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**QUALITY OF LIFE OF THE FAMILIES WITH CHILDREN
WITH DISABILITY IN LATVIA**

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INTRODUCTION

Topicality and practical importance of the promotion work

Nowadays in the most developed countries the research of quality of life has become the pivotal issue of all social reports that reflects not only the effectiveness of social policies, but also the country's population welfare and the factors influencing. Research oriented toward analysis of quality of life provides an opportunity to determine the developmental tendencies of state social policy and assess the effectiveness of current policy not only in different social areas, but also within the context of different social groups. Since the goal of social policy is to ensure particular standard of quality of life to those groups of society that do not possess sufficient resources or are in danger of losing the resources necessary to meet their needs, for example, families with children with disability, many studies that analyze the quality of life allow us to assess whether the support provided by the state matches the needs in the area of quality of life. The topicality of family quality of life research is made stronger by the socio-economic crisis; as a result of it, the quality of life of many families connected to the meeting of their basic needs declines due to the lack of resources. Due to this crisis the families that enjoyed the quality of life that matched their needs are forced to seek help in social services. The studies that are targeted toward assessment of family quality of life are not just informative; they also have a practical importance in the area of improvement of quality of life of particular target-groups. It is essential to determine real quality of life in order to develop new strategic directions in social policy guidelines targeted toward the improvement of quality of life of families with children with disability.

It can be concluded that the research of family quality of life is crucial in order to reflect on family's ability to meet their needs, while the possibility for families to meet the needs largely depends on the support provided by the state, municipalities, NGOs and the society as a whole. So in making the social policy guidelines that are connected to the support for families the state must focus on supporting those families whose access to the resources is for various reasons limited. For example, opportunities to use the means for meeting the basic needs for families with children with disability are often affected by the factors connected to the specifics of these children.

Novelty of the study

There are comparatively few publicly available studies in the area of family quality of life in Latvia. The studies that have been done and are publicly available only reflect a single aspect connected to the family quality of life. There has been no study in Latvia in the area of family quality of life that would view the influence of children with disability on the family quality of life. Such research would allow not only assessing the effectiveness of the current social policy in the area of improvement of family quality of life, but also identifying the support families in Latvia truly need in order for their quality of life to be improved in accordance with the socio-economic situation of the country. Based on the study results, it is possible to identify the type of support needed for meeting children's special needs, and also to highlight the tendencies in how the lack of this support affects their family quality of life. This study reflects the factors that affect the quality of life of the families with disabled children.

Basis of the study

In January 1st, 2010 7009 families were registered in Latvia as the ones that receive state support for a child with disability, which tells us that there are children with disability in these families that have been granted disability. (Supplement to the family state benefit, 2010) The data of the State Social Insurance Agency reflect the number of registered families with children with disability and state granted disability status due to the special needs. But the real number of the families with children with disability that could have received the disability status but for some reason have not been granted could be bigger. Based on all of the above, the author does not use the term „children with special needs”, which considering ethical aspects of the term would be the most appropriate name for this group, but this paper uses the term „a disabled person/a person with disability”, applying it to children as well, because target group of the research is

families with the children that have been granted disability. Since the promotion work is targeted towards the research of the quality of life of the families with children with disability, the author has used the data of the State Social Insurance Agency as the basis of this research. Families with children with disability make up 2.7% of all families with underage children. (Family state benefit, 2010) In connection with the researched problem, the promotion work analyzes the quality of life of the families with children with disability that do not reside in social care institution, but live with their families.

Substantiation of the research problem

The quality of life of the families with the children with disability is often affected by conditions that are connected to the meeting of these needs which in turn restricts ability of these families to meet their needs. Parents of these children quite often are limited in their employment, as well as education opportunities that interdicts the necessary resources for these families to meet their needs, as well as get involved in cultural life of the community, create social contacts, and ensure life condition adequate to the family needs. Such a situation has developed not just because of the socio-economic situation in the country, but also due to the disinterested disposition of the society towards the phenomenon of special needs and the limited capacity of the state to provide the necessary support.

