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DOCTORATE IN SOCIOLOGY**

**QUALITY OF LIFE IN FAMILIES OF CHILDREN WITH NEURO-MOTOR  
DISABILITIES**

**ABSTRACT OF THE THESIS**

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**Key words:** child, disability, family, family quality of life, family functioning, social policies for children and families, services.

## SYNTHESIS PAPER

This thesis aims to address a less studied topic, referring to a child's disability, namely the family quality of life, relating to the way in which families with disabled children function, adjusting to the presence of a disabled child within the household.

Throughout this thesis, I opted for the term "disability" because it is the term which renders most accurately the implications of neuro-motor deficiencies on both child and family members. Disability is seen as a limitation especially within the context of social opportunities and experiences that restrict the individual's ability to relate to others and access different locations. From this perspective, disability can lead to social exclusion, and since it is perceived in relation to social barriers, it denies the opportunity to engage in relationships with others (Burke, 2008). Neuro-motor deficiencies affect the person's motor functions, mainly as a result of damage to neuronal structures at the central and peripheral levels, but also due to the quality of mental processes influencing the control and functioning of the neuromuscular mechanism (Ghergut, 2007). In addition to the clinical presentation including marked neuro-motor symptoms, paralysis and neurological problems are often accompanied by psychological issues. Cognitive impairment, sensory deficits, communication disorders and emotional problems seem to be the most common (Popescu, 2001). Difficulties within the cognitive area are often associated with a decrease in intelligence. Children also develop learning difficulties and attention deficit problems. Mnestic performances in children with neuro-motor disabilities may be lower, in comparison to non-disabled children of the same age. Regarding the emotional dimension, it is estimated that up to 50% of children with hemiplegia (one of the forms) have an emotional disorder. These are correlated with a low self-esteem and difficulties in social integration, social isolation being common among these children. Isolation, withdrawal are at the same time consequences of the social stigma associated with neuro-motor deficiencies. Integration into the peer group is reduced also due to the children's deficit within the social cognition area. It appears that neuro-motor problems are often accompanied by difficulties in understanding the behaviour, intentions and attitudes of others, problems in correctly identifying social and emotional cues, as well as metacognitive difficulties (Goodman, 1997). This is the clinical outline of the problems children with neuro-motor deficiencies are presented with and also the challenges family members have to cope with, considering that the intervention involves a process of recovery which in most cases lasts throughout the disabled child's life. The child's disability is a triadic experience,

involving the co-interactions between the child, who experiences the dysfunction, the family affected by the child's problem and the external environment where the disability manifests itself (Falik, 1995 apud Heiman, 2002). The crisis generated by the diagnosis revealing an abnormality within the child, is probably the most difficult and disabling experience for the parents. In most cases, the parents display negative reactions, similar to an irrecoverable loss. Families either adjust in a flexible manner and mobilize towards efficient actions, or remain stuck in reactions of varying levels of inflexibility and inefficiency. There are circumstances in which parents tend to oppose or even deny the diagnosis. Changes in daily activities are necessary in order to provide the child with the best care, yet with significant effects on family functioning. The additional stress caused by fatigue is associated with a low morale among adult family members, in relation to the child's progress, which in the case of neuro-motor disabilities, often fails to meet the parents' expectations (Heiman, 2002).

Local communities, by providing the medical, educational and social services, and developing activities to raise public awareness about the needs of families with disabled children, can contribute to an improvement in the quality of life of these families.

National policies and strategies on disabled persons are based on a series of principles focusing on the protection, social integration and inclusion of the disabled in order to eliminate the potential barriers between them and others members of the community. Thus, in Romania, persons with disabilities may benefit from a series of social, psychological and psychopedagogical provisions aimed at early intervention, enabling access to educational, medical and social services, the professional and social integration of disabled persons. All of these measures take into account the involvement of family members, who play an extremely important role in the lives of disabled persons. However, outside the family, social work provisions have a primary role in maintaining stability at the individual and societal levels. The main objective of interventions is the protection of persons, who due to economic, physical, mental and social reasons, cannot meet their social needs, or develop capacities and skills for an active participation in society. In this context, social work, as a component of the social protection system, consists of "the social services and benefits provided in order to develop individual and collective capacities to meet social needs, improve quality of life and promote principles of cohesion and social inclusion" (Law 47/2006, p.1).

Therefore, the emerging idea from this discussion is that of increasing quality of life. This issue is often addressed in relation to disabled persons, "considered to be a social category at a high risk for multiple social exclusion", with consequences affecting not only the individual, but also the family, community and society (Lazar, 2009, p. 206).

