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## Functionality of the family system within families with disabled children

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### ***Abstract***

This study aims at inquiring family functionality in families with disabled children in the Republic of Macedonia. 130 parents of children with different types of disabilities took part in this study, using the simple, random and convenient sampling methods. The study adopted the descriptive survey design, using a questionnaire for parents of children with disabilities for providing information about functionality and cohesion in families with disabled child. The questionnaire contained closed type questions, and a Likert scale of a series of statements, on a five-step scale from 1—completely disagree to 5 – completely agree. Parents' stress levels were measured using the DASS 21 scale. The results of those series of questions showed that in most cases interrelationship does not change, between many parents the relationship strengthened, the spouses became more connected, openly discussed problems and found solutions together, but all their time and devotion was directed towards the child, and very little to their own needs. In terms of family functioning, the families involved in the research shows structured and balanced flexibility, which is the willingness of families to change family rules, which is an important aspect of overcoming the crises that the family faces. Scores on the DASS 21 scale showed severe level of parental stress.

***Keywords:*** family system, family functionality, parents, disabled children, stress

## Functionality of the family system within families with disabled children

### 1. Introduction

Children and their birth are a family joy, but also a developmental life crisis for parents who move to a "new life" that requires changes and adjustments in order to maintain family stability. These changing points of family development require the activation of adaptive individual and family mechanisms, but burdened with diagnosis, disease, disability means family shock. Then the joy of parenthood is mixed with stress, despair and sadness. Several unavoidable emotional themes dominate: negation versus acceptance, despair versus hope, secrecy versus sharing, guilt versus forgiveness, burden versus liberation, isolation versus connection, fear versus courage, and meaninglessness versus meaning. These emotional polarities indicate the emotional experience of illness and disability in the child. But on the other hand, these tensions activate the basic human values, and that is the meaning of life, interpersonal relationships and wisdom. In their struggle that means frequent hospitalizations, diagnostic procedures, criteria, the need for constant 24-hour care for the child, parents often exhaust their strategies for

Families with children with disabilities are like any other families in many aspects – their own style, family dynamic, culture and preferences. However, there are certain experiences that families in this circumstance have in common. (Roehrer Institute, 2000). Most children with disabilities are valued members of their families. They grow within loving relationships with their parents and their brothers and sisters. They share the joys and sorrows of family life. While in the past many families were told their children should be institutionalized if disabled, today most children with disabilities live at home with their parents and siblings – and they are likely to do so for most

### 2. Literature review

#### 2.1 *Influence of the child's disability on the family functionality*

Family functioning is defined as the way in which the family members interact, react to, and treat other family members; it includes variables within the family such as communication styles, traditions, clear roles and

Families throughout their life cycle usually go from one stage to another through more or less normative imbalances that are predictable and expected events, until the establishment of a new level of balance of relationships, boundaries and mutual communication. Usually the birth of a child is a joy for the family, but at the same time it throws the marital system out of balance, and imposes a rapid reorganization of the family structure with the need to create new family transactions, in the newly formed subsystems - parent subsystem and parent-

child subsystem. Parents are required to maintain the marital subsystem, but at the same time to function differently as parents who share their responsibilities for the offspring, as well as to develop the mother-child and father-child subsystem.

In the new subsystems, the major tasks to be created are care, nursing, socialization and further projective support of child autonomy. Every family system is subject to a certain amount of stress when one of its members, especially when a baby or young child is diagnosed with a disability or a chronic illness. Emotional arousal occurs in the form of fear and anxiety mainly due to the potential threat of loss or disability in the child, which sets difficult demands from family members for mutual support, reassurance and sharing. Illness and disability are especially important in individuality and family history. Several unavoidable emotional themes arise in connection with them: negation versus acceptance, despair versus hope, secrecy versus sharing, guilt versus forgiveness, burden versus connection, isolation versus taking, passivity versus action, fear versus courage, fear versus courage, meaning. These emotional polarities signify the emotional experience of illness and disability. But on the other hand, these tensions activate the basic values of man: the meaning of life, interpersonal relationships and wit. Of course not every family deals with all these emotional issues, but rather every family has its own history. Some challenges are easier to deal with, while others are much harder. The way the family faces and overcomes the problems related to the child's disability mainly depends on several factors, as follows:

- What kind of disability the child has, because it also depends on the care that should be provided to the child
- The personality of the parents and their previous experiences - the personality of the parents determines the defense from this traumatic situation. Some parents become depressed, others aggressive directly or indirectly, others use precision asking why they must have such a child. Some parents are more or less able to take modest or realistic measures to help the child.
- Functioning of the marital system - the functioning of the marital system plays a big role in the mutual support of the parents, the sharing of the care around the child, the understanding of the emotional state of each of them. The better and more equitable the marital relationship, the better parents can cope with the day-to-day difficulties of caring for a child with a disability.
- Wider family and social support of the family - such families need a wider understanding, support and help from the wider family in sharing responsibilities, emotions, difficulties. The child with a disability also requires the engagement of other family members, if the parents work, to take care of him/her in their absence.
- The quality and services they can receive from health, social and educational institutions - the need for regular monitoring of the child by health and social services and rehabilitation that should be carried out properly and in a timely manner is very important in the care and support of the child. On the other hand, the necessity of his/her socialization, support of communication, stimulation of speech and understanding are the key domains of working with the child, which should be provided by both parents and professional services. In an environment with few resources for these children, the entire burden of care, development and socialization is left to the parents.