The goal of the research is to study the quality of life of the families with children with disability and its influencing factors, accentuating the role of social policy in ensuring the quality of life.

The objectives of the research:

1. To give the theoretical explanation of quality of life within the context of sociological perspectives.
2. To describe the family quality of life research approaches.
3. To describe the support to the families within the context of the state policy.
4. To study the life conditions and life satisfaction with the quality of life in the context of domains describing it of the families with the children with disability.

The main hypothesis of the research – The support provided by social policy to the families with the children with disability recompense the effect of the special needs of children on the family quality of life in any of the areas of quality of life.

The research methods: survey using structured interviews and an analysis of normative acts

Structure of the promotion work

The promotion work is structured into four chapters that give the theoretical basis of the research and the results obtained in the research.

The first chapter gives the theoretical explanation of the quality of life that includes short description of the development of the concept of quality of life, the explanation of the quality of life, as well as the explanatory approaches of quality of life from the sociological perspective, but the last part of the chapter gives a characteristic of the quality of life research.

The second chapter is dedicated to the specifics of family quality of life research; it includes the theoretical explanation of the family quality life, as well as the specific aspects of the research of family quality of life. Based on the international studies, this chapter reflects different approaches to the study of family quality of life and analyzes the areas that have been highlighted in different international studies as the ones that describe family quality of life.

The third chapter describes the state support to the families with the children with disability, as well as gives an explanation of the concept of disability.

The fourth chapter contains the analysis of the previous studies of the family quality of life that is followed by a description of study methodology and sampling, as well as the analysis of the research results about the quality of life of the families with children with disability in Latvia. The analysis of research results is given in accordance with the areas of family quality of life.

The approbation of the results of the promotion work

The published scientific articles on the topic of the promotion work

1. J.Millere. (2011). Materiālā labklājība kā ģimenes dzīves kvalitātes komponents: bērnu ar īpašām vajadzībām ģimeņu materiālās labklājības raksturojums. *Zinātnisko rakstu krājums*. Latvija, Rīga, RSU, 210.-219. lpp.
2. J.Millere. (2011). Support Provided by Municipalities for Families: Experience of Families with Children with special needs in Latvia. Starptautiskas nozīmes rakstu krājums. Latvija, Rīga, RSU (Pieņemts publicēšanai)
3. J.Millere. (2011). Family Quality of Life in Urban and Rural Areas: Experience of Families with Children with special needs. *Journal of International Scientific Publications: Language, Individual & Society*. Vol. 5, Bulgārija. Pieejams: www.science-journals.eu
4. J. Millere. (2011). The Role of the State's Social Policy in the Provision of Family Quality of Life. Polija, Olština. (Pieņemts publicēšanai)
5. J.Millere. (2011). Ģimenes dzīves kvalitāte kā pētniecības joma. *Zinātnisko rakstu krājums*. Daugavpils, Daugavpils universitāte, 866-872 lpp. Pieejams: http://www.dukonference.lv/files/zinatniski_petnieciskie_52konf.pdf
6. J.Millere. (2010). The socio-economic security of the family life: socio economic problems of families with children with special needs. CRFR International Conference 2010, „Changing Families in a Changing World” UK, Edinburga, Centre of Research on Families and Relationships (CRFR) (CD formāts)
7. J.Millere. (2010). Ģimenes dzīves kvalitātes būtiskākie aspekti. *Rakstu krājums „Sabiedrība un kultūra”*. Latvija. Liepāja
8. J.Millere, S.Dobelniece. (2010). The Socio-economic Security as a Component of Social Quality of the Family Life: Experience of Families with children with special needs. *Zinātnisko rakstu krājums*. Latvija. Rīga, RSU, 180-187lpp. Pieejams:http://www.rsu.lv/images/stories/dokumenti/publikacijas/zinatniskie_raksti_2009/socialas_zinatnes/vol_6/026-10-ZRS_A-180-187.pdf
9. J.Millere, G. Darbiņa. (2010). Bērnu īpašo vajadzību ietekme uz viņu ģimeņu dzīves kvalitāti. *Starptautisks zinātnisku rakstu krājums*. 6.sēj. I daļa. Latvija, Rīga, Baltijas Psiholoģijas un menedžmenta augstskola, 191- 197. lpp.
10. J.Millere, G. Darbiņa. (2010). Sociālā palīdzība pašvaldību komunikācijā ar sabiedrību. *Starptautisks zinātnisku rakstu krājums*. 6.sēj. I daļa. Latvija. Rīga, Baltijas Psiholoģijas un menedžmenta augstskola, 179- 186. lpp.
11. J.Millere. (2009). Dzīves sociālās kvalitātes konceptuālie aspekti. International Scientific Conference „New Dimensions in the Development of Society 2009”. Latvija, Jelgava, LLU (CD formāts)