This thesis aims, on the one hand, to present the setting concerning the quality of life in families of children with neuro-motor disabilities in the Bihor county (descriptive study) and on the other hand, to generate a comparative analysis regarding the quality of life in families of children with neuro-motor disabilities and families of healthy children (comparative study). The paper is structured on five chapters. Three of the chapters present the theoretical framework, relating to the implications of the child's disability on family members, the conceptual framework for quality of life in general and for family quality of life specifically, as well as family quality of life indicators. The next two chapters reveal the results of several qualitative studies and one quantitative study focusing on identifying the problems and needs of families with neuro-motor disabled children, the network of services and also an analysis of family quality of life by comparing families of children with neuro-motor disabilities in the Bihor county, from both urban and rural areas, and families of non-disabled children.

In the first chapter – "The functioning of families with disabled children", the impact of disability was conceptualized in regards to the child and family members, emphasizing disability implications at the individual and family level, and enabling connections with results of previous research. Most researchers concerned with this issue have stressed the idea that when, referring to children with disabilities, one cannot overlook the problems family members are faced with. The chronic distress caused by the child's disability carries far-reaching implications on family functioning in general. As a system, the family can experience intense periods of stress, can learn from such experiences and can increase its strength (Singer and Powers, 1993). In this setting, social support, ways of relating to self and others, and of interacting in certain contexts are factors that can make for parental reactions to the stress generated by the child's problems, factors that can lead to an increase in family self-efficacy, to adopting efficient coping strategies, allowing for an increase in the degree of *family adaptability and functioning*.

The issue of disability and its implications at the individual and group levels has a strong social quality. Therefore, it is necessary to mention the main sociological theories that can guide us in the study of disability. Of the sociological theories presented in this chapter, we name the structural-functional theory, the systems theory, symbolic interactionist theory, labeling theory, as well as social comparison and network theories. The systems theory, the social comparison and network theories are most relevant to this thesis, making up the conceptual framework for the actual research. These theories explain relations between variables associated with intra- and extra-family relations, family dynamics, family self-perception etc.

Chapter II, "The Conceptual framework for the assessment of family quality of life ", presents conceptual aspects regarding the quality of life, theories in this field and research aimed at quality of life

in general and family quality of life in particular, with an emphasis on dimensions and indicators relevant to the study of quality of life.

In families of disabled children, we identify a series of dimensions and indicators, influencing family functioning. The ones referring to the implications of disability on family health, income, social support etc, can influence the quality of life for family members, while being indicative of the ways families cope with difficulties and adversities and know how to use social resources. Quality of life is the concept that unifies these characteristics.

Quality of life assessment in relation to different sub-groups, including disabled persons, is at the core of multidisciplinary concerns (social, medical etc.), and one of the issues raised in this context is whether the procedures used can accurately render the objective and subjective dimensions of quality of life. The concept of quality of life incorporates all the characteristics of life, being based on two variables that can be used as indicators: social, objective variables, represented by environmental conditions, meeting basic human needs, and psychological, subjective variables, represented by satisfaction and happiness (Bigelow et al, 1982 apud Pah, 2000).

The III<sup>rd</sup> Chapter, "Children with disabilities and family quality of life indicators at the European and national level", contains a brief presentation regarding the concerns of decision-makers in relation to social policies for children and families (including disabled children and implicitly their family members). The year 2005 marks in our country the onset of concern for developing strategies aimed to support this group of population. One of results generated by the partnership between specialists working for central and local authorities, NGOs and the civil society was: The national strategy for the protection, social integration and inclusion of disabled persons in the period 2006-2013 "Equal opportunities for disabled persons – towards a discrimination-free society". The Law no. 47/2006 regarding the National Social Work System and the Law no. 448/2006 regarding the protection and promotion of the rights of disabled persons complete the legal landscape with implications for disabled persons and establish the framework necessary for implementing the aforementioned strategy at the national level. Protective measures are envisioned to facilitate the social integration of persons with disabilities, a fundamental value shared by all societies founded on human rights, which is an important element within the current European Union and Romanian setting and a policy goal of the Member States. The main objectives towards achieving this goal require reducing and eliminating physical and psychological barriers, facilitating access to education and professional training, enabling the integration of disabled persons on the labor market and encouraging their participation in community life. Measuring the impact of social policies on groups at risk makes it possible to monitor the results of the

effort to integrate service-users in the community and to run a comparative analysis of the results obtained by different countries.

