a medic putting a disabled child and his mother for few days in the same children's cot, about the head of an educational facility who suggested to a mother that she reject her child instead of being emotionally supporting and appraising. Families represented their biggest despair in feeling unshielded when encountering a lack of professionalism and a violation of human rights in that they still have to ask for social support from the same providers having no alternative choice.

In generalizing representations on emotional concern and appraisal, families reflected the medical system as the most insensitive. Families described features of a clear medical model that was met with more often. However, during high stress situations the application of a clear medical model was welcomed by families. Families were satisfied with the application of this model because of the positive results achieved in their opinion.

The educational branch was full of different emotional colours represented by families. All families were speaking of emotional concern and appraisal problem when meeting educators. Though, in constructing a projection to future relationships families tried to find a safety niche for the child and change institution from unwelcoming to befriending. Though, representations by two families showed that they did not succeed.

Social work as represented by one family showed emotional concern and appraisal professionally. But this family mentioned only one such contact in their life. In the context of other professions the social worker was represented as rather weak, uncolourful or absent than as a representative of families' rights. Families that met social workers in sanatoriums represented these specialists as emotionally concerned and appraising in a way that creates a friendly environment. In general representations of the social support system were summarized by the words *they do not care about us*.

In the DAT sphere families projected representations of having features of emotional concern and appraisal. Both of these social support constituents were represented as tied with an expectation of very positive emotions that families lack from other systems of external resources. Previous negative emotions experienced because of neglect in this sphere also find explanation by the family pointing to outside reasons.

At the level of instrumental aid

This level was the weakest in the social sphere. Despite negative representations about medics, the majority of families' were satisfied with the result which was achieved because of professional instrumental aid. The educational level was only in some cases perceived as weak in instrumental aid. These cases directly related to the lack of emotional concern and inappropriate personnel and to the lack of finances of the system.

The social sphere was represented as weakest because of a few main aspects: service, law and information. When families were speaking of social services, the main problems appear in the sense that the system is not created for the client, but for working personnel. The system was perceived as being inflexible; therefore, Figure 6 shows a dotted line between families and professionals without arrows at the beginning or ending. The research revealed that families try to contact social workers but after the first attempt they generate a feeling of not wanting to come back there anymore.

Instrumental aid from the social sphere was perceived as needing improvements. Families represented that social service is too generalized not seeing each case as very special and in need of attention. Families speak of the creation of a general service leading to the understanding that all children are equal instead of seeing unique needs. Families gave comparisons of children having severe disability as: if one child were blind, another – deaf, they would both have absolutely different needs. Therefore, having such different needs families speak of revealing the absurd in the social system because they were measured against the same diagnose and general social services that cannot be used.

For example, families gave examples where one child could use a limited amount of governmental money for buying a wheelchair and deaf-aid. Due to the law the same child can have both benefits. But if child never had need of a wheelchair, if it were just a deaf-aid the parents would still have to save money for covering the same apparatus. Or another case that the government covers a concrete percentage part for the purchase of a wheelchair, or gets a loan for buying accommodation, but it strictly puts limits on the price. The trick is hidden here that if the child with severe disability cannot use the cheapest wheelchair and the family has to buy a more expensive one, then the government does not cover anything at all.

Families speak of such legislations as if they are putting some quality level on the devices and instrumental aid to make it possible for use by the disabled. They call such legislation as an example of bad practice, because from such a point of view all disabled people are put into the category of poor people. They are forced to choose the worst category of equipment, buy cheaper flats, cars and get second class devices. Otherwise a family will not get any support from the government. Families were speaking of setting some fixed amount of money that could be spent on instrumental aid that would show more equality than now. For example legislation compensates some expenses for using public transport. But in case it is impossible for child to use public transport, this sum of money could be compensated for parents using their car. Families represent the importance to of feeling real participation in the decision making process while taking care of their child.