Published thesis

1. J.Millere. (2011). Ģimenes dzīves kvalitāte kā pētniecības joma. 133 lpp. Pieejams: <http://www.dukonference.lv/files/Tezes.pdf>
2. J.Millere. (2010). Socio-Economic Security of Families of Children with special needs. (abstract) Internacional Sociological Association, Gothenburg, Sweden, pp. 318
3. J.Millere. (2010). The socio-economic security of the family life: socio economic problems of families with children with special needs. CRFR International Conference 2010, „Changing Families in a Changing World” UK, Edinburgh, CRFR Pieejams: <http://www.crfr.ac.uk/events/intconference10/presentations-wed/JMillere.pdf>
4. J.Millere, S.Dobelniece. (2010). Ģimenes dzīves kvalitātes konceptuālais skaidrojums. Latvija. Rīga, RSU, 391.-392. lpp.

Participation in International Scientific Conferences

1. Latvija, Jelgava, LLU, International Scientific Conference „New Dimensions in the Development of Society 2009” ar referātu „Dzīves sociālās kvalitātes konceptuālie aspekti”, 2009. gada 2., 3. oktobrī
2. Latvija, Rīga, BSA, Zinātniski praktiskā konference “Psiholoģijas, biznesa un sociālā darba perspektīvas un iespējas mūsdienīgā Eiropā” ar referātu ‘Bērnu īpašo vajadzību ietekme uz viņu ģimeņu dzīves kvalitāti’, 2009. gada maijā
3. Latvija, Rīga, BSA, Zinātniski praktiskā konference “Psiholoģijas, biznesa un sociālā darba perspektīvas un iespējas mūsdienīgā Eiropā” ar referātu ‘Sociālā palīdzība pašvaldību komunikācijā ar sabiedrību”, 2009. gada maijā
4. Daugavpils universitātes 52. starptautiskā zinātniskā konference ar referātu “Ģimenes dzīves kvalitāte kā pētniecības joma”, 2010. gada 14., 16. aprīlī
5. Latvija, Liepāja, Starptautiskā zinātniskā konference „Sabiedrība un kultūra” ar referātu “Ģimenes dzīves kvalitātes būtiskākie aspekti”, 2010. gada 29. un 30. aprīlī
6. Zviedrija, Geteburga XVII WORLD CONGRESS OF SOCIOLOGY ar referātu Socio-Economic Security of Families of Children with Special Needs, July 11-17, 2010
7. Anglija, Edinburga CRFR International Conference “Changing Families in a Changing World” ar referātu “The socio-economic security of the family life: socio economic problems of families with children with special needs”, University of Edinburgh, June 16 – 18, 2010
8. Latvija, Rīga, RSU Zinātniskā konference ar referātu “Ģimenes dzīves kvalitātes konceptuālais skaidrojums” 2010. gada 13. un 14. martā
9. Latvija, Rīga, Rīgas Tehniskā universitāte, 51. starptautiskā konference ar referātu “Ģimenes dzīves kvalitātes izpēte starptautiskās un Latvijas pieredzes kontekstā”, 2010. gada 15. oktobrī
10. Bulgārija, Sunny Beach, International Scientific Conference ‘Language, Individual & Society’ 2011. gada 07.-12. septembrim ar referātu ‘Family Quality of Life in Urban and Rural Areas: Experience of Families with Children with Special Needs’.
11. Polija, Olština, Starptautiska konference ‘Life Chances and Quality of Life in Contemporary Families’ 2011. gada 12. – 13. maijam ar referātu „The Role of the State’s Social Policy in the Provision of Family Quality of Life’