The process of setting and monitoring targets for social policies is achieved through indicators, which is the reason why in this chapter we analyze the indicators measuring family quality of life at the European and national level.

Chapter IV, "The living environment, the needs of families with neuro-motor disabled children and services available in the Bihor county. Qualitative studies" renders the results of three qualitative studies with a common goal to identify the needs of families with neuro-motor disabled children and the services they have access to. The studies analyzed objective aspects regarding the daily life of these families (housing, income, employability, social life, access to services etc) in an attempt to determine the needs and means of support provided by local communities through the services developed.

The idea emerging from the qualitative studies is that the presence of a neuro-motor disabled child within a household is responsible for continuous stress, that can lead to several problems in all dimensions: social (intra- and extra-family relationships, support network, friendship, instruction, access to services, employability etc.), economic (low income in relation to necessary expenses etc.), medical (the development of somatic or psychiatric conditions especially in mothers of disabled children etc.), psychological (emotional), behavioural (changes in the parents' behaviour), noticeable in the child and family members. Local communities, through the medical, educational and social services provided, can contribute to an improvement in the quality of life of disabled children and also their family members. According to the analysis of services and the case studies presented in this thesis, in the Bihor county, there are a series of social (psycho-social), medical/recovery and educational services for children with neuro-motor disabilities and their families. In relation to the needs identified, one can notice that these do not fully respond to the necessities of this group. Another important issues refers to the differences in access to services, observed along areas of residence, outlining the limited access to specialist services for children and their families living in the rural area.

The results of these studies contribute to our understanding of the needs presented by families with a disabled member, of their functioning, and also of the intervention strategies employed to meet their needs as well as the resources available in the community.

Chapter V, "Quality of life in families of children with neuro-motor disabilities in the Bihor county. Quantitative study", presents the analysis of the results revealed within a quantitative study (the method used being questionnaire based inquiry) aiming to investigate the characteristics of families with neuro-motor disabled children. Specifically, the study examined quality of life in families of children with neuro-motor disabilities, in comparison to quality of life in families with healthy children, families



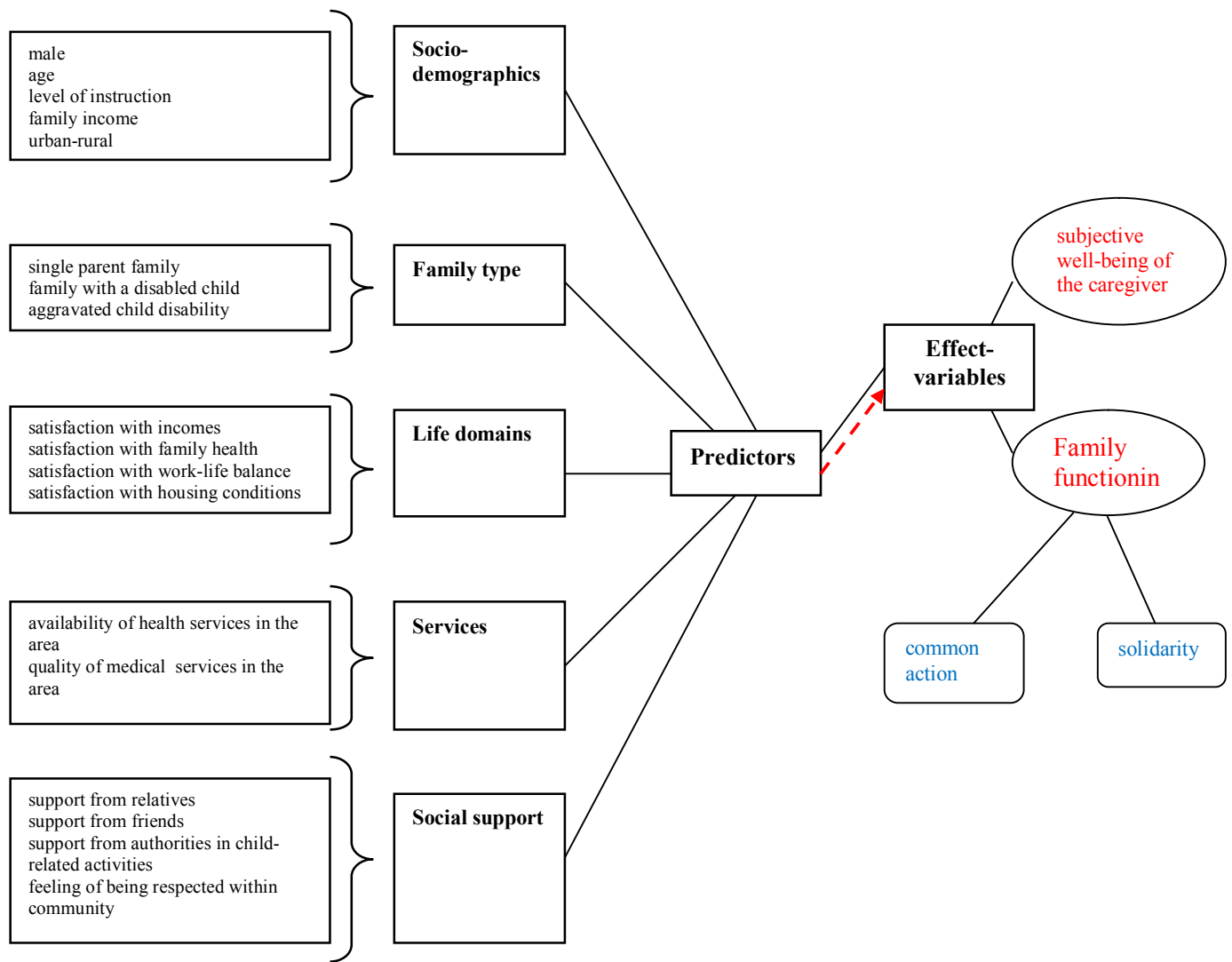
living in both rural and urban areas. The research was conducted in two phases. The first phase involved an initial study, describing the results of two focus group sessions, where specialists working with neuro-motor disabled children and family members were asked to identify the problems facing the target group as well as the domains and related indicators that best capture aspects regarding family quality of life in general. The information obtained from these sessions led to the questionnaire development (appendix no. 3), the instrument used to collect the data. The second phase consisted in the study itself – questionnaire based inquiry. The results of the study are summarized below.