The most common parental reactions that occur when parents find out that their child has a developmental disability are:

- Shock, denial, numbness and disbelief
- Feeling of crisis and confusion when trying to overcome the knowledge of the child's diagnosis
- Feeling of losing the desired child

- Feelings of grief similar to those of a loved one who dies
- Expectations and hope for the future are changed and destroyed
- Feelings of guilt, responsibility and shame
- Expressed anger towards health care staff and professionals working with the child
- Dilemma about whether it could be better if the child is dead
- Disruption of parents' self-esteem and mutual trust
- Marital and other family relationships become tense
- Disruption of family everyday life (Krstić, 2013).

The knowledge that a child is diagnosed as a child with a disability causes grief in parents, which is similar to the experiences of people who grieve after the death of a loved one. Sometimes the grief process is difficult to determine. One of the complications is recognizing exactly what the parents are sad about. Physically their child is not lost, but parents grieve for their hope of a child - a child they expected to have someday. The grief that grows into guilt that the parents feel lasts a long time and it is difficult to imagine full acceptance of the child's condition, but still if the intense grief lasts much longer than expected, then the question of parenthood is seriously disturbed. After all, while grieving for the lost healthy child they were expecting, they are constantly confronted with the present child who needs a lot of attention. Parents make requests for reevaluation of the course of their proper future and the future of their child. Research has shown that revised intense grief and fear over and over again in a child's health and condition may occur when he or she grows up and does not master certain developmental directions.

All parents have desires and aspirations for their youngsters' lives, but parents with special needs children have a harder time meeting these goals (Hanvey, 2002; Janus et al., 2008; Reio & Fornes, 2011). Parents take on many responsibilities with raising a special needs child, such as caring for the child's physical requirements because of disability, helping the special needs child to create and maintain relationships, and creating a place in the community for the special needs child to belong (Hanvey, 2002). Special needs families often experience higher levels of stress than non-disabled families (Gottfried & McGene, 2013). These higher stress levels are created by various factors that influence a special needs family. Special needs families are often in a lower income bracket due to the need for one parent to become the primary caregiver of the special needs child (Hanvey, 2002). When that aspect is compounded with the high financial necessities for a special needs child, the situation can create even greater stress for the family (Hanvey, 2002). Families with special needs children also experience higher levels of breakdown in the family unit, resulting in divorce and single parenting. These various factors intensify anxiety levels, creating a situation in which high numbers of parents with special needs children report being discouraged, stressed out, and exhausted (Gottfried & McGene, 2013; Hanvey, 2002; Reio & Fornes, 2011). This has a spill-over effect on the family as a whole unit and influences the health and well-being of all family members (Gottfried & McGene, 2013; Hanvey, 2002; Orfus & Howe, 2008; Van Haren & Fiedler, 2008). The health of the family depends on the well-being of the entire household unit (Orfus & Howe, 2008).

The view that having a child with an intellectual or developmental disability creates negative family outcomes including added stress and parental depression has underpinned much of the research of the past three decades (Baxter, Cummins, & Yiolitis, 2000). Yet, research on this subject has suggested varying outcomes for families. In support of the view that disability leads to negative outcomes, a couple of comparative studies have noted greater stress in parents of children with disabilities than parents of children without disabilities (Baker-Ericzen et al., 2005; Dyson, 1997). Likewise, two studies, focusing specifically on mothers, have found that mothers of children with mental retardation experience more depression than those of typically developing children when compared using the Beck Depression Inventory (Olsson & Hwang, 2001) and the Center for Epidemiologic Studies D

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it is important to note that they did not control for variations related to the diagnosis or care demands associated with the disability.

In addition, the way the family functions in response to the child's disability has a critical relationship to family outcomes. Researchers have noted that marital and family functioning may be far more important predictors of parenting stress and depression than the presence or absence of childhood disability. Abbeduto et.al. (2004) found that diagnosis-specific differences in parenting stress disappeared when child behavior, parental coping style, maternal education, family income, age of the child, and number of children in the family were controlled. Kersh et al. (2006) found when controlling for marital quality, neither child functioning nor child behaviors were significant predictors of maternal and paternal depressive symptoms or parenting stress. Smith et al. (2001) noted that although poor social skills in the child were a predictor of parent stress, family functioning was a much stronger predictor. The causal directions between stress and family functioning cannot be determined from these findings. Yet, these studies point to the need for practitioners to pay attention to parental relationships and overall family functioning because these can be important risk factors for parental stress.