1. THEORETICAL EXPLANATION OF QUALITY OF LIFE

Originally the research of the quality of life included economic variables that indicated the standard of living of households; they described family life conditions and not the quality of life. Measurements of the family living conditions have been a point of interest of American sociologists starting 1918. Socio-economic status, the standard of living and social status are the names that point to the mixed measurements of family living conditions, and at that time they were used as indicators of family 'quality of life', even though the term 'quality of life' was not really used yet. Sociologists at that time were more interested in tendencies, not reasons. For example, sociologists William F. Ogburn and F. Stuart Chapin in their research tried to answer the question 'how' and not 'why', which tells us of the objective nature of the sociological research at that time (Bannister, 1991, 6). Sociologist Stuart Chapin that was one of the first to focus on research of the aspects of quality of life created a scale that was used by social workers to assess different families. Later this scale was used to identify the social class particular family belonged to. (Sirgy, 2006,367-368; Ferriss, 2004,41)

As a result of the development of these measurements in the 20th century 1960-ies, the quality of life became the main issue in "research of social indicators" that emerged as a reaction on the dominating status of economic indicators. Generally and in connection with specific areas of life, quality of life can be researched, using both subjective and objective indicators (Sirgy, 2001). Also it is possible to analyze it using different indicators and on different levels: micro, mezo and macro levels, that is on individual, group and societal level (Stepčenko, 2006). Joseph Sirgy believes that quality of life can be studied on four levels – individual level, family level, and community/regional and society level.

Quality of life is usually understood as the conditions of human existence: material provision, safety, accessibility of health care, education opportunities, and opportunities of personal growth, the state of environment, social relationships in the society, and freedom of speech and an opportunity for citizens to affect political decisions. Quality of life is determined in all areas and aspects of human existence: nature, family, work, social order, education, recreation etc. (Белкин, 1999, 21) Referring to David Phillips' explanation of quality of life, the quality of life requires that basic material and social needs of people are met and that they have sufficient autonomy to choose to enjoy life, to participate in the activities of the society as citizens of the society with high level of civil integration, social reconciliation, trust and other integrative norms, including justice and equality in a physically and socially sustainable environment. (Phillips, 2006, 242) Regina Berger-Schmitt and Heinz-Herbert Noll define quality of life as a combination of subjective wellbeing and objective life conditions where the latter includes all aspects of life situation that essentially affect individual's wellbeing (Beck, 2001).

The quality of life describes the level of satisfaction of human needs that is determined in accordance with the existing norms, habits and traditions of particular society, as well as in comparison with the level of personal ambition. The definition of the quality of life depends on the content included into the study of the quality of life. For example, the researchers of the quality of life in England have split all quality of life definition into four types:

The first type accentuates objective indicators and explains quality of life through the living conditions that also implies individual life satisfaction.

The second type – just like the first one – highlights objective indicators of the quality of life, but the difference is that these definitions views quality of life as satisfaction with living conditions. This type of definitions allows dividing the areas of living conditions and assessing the quality of life based on the subjective satisfaction of an individual with them.

The third type includes both living conditions and individual's satisfaction with them in the concept of quality of life. This type of definition has both the objective and subjective dimensions of quality of life.

The fourth type explains the quality of life by the objective and subjective dimension and their significance is assessed through a special scale. This type of definition gives a comprehensive perspective of individual's quality of life considering his or her values. (Quality of Life and..., 2006)

The choice of quality of life definitions depends not only on what scientific framework is used for particular quality of life research, but also on the specifics of the target group and the goal of the research. If the research is focused on the family quality of life, an author must use the definition that point both to the assessment of family living conditions and allow assessing the quality of life of families considering their own subjective satisfaction with their living conditions. Thus it can be concluded that the quality of life is characterized by the individual's satisfaction with the current living conditions that provide satisfactions of the needs in all areas that affect his or her everyday life.