The analysis regarding the characteristics of families with a neuro-motor disabled child (the general objective) by examining general aspects concerning families with children and, specific aspects related to the quality of life in families with neuro-motor disabled children reveals that on the one side, there are similarities between the two batches involved in the research in regards to certain day-to-day aspects, despite the area of residence (access to some services, such as educational, family practitioner, social services, provision of housing assets, intra- and extrafamily relationships), but also differences (income, access to specialist medical services, the respect felt within the community, leisure etc.), that display an image of the perceived quality of life on the two batches.

Following data analysis, we propose that the most important aspect is that of family functioning. Despite family type, the general positive scores are high, suggesting a high degree of cohesion in the families participating in the study. We must however take into account the possible influence of social desirability on the results.

As to the results classified by family type, there aren't any significant differences in the assessment of families with disabled children and families with non-disabled children. In the attempt to observe the independent influence of factors on variables associated with family functioning and subjective well-being, we applied several regression models, containing a series of effect-variables – family functioning, common action, solidarity, subjective well-being of the caregiver, and a series of predictors – social support, access to services, satisfaction with certain areas of life, family type and socio-demographics.

The general conclusion of the data analysis is captured in the model below, an overview of the interrelations determining family functioning. As it was previously mentioned, predictors make up 5 dimensions: socio-demographics, family type, life domains, services and social support. The regression analysis showed that in relation to these predictors, there were two effect-variables emerging through the methodology used: *family functioning* and *subjective well-being of the caregiver*. The data processed revealed that family functioning is determined by two main factors: "*common action*" and "*solidarity*".

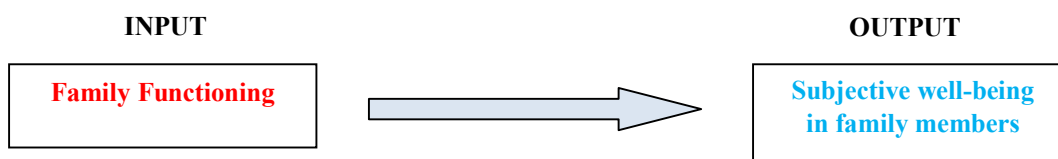


**Figure 5.8. Predictive model of family functioning**

After checking the relationship between life domains and their influence on family functioning and subjective well-being of the caregiver, the variables that proved to influence family functioning can be distinguished in the displayed figure. Socio-demographics relevant in predicting family functioning are: male gender, age, level of instruction, family income, area of residence. Considering the issues identified in the theoretical framework, we can maintain that these factors confirm the results obtained so far in this area (Marginean and Balasa, 2006; Raina et al, 2005; Magill-Evans et al, 2001; Brehaut et al, 2004; Kaplan, Sallis, Patterson, 1993 etc.). Family type, with the three variables: single-parent family, family with a disabled child and aggravated child disability, is also a predictor of family functioning. Satisfaction with different life domains is another dimension of family