Although several studies have examined the negative impacts of poor family functioning, Lustig (1997) found that most families of children with disabilities do not experience poor functioning. In a study of family typologies, Lustig (1997) found that most families of children with disabilities displayed either a coherent or flexible profile, and that only 7% of families exhibited a vulnerable profile which was characterized by a lack of functioning, coherence, resources, and adaptability. The results of Lustig's research suggest that families of children with a disability may not experience more difficulties with functioning than other families. Thus, practitioners should not equate poor family functioning with childhood disability. While poor family functioning may be a risk factor for stress when it is present, many families function quite well.

Lustig (2002) found that families who could re-frame the disability in a positive way and perceived themselves as competent rather than passive had better family adjustment. Weinger (1999) found that mothers with a more positive perception of the child with a disability rated their family functioning higher. Finally, research indicates of how each parent copes with the disability may impact the spouse's coping. Hastings et al. (2005) noted that spousal depression was a significant predictor of stress in both mothers and fathers. Thus, the literature suggests that practitioners need to pay close attention to how families define their experience of caring for a child with a disability. Negative cognitions about the disability may represent risk factors for families.

There are many ways in which parents can reframe the disability experience into a positive one. In qualitative studies, parents have reported that their child's disability has given them an increased sense of purpose (Stainton & Besser, 1998); personal growth (Scorgie & Sobsey, 2000; Stainton & Besser, 1998); improved relationships

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### 3. Methodology of the research

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**Goal of the research** - The main goal of the research was to examine family functionality in families with disability children in the Republic of North Macedonia. Families with a higher degree of functionality have a clear distribution of power and roles, open and clear communication, show a greater degree of flexibility, respect for the developmental and individual needs of their members, and emotional connection provides both belonging and personal freedom. The main goal of the research was realized through the following tasks:

- Examination of the influence of the child's diagnosis on the mutual communication of the parents.

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- Examination of flexibility and ability of the family to adapt to changes.
- Examination of family cohesion in families with a child with a disability.
- Examining parents' attitudes about the level of stress they are going through.

**Methods, instruments and sample of research** - The research was conducted with a descriptive - analytical method that is adequate and in accordance with the nature and character of the set goals of the research. The analytical method analyzed the views and opinions of the respondents covered in the sample of the research. The research was carried out using a questionnaire for parents of children with disabilities for providing information about levels of functionality and cohesion in families with disabled children. The questionnaire contained closed type questions, and a Likert scale of a series of statements, on a five-step scale from 1 – completely disagree to 5 – completely agree. Parents' stress levels were measured using the DASS-21 scale. The Depression, Anxiety and Stress Scale - 21 Items (DASS-21) is a set of three self-report scales designed to measure the emotional states of depression, anxiety and stress. Each of the three DASS-21 scales contains 7 items, divided into subscales with similar content. The research sample was randomly selected and consisted of 130 parents of children with different types of disabilities.

**Data processing** - The data were processed quantitatively and qualitatively using the excel and statistics computer programs which were grouped according to the number of matching in certain categories and then placed in tables. The data were calculated with frequencies for which a percentage was calculated.

#### 4. Results and discussion

##### 4.1 The influence of the child's diagnosis on the mutual communication of the parents

According to Walsh (1998), one of the processes having a significant influence on the elasticity of the family is the set of parental communicative processes, with the help of which trust is aroused in the family and which forms an open form of expression amongst family members. Communication is the measure of a family's functioning with disease, and has by many authors been underscored as a significant source of stress, but also when it is correctly shaped and directed it may constitute a potential and source in coping with the challenges and the specific problems caused by the child's disturbance or disability. The first task of the research is to examine the influence of the child's diagnosis on the mutual communication of the parents.

**Table 1**

*The influence of the child's diagnosis on the mutual communication of the parents*

	Never %	Rarely %	Sometimes %	Often %	Always %	Total %
Do you discuss problems openly with your spouse?	2	8	9	12	69	100
Were there any changes in communication with the partner when the child's disability became known?	9	54	11	26	/	100
How often are you satisfied with the communication with your spouse?	5	9	15	29	42	100

From the results presented in the Table 1, we can conclude that most of the parents (69%), always openly discuss the problems that arise in the family, while 12% said that they do it often, 9% of the parents sometimes. Most of the parents 54 % respondent that their child's disability rarely causes a change in the relationship with their partner, 15% sometimes notice changes in communication, and 26% believe that often the child's disability is the reason for a change in mutual communication. 42% of the respondents are very satisfied with the communication with their spouse, while 29% are satisfied. Out of the total number of respondents, 15% answered that they are partially satisfied, and 14% that they are not satisfied with their communication.