The concept "quality of life" is made up of many components that objectively affect human life and subjectively expresses itself as the satisfaction with life. The quality of life is good living conditions combined with subjective feeling of comfort. Generally speaking, the quality of life is determined by the great number of the components of the living conditions and subjective wellbeing. The living conditions must be understood as 'tangible' conditions of life: income, work conditions, relationships in the family and social contacts, health condition, social and political activity. In turn, subjective wellbeing means that individuals themselves define the specific conditions of their lives and life in general. (Ventegodt et al., 2003) Thus, the conclusion is that the quality of life includes both - objective and subjective dimensions.

The concept of quality of life is complex by nature and can be viewed from the theoretical viewpoint of various fields of science; also it can be ascribed different contents. Referring to previously discussed theoretical postulates that are connected to the specifics of the explanation of quality of life, the conclusion can be that the concept of quality of life reflects both the opportunities that are given to the members of the society and the factors that influence the use of this opportunities and the aspect that affect the everyday life, for example, living conditions, relationships between family members, recreational opportunities, cultural involvement, as well as an assessment of the everyday life in accordance with one's opinion about good everyday life. It indicates that an explanation of the quality of life is underpinned by particular scientific postulates that are focused on the theoretical explanation of the content of the concept of quality of life.

The most difficulties that researches faced while developing the theoretical framework of quality of life were connected to the multidimensional nature of the quality of life that obliged a researcher not just include all the areas affecting the quality of life, but also describe it in the context of both micro and macro levels, since the quality of life is influenced not just by the micro level (aspects connected to individual's activities), but also the micro level social processes that include the aspects of prerequisites of the collective behaviour. And this type of integration of the analysis of social processes has been applied by many scientists such as Anthony Giddens, Pierre Bourdieu, Jurgen Habermass and others.

The author believes that Anthony Giddens has most vividly revealed the essence of the integration of micro and macro levels and its role in the analysis of social processes. According to Giddens' **theory of structuration**, the quality of life is a type of social reality that is made up of particular social practices; those practises are made up of social subjects (structures and agents) and they come into effect within different systems. According to Giddens, any cyclical social relationships form a social system. Even a friendship of two individuals is a form of system (Giddens, 1984, 1-28). In order to ensure the quality of life necessary to meet family needs, family members must get involved in a large number of social practises involving the provision of material, emotional, social and physical wellbeing. Similar to Giddens, Habermass creates a theoretical basis that is broad, complex and theoretically multidimensional.

In connection with **Habermass's sociological theory**, the quality of life can be viewed as an interaction of three dimensions (material, practical-moral and emancipative dimensions of quality of life); their communicative activity is fundamentally important. (Appelruth, 2008) In connection with **Habermass's sociological theory**, the quality of life can be viewed as an interaction of three dimensions (material, practical-moral and emancipative dimensions of quality of life); their communicative activity is fundamentally important (Appelruth, 2008). According to the explanation of quality of life it is important to consider both the characteristics of the environment and its influence on the areas of life activities and the analysis of the factors affecting individual's capacity that we can see in Bourdieu's theoretical work.

According to Bourdieu, the social practises of individuals are made of habitus, the resources available to individuals and the field that determines the rules of actions. (Bourdieu et al., 1996,98) From the basic insights of Bourdieu's theory, it can be concluded that the quality of life is made of a body of social practices that ensure individual's wellbeing. Social practices are made of the system of social dispositions or habitus (the capacity of an individual), cultural, symbolic, economic and social capital, as well as the field and the conditions of the field where individuals or social groups operate. Quality of life is influenced by such factors as individual's ability to manage the available resources, as well as environment that not just affect individual's ability to obtain the necessary resources, but also largely determine individual's possibilities to improve quality of life