Another aspect is about the difference in benefits for carers; all the mothers were unemployed because of a governmental decision. Children and mothers are taken out of the social participation process. It creates a lack of finances and dependence on the father's salary. All families were saying that the main difficulties and stresses arise from taking care of the child's situation. Families spoke of feeling exhausted and needing rest. The majority of parents said they have not been alone as a couple any time after the birth of the child. Many of the families had been living four or more people in one room for many years. It means that all the family concentrates on the problems of the child for many years. The problem of the child is the main aspect of family functioning. Therefore, families perceived DAT as a rest and unwinding of problems after the perception of the medical aspects of DAT.

Families pointed to the problems of not specified and not enough professionalized educational services. First of all, it is essential to apply supervision in educational institutions. The working hours of educational institutions are not allowing mothers to come back to the labour-force. The majority of families said that they could not leave the child for longer periods even with the closest family members, because many medical aspects of care must be perceived.

Few families said that benefits are not so much helpful, because employers take a disabled child to be rather an obstacle for employing than normality. Therefore, the educational service is perceived as the

most influential in longitudinal social support and that it has to be strengthened (longer working hours, flexibility, working on weekends, and more professional personnel). Also families living in small cities mentioned that they did not have the possibility to choose an integrated educational institution in their home region.

One of the main ideas that has to be implemented in the social work field was longitudinal supervision. Families were not telling of mediation functions directly, but they all were stressing a lack of being in the process and taking care. Therefore, a guarantee of being in some process creates a sense of activity of life.

Families pointing to the problems of the social sphere were constantly emphasizing the small number of families with such children.

It seems realistic to strengthen the current model of the social system. Each maternity hospital must have a social worker position. In such a way positive contact with families could be established at the very early stage. These social workers could be responsible for emotional support, information and family consultation. They would create a file for each family containing all information: family itself and provided consultations. This file could later be sent to a social worker or educator in the early intervention service and educational facility. In this way the following professionals would have pre-information about the family and it would help to specify support. Later a file with family history would be passed to the social educator at school.

Such a model would shape a clearer vision for families and create a sense of activity, participation, longitudinal supervision. Knowing to whom families could come for social support would create a choice and calm family stress. The passing of files would allow a saving in time spent on gathering the same information. Concrete model of the social system would create activity for families. Also families together with professionals could discuss the individual scenario for each child.

Generalizing the representations by families on the medical service reveals problems in many spheres. The main problem as in the social system was also perceived as generalization. Families represent that they had to access medical service for the child as quickly as possible, because the child was different; his sense of pain is also perceived differently. Examples given by families revealed the perceived inflexibility of the medical service that is created in a way that families having a disabled child

need reams of additional paperwork from various medical institutions. Families are afraid to seek even the simplest medical instrumental aid because of the masses of papers needed. Even urgent instrumental aid is perceived as not always accessible. Some of the families say they are afraid of any condition that were to repeat in the child as they would have no idea whom to call.

Families represent their wishes that medical procedures for severe disability children are going to be reviewed and improved. They are speaking of the needed easier access to medical services, in case where there is a need for additional consultations or references of other professionals it has to be organized more flexibly. The current situation is formed in a way that parents must go some hundreds of kilometres to change drugs or get a reference from a psychologist for a tooth filling. These laws must first of all be based on reasonable practice.

The instrumental aid for DAT was built most expressively. Families were seeking DAT not only for the expected achievements of the child, but also because of the perceived positive influence on the family – relax and relaxation. As an instrumental aid DAT was more often seen as an alternative branch of medical support where a natural drug – dolphin is applied. In comparison with educational support, DAT was perceived as a possible sphere to achieve concrete changes in language, functioning, understanding etc. DAT in comparison to the social system was seen as an urgent supporter in a high stress situation as a stress-buffer. Families sought DAT in order to help the child and to get support for the whole family.

At the level of information providing

This level was evaluated by families as the weakest in the medical and social spheres. The educational level was evaluated as the strongest. Families represent a sense of security in knowing that the educator knows the methods of approaching the child, but parents are orientated to create parent-over relationships and are *on the defensive*. Medical professionals are represented as using an expertise approach when the child needs a medical service. Using the expertise model they tend not to share information with parents. Therefore instead of a holistic approach only

negative feelings, stress and insecurity are aroused during the process. But as was mentioned all families were satisfied with the results of this model's application.