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them has strengthened, that rely on each other, that they openly discuss problems and that they adapt to the situation of the child and are committed to him, to finding means, drugs, therapies, and many others. The other answers were that „the communication with the spouse is reduced, the level of stress is higher; many sleepless nights; as a reason for impaired communication was the unemployment of one of the parents, most often the mother who divorce.

#### 4.2 Family flexibility in families with disabled children

Flexibility is the family’s ability to change and adapt to life events. Family adaptability is defined as the ability of a family system to change its power structure, role relationships and relationship rules in response to situational and developmental stress. Healthy functioning families strive to maintain stability and continuity with the family system while adapting to various life events. Healthy functioning can help families when faced with adverse changes. The second task of the research is to examine the flexibility and ability of the family to adapt to changes. According to Olson (1993), it refers to the degree of change in family "leadership", the division of roles and the rules of mutual relations. Certain concepts that are included within this dimension of family functionality are:

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**Table 2**

*Family flexibility in families with disabled children*

	Never %	Rarely %	Sometimes %	Often %	Always %	Total %
Are responsibilities for caring for a child with a disability divided among family members?	12	5	38	/	45	100
Do you find it difficult to organize yourself around the responsibilities and care of a child with a disability?	12	20	49	16	3	100
How often are family members frustrated by changes in responsibilities and rules?	15	28	48	8	1	100
Are there clearly divided roles and rules in the family?	21	10	38	/	31	100
How well is the family able to adapt to change when needed?	/	1	19	37	43	100

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#### 4.3 Family cohesion in families with disabled children

Cohesion is defined as the emotional bonding that exists between family members. With the questions from the questionnaire we wanted to find out what is the family cohesion in families with a child with a disability, what is their emotional connection within the family, do they care for each other, do they spend their free time together. The results of these questions are shown in the following table.

**Table 3**

*Family cohesion in families with disabled children*

	Never %	Rarely %	Sometimes %	Often %	Always %	Total %
Do you spend your free time together with your children?	/	/	20	/	80	100
Do family members care about each other?	/	3	9	29	59	100
Do I get along better with people outside the family than	72	/	19	8	1	100

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inside the family?						
Do family members avoid contact with each other when they are at home?	61	14	17	/	8	100
How often do family members support each other in difficult times?	/	6	6	17	71	100

With the analysis of these questions, which aimed to examine the family cohesion in the family where there is a child with a disability, we came to the conclusion that the cohesion in the families is on high level. The results show that there are extreme feelings of emotional closeness in the family and that there is family loyalty, i.e. the results showed that a most of respondents answered that they spend free time with their children and that they have a high degree of intimacy, that they care about each other, support each other in difficult moments, do not avoid contact and are not under pressure when they spend most of their time together.

#### 4.4 How parents assess the level of stress they are going through

Parents' psychological well-being is considered to be very important. Research stress the importance of intervention programs in parental stress in order to alleviate it , because high levels of parental stress may have a negative impact on the functioning of the child with disability. Parents may behave in ways that have a negative impact on children (Hastings, 2002). Studies suggest that parents who experience higher levels of stress interact differently with their children, compared to parents who experience lower levels of stress, and they respond differently to their child's problematic behavior (Conger et al, 1995). The child with disabilities is not the only one who affects his family's life and dynamics. The family also affects positively or negatively the child's development. Research suggests that higher levels of parental stress predict less positive outcomes from the early intervention programs for children with disabilities (Brinker et al, 1994).

Parents' stress levels were measured using the DASS-21 scale. The scale contains 21 statements and the

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**Table 4**

*Parents' stress levels*

DASS 21 stress score	Parents (%)
Normal stress (0-14)	4
Mild stress (15-18)	11
Moderate stress (19-25)	17
Severe stress (26-33)	65
Extremely severe (34+)	3

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**Table 5**

*Average value*

	Min.	Max.	Mean
The level of stress, anxiety and depression (minimum 0 – maximum 63)	(minimum 0 – maximum 63)		
	4	54	44,76

**5. Conclusion**

From the research conducted on 130 parents of children with disabilities in Republic of North Macedonia, we present the key conclusions. The results of a series of questions related to mutual communication of the parents, showed that in most cases interrelationship not change, in many parents the relationship strengthened, the spouses became more connected, openly discussed problems and found solutions together, but all their time and devotion was directed to the child, and very little to their own needs. The number of respondents was significantly lower where the child's disability caused problems in the marital relationship, shifting the blame and the obligations and needs of the child. In terms of family functioning, the families involved in the research show structured and

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balanced flexibility, which is the willingness of families to change family rules, which is an important aspect of overcoming the crises that the family faces. According to the results of DASS-21 stress score, most of the parents 65% face severe stress.

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