Scientific literature widely uses different modifications of need theories to interpret the quality of life. **The theory of satisfaction of needs** is used in a fairly wide sense, including the analysis of everyday life. Needs are traditionally associated with the quality of life in the sense that when the needs are met, the level of quality of life is high. Needs are an expression of human nature: something common to all people. Satisfaction means feeling that everything in life goes the way it should. When outside world matches human expectation, needs and desires - he is satisfied. (Ventegodt, 2003) **Integrative approach to** quality of life interprets it through the ability to meet one's needs; it also accentuates the role of politics in the area of meeting of needs. (Costanza et.al., 2008). Integrative approach implies that policy makers are responsible for every member of society to have equal opportunities to obtain the necessary capital which in turn opens up opportunities to meet his needs. Family quality of life as well is connected to the securing of family wellbeing that is described by the ability of families to meet their needs. Referring to the previously viewed quality of life approaches, it can be concluded that family quality of life equals to the level how the family needs are met; and the meeting of needs is affected by the family's ability to use the available resources.

2. THE RESEARCH SPECIFICS OF FAMILY QUALITY OF LIFE

Scientist Denise Poston believes that a family includes people who think of themselves as part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis. (Poston et al., 2003).

Family quality of life, just like quality of life in general is multidimensional by nature and reflects interaction of different areas and their influence of family life; for this reason it becomes possible to study it in the context of different approaches. Professor Robert Schalock believes that **family** quality of life is connected to the study of the areas featuring family wellbeing and defines it as a dynamic understanding of family wellbeing, collectively and subjectively defined and informed by the family members where individual and collective needs interact (Schalock, 2008) Scientist Denise Poston defines **family** quality of life as conditions where family needs are met and family members are free to do what they really deem important. (Wang, 2004,145) The conclusion then is that there isn't a single definition of family quality of life since there are different approaches to defining and interpreting quality of life; they determine the specifics of quality of life research and the range of areas that form it. Definition of family quality of life by Denise Postone is used in the research.

The research of family quality of life, on one hand, is associated with identification of family needs; on other hand, it is associated with the analysis of opportunities for satisfaction of family needs; this analysis has to do not just with the opportunities of families to meet their needs, but also the factors that affect the use of those opportunities. All the components that constitute equality of life are inter-related and affect family quality of life as a whole, since, for example, poor infrastructure in the neighbourhood where family resides can aggravate family's opportunities no provide the necessary material, physical and sometimes also social and emotional wellbeing.

According to the family needs, it is possible to single out three areas where family needs are met; satisfaction of these needs make up the family quality of life. For example, the area of material wellbeing includes all aspects associated with the opportunities to meet social needs, for example need for social contacts, activities of self-realization; in turn the area of emotional wellbeing describes the interaction among the family members and their opportunity to gain emotional support. The area of physical wellbeing characterizes ability of family to function physically and fulfil the functions necessary for the society.

Family quality of life is affected by three factors that include economic, social and community context and is characterized through economic welfare, social networks and support, as well as relationships with neighbours and the rest of community. The economic context is connected to the possibility to be employed and gain financial stability that constitutes an important indicator of the family quality of life. Social context of family quality of life reveals the possibilities of social integration. Social integration often is studied through the involvement of children in school life and peer groups, as well as through the contacts of the adults with their friends, former co-workers and family members. The community context reflects the belonging of a particular family to the place of residence and its influence on its possibilities to improve its quality of life. (Behnke, 2004) The quality of life of the families with the children with disability is often affected by conditions that are connected with the meeting of special needs of children, availability of the necessary resources, getting involved in cultural life and self-realisation possibilities as well as environment accordingly to special needs of children. So the conclusion can be drawn that when conducting a study focused on family quality of life it is important not just to analyze the areas that describe family quality of life, but also the factors affecting it, which most of the time is not done.

Analyzing the areas of family quality of life highlighted by different authors and organizations it can be concluded that the analysis of family quality of life must include the following areas that characterize family quality of life: material, physical, social and emotional wellbeing, and also describe the factors that affect family wellbeing.