Social sphere was perceived as the weakest in sharing information about law changes and new benefits. Families felt they were enemies rather than belonging to system. Families have always been in search of news in law that they barely understand. They told of the need for mediating between them and new legislations.

The word of mouth method turns into a silent fight creating mutual groups against systems instead of collaboration. Families speak of slight changes in this system that can change their stressful situation to a more beneficial one. They say that all families having children with severe disabilities have to be on the social support list. Parents could be delegated a function to fill in the papers and register onto this list. Therefore, families could be included on the families-at-risk list. But for that we have to expand the concept of family-at-risk, as the term created by the Minister of Social Security and Labour is rather one of labelling than supporting. Families represent that having such a list, social care workers could be responsible for sending a brochure, calling, and writing e-mails, organizing meetings or informing families in other ways about changed laws. In such a way families would be in the process and could feel important for the system and that somebody takes care of them.

At the collaboration level

The research revealed that all families need social support constructed outside the family. In stressful situations all families tend to seek professional social support. Families representing emerging high stress situations say that at this period of life they strived to reach any social support provider. All families during stress prevalence needed an urgent stress-buffer.

Families pictured all systems of social support as being more fragmentized than open to collaboration. DAT was pictured as a competitor rather than a benefit and an additional resource of social support that can be used. Representations by families opened the very sensitive topic that in critical situations when they are faced with the

disability of the child they definitely need support from outside systems. In case such support is impossible to receive, families are trying to seek it from other resources. All families registered children to DAT in the most edgy period of family life. And it did not happen because of support received from external resources.

Representations by families showed that the needs of families cannot be neglected, as the family itself does not have such capabilities to provide as much social support as is needed. Families speaking of social support were mentioning peculiar aspects that are impossible to implement by internal resources. When families were not getting support from one stream they were searching other options and possible supporters.

Families represented many problems they perceive about the whole system of social support. First of all the system dealing with the issues of the family is not clear. The law determines that social workers have to collaborate with other professionals. But the law regarding other professionals, such as educators and doctors does not define this function. Therefore, legislation must be reviewed and synchronized. As current practice is built on the concrete will of the professional.

Some of the resources were mentioned as used not as effectively as they could be due to the understanding of the families. Families were representing that there is a lack of activity in actions, for example in organizing an inclusive environment in educational institutions. Each member has to feel being a part of this process, otherwise representations of society will not change in the future. The same situation is true about the DAT programme. Families represented that educators supported families wish to visit DAT and were waiting for them coming back. The most critical medical system did not see DAT as a possible resource that could be used effectively. Representations by families showed that medics used to create a competitive relationship with DAT because of seeing DAT as having an impact on the waves of the brain (mentioned in Brakes and Williamson, 2007) or sound impact theories (mentioned in Brensing, 2004, Brensing and Linke, 2003).

The main connection of DAT and the external systems in providing social support was based on the searchings of families for emotional concern and appraisal. Some aspects of instrumental aid, and information were believed to be fulfilled in DAT that were not found in the external

systems. DAT initially was perceived as a programme of relaxation, relief, and support. All families were representing the labelling of representations met in each external system of possible support. Families were not feeling welcomed. Families felt as if professionals they met in the governmental sector tended to stress the lower position of the family and stress the favour they provide for the family.

Representations by families picture the social workers as *out-of-face* general professionals in the social care system. The social system was perceived as the most vulnerable and weak in constructing social support for families. Families reflected on the changes that would be essential for them.

Lazarus & Folkman (cited in Hartley *et al.*, 2005, Snell, Brown, 2006) family coping schema (see Figure 1) allow me to notice the applied consequences. The research showed that families adjusting their coping behaviour reach more often satisfying physical consequences for the child but not for the family itself. The families are experiencing a tight attachment to the disability of the child therefore social support is perceived as insufficient for the whole family. The common psychological consequences mentioned by families were deprivation, readiness to fight, exhaustion, social consequences of opposing the governmental sector, leading own cases, becoming doctors, social workers and lawyers.

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