functioning. Significant factors were: satisfaction with incomes, with family health, work-life balance and housing conditions. Given the nature of the topic analyzed, the availability and quality of health services in the area of residence was also one of the predictors of family functioning. In addition to these predictors, the studies mentioned before emphasize the importance of social support for good family functioning. In the batch included in the research, we notice that support from relatives, friends, authorities in child-related activities and the feeling of being respected within the community are dependent variables of family functioning and of the parent directly responsible for the care of the child (in this study, the caregiver is mostly the mother).

There is a strong connection between family functioning and subjective well-being of family members. Thus, family functioning determines a higher subjective well-being in family members, and the latter can exert a positive influence on the former. Following the analysis, we can say that family functioning determines subjective well-being in members, but we cannot maintain the converse (the degree of influence exerted by subjective well-being in members on family functioning).



As a result of this research, one can realize how difficult it is to identify aspects concerning the quality of life, due to the complexity of causality that determines the overall satisfaction with life. The research described specific aspects regarding the selected batch (families of disabled children and families of non-disabled children), that cannot however be extended to the general population; the results obtained cannot be generalized. The data results provide us with a general picture of the studied batch, but since the research was descriptive, they cannot be generalized. It should be noted that the research approach was extremely difficult. Also, one cannot estimate to what extent the answers provided by respondents to a series of sensitive topics (intra-family relationships, income etc) were motivated by social desirability.

Considering the problems identified related to children and families (regardless if the children are or not disabled), we should recommend a representative research at the county/national level with the purpose of identifying the needs and of proposing efficient intervention strategies.

As it was pointed out before, the research was developed based on specialized studies, that highlight the factors involved in the good functioning of families with disabled neuro-motor disabilities: parental characteristics; degree of disability/illness severity; quality of the parent-child relationship;

social factors; economic factors and the cultural setting. The research aimed to include these factors, in order to generate an overall image of the quality of life in families with neuro-motor disabilities. The result was a predictive (causal) model of family functioning. The general conclusion of the study was that there are several factors contributing to the functioning of a family with a neuro-motor disabled child and implicitly to the well-being of its members. These are socio-demographics (gender, age, level of instruction, income, area of residence), family type, satisfaction with certain life domains, access to certain types of services and social support. These factors are predictors of good family functioning.

Through the conclusions of this thesis, I fall in alongside those supporting the idea that there are two categories of factors in determining quality of life: endogenous and exogenous. Endogenous forces include mental, emotional and physiological responses of the individual in relation to living conditions, the actions undertaken by each individual. Exogenous forces include social and cultural structures, psychological influences of the social environment that guide the individual, group and community (Hagerty et al, 2001 apud Ferriss, 2006). Family functioning cannot be taken out of the social context. No matter how strong or cohesive, a family also needs support from the other members of society. Moreover, since the social perception of disability is mostly negative, social inclusion is inevitably thwarted by societal and cultural barriers (Ghergut, 2007; Roth, 2007). As we can see, this is where the role of society and the values it promotes come into play, which are also factors that contribute to the integration of this group in the community.

Summarizing the data obtained by qualitative and quantitative analysis, the most important problems/needs observed in families with a disabled child were: difficulties in accessing specialist medical services, problems concerning the integration of children in an educational structure, insufficient financial resources, difficulties of children and families living in rural areas in regards to access to services (specific therapies, recovery medical services etc.), lack of information regarding the services children and families are entitled to, difficulties in understanding the information provided by specialists, the parents' concern about the child's future, since services such as: sheltered workshops, centres for occupational therapy, residential centres and respite centres etc. are underdeveloped or non-existent.

Considering the specific needs of disabled children and their families, in order to improve the individual and family quality of life, we propose a series of interventions: applying for non-refundable financing in order to develop new services currently non-existent; campaigns raising public awareness about the implications of disability on the individual, family, community and the society, and the important role of active participation by each society member in supporting the persons affected by disability; initiation and development of specialized research in order to accurately assess the

phenomenon and find proper ways of intervening; development of partnership between public and private providers and the civil society; integrating the actual needs of this group into legislative measures.

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