Joseph M. Sirgy distinguishes two rather significant differences in the area of the study of family quality of life that provide for two research approaches – the study of family quality of life on the individual level and on the family level. (Sirgy, 2001)

On the individual level, family quality of life approach is used where the analysis unit is an individual and the focus is placed on the quality of life in connection with his or her family life.

(Poston, 2003,319) But the research of the family quality of life that is focused on a family mostly views the quality of life of a family as a social unit. This approach describes the functionality of a family as a social group and reflects the influence of the individual quality of life on a family as a whole and is connected to the assessment of family life area. (Sirgy, 2001)) In this paper the author has used family quality of life research approach that is focused on family, since the goal of the study was to investigate family quality of life, the factors affecting it, focusing on a family as a unit and not on individual family members.

3. STATE SUPPORT FOR ENSURING QUALITY OF LIFE TO THE FAMILIES WITH CHILDREN WITH DISABILITY

The children with disability have the same needs as the other children at particular age, but also they have additional needs, unique and distinctive to particular child (Warner, 2006). Parents of disabled children face some difficulties that affect their quality of life at the moment when they are announced the cause of the child's functional disorder or diagnosis; that is a moment of great stress. Families of the disabled children face the necessity to alter their

lifestyle which now must be adjusted to child's state of health and the particulars of his/her special needs. Lifestyle and quality of life are interrelated areas where lifestyle is individual's, family's or society's living style that is expressed through physical, psychological, social and economic environment in everyday living (Luthra, 2007-2011). Quality of life, on the other hand, reflects the extent in which individuals and families are able to meet their needs and implement their wishes within the self-chosen lifestyle.

The professor of sociology William C. Cockerham has used theoretical conclusion of Weber and Bourdieu and has developed the health lifestyle model that describes health-related behaviour which exemplify which of the offered options of action an individual chooses, as well as the aspects affecting his choice. According to the health lifestyle model the structural conditions of human living that determine family's chances to adopt a healthy or unhealthy lifestyle, as well as chances to improve it in accordance with the family needs. So it is not just individual choice that is important in this sense; it is also his or her social and material conditions. Individuals with disability often need to bring their living conditions in line with their special needs which imply additional resources and the necessity to adapt the environment. An individual with disability often has to adjust their living conditions to his/her special needs, which implies additional resources and changes of environment. Living conditions is the one category of structural variables that relate to the differences in housing quality, adequacy of environment and provision of basic amenities, infrastructure and personal safety. So it can be concluded that health-promoting lifestyle is possible in good conditions, but health-aggravating lifestyle – in bad conditions. (Cockerham, 2007,58-75 So living conditions can both restrict and free individual's choice in the area of lifestyle that is expressed through quality of life. Social environment is like 'raw material' for forming family's lifestyle which – through the process of socialization – forms the experience for conscious choice, since the understanding of family situation guides its choice towards particular behaviour. Chances are socially determined, and the social structure is the arrangement of these chances. Life chances (structure) either restrict or promote the life choice (agency), since the interaction of the choice and chances form individual capacity (habitus). Therefore families arrange their goals, needs and desires in accordance with their chances to carry them out and choose a lifestyle in compliance with the assessment of the resources available to them and their social conditions.

Scientists argue that the understanding of social issues is created in us – at least in part - by the words we use. (Oliver, 2004,280) During the past few decades we have heard criticism of the terms that were historically used by the members of the society when discussing disability. Nowadays people are a lot more cautious when using terms describing disability, for example, the term 'an invalid' and more often are used terms as "special needs" or "person with disability".

One of the ways how society can support a child with disability in order to improve the quality of life of his/her family is to create the social policy that is adequate to the needs of these families and would be focused on providing of support to those families that face difficulties in the area of availability of resources. State and municipal support to these families play a crucial role in the meeting of their needs.

The family policy of the Republic of Latvia originally is formed according to the concept of "The Guidelines of State Family Policy for 2011-2017". The goal of these guidelines is to promote the establishment, stability and wellbeing of families and to encourage fertility. The principle of a the support that is adequate to family needs is postulated as one of the main principles of the state policy in the area of family; it includes the system of state and municipal support, increasing its availability in the most crucial moments depending on state and needs of families. (Ģimenes valsts..., 2011, 7) So it can be stated that that the main principle of the document implies the family policy fitting family needs; yet this document does not reflect all the problems families face in the area of meetings their needs. (Ģimenes valsts..., 2011, 62)

State provides families with two types of support – social assistance that includes material support and support in the area of social services. In the area of social assistance, families with children with disability are entitled to family state allowance (LVL 8/a month for each child) and supplement to the family state allowance for disabled children (LVL 75/a month). (Noteikumi par ģimenes valsts..., 2009) If a child needs special care, the state provides child-care benefit (LVL

150/a month), as well as transport refund. In addition to the state support for families with children in form of different benefits, there is also personal income tax relief for the dependants in person's care.

The state supplied **social services** for families with children with disability include:

- provision of technical aids;
- annual rehabilitation in the rehabilitation centre "Vaivari".

The **municipality** supplied **social services** include social care and rehabilitation. Families with children with disability are entitled to the support in the area of social services that include consultations of a psychologist, consultations of a social worker, home care, day-care centres for disabled children, rehabilitation for children with mental disorders. (Sociālo pakalpojumu..., 2002)

Municipalities proved social assistance for families mostly when family is not able to meet their need on their own. Then the municipal social workers assess family income and grant them "needy" or "low-income" family status which serves as basis for providing adequate material support.

A family can be recognized as "needy" if its average monthly income during the last three months on 2011th (on the each family member) has been less than LVL 90 and if:

- it does not own savings in cash, negotiable securities or real estate;
- it has not entered into a maintenance contract;
- it is not a recipient of services of long-term social care or social rehabilitation or is not imprisoned;
- a person has registered in National Employment Agency as unemployed or job seeker. (Noteikumi par ģimenes..., 2010)

A family can be granted a status of "low income" family if family' average monthly income (on the each family member) exceed LVL 90; it is more that the income of a "needy" family, but every municipality determines the income level of the low income status in their territory. (Par pašvaldībām, 1999)

In case family income matches the requirement for granting the poor family status, families regardless of whether they have children with disability or not are entitled to receive **social assistance** from the municipality; it includes:

- allowance to ensure minimum guaranteed income level. The guaranteed minimal income (GMI) allowance is LVL 40 for adult family members and LVL 45 – for children, (Kārtība, kādā...2009, 5.p.)
- housing allowance;
- extraordinary allowance in a case of emergency;
- and other allowances for meeting family's (person's) basic needs. (Sociālo pakalpojumu...,2002,35 p.)

In connection with normative acts, municipalities must first provide social assistance to the „needy” families and when the requests of these families for material support have been met, can provide material support to the families that have been granted the „low income” status. The next chapter contains a short summary of the study of the quality of life of families with disabled children.

4. ANALYSIS OF QUALITY OF LIFE OF FAMILIES WITH CHILDREN WITH DISABILITY

4.1. Description of Research Methodology

From January, 2010 till April, 2011 the author conducted a quantitative research in order to study the life quality of families with children with special needs and the factors affecting it, accentuating the role of social policy in the provision of life quality.

The study included families with children with disability. According to Floyd J. Fowler, the research of both life quality and households is connected to research of the issues associated with the specifics of family life, and because of it the author has used Floyd J. Fowler's sampling approach: in the process of obtaining data a grown-up family member who is the most knowledgeable about the situation in the areas of family life quality was chosen as a respondent (Fowler, 1993, 24). In the survey participated 247 mothers, 11 grandmothers, 15 fathers a one other person – child's' aunt.

The volume of the sample was formed according to 6 % sample error that is acceptable in the studied that do not put a claim on the comparison of statistically significant data (Ядов, 2007:98). The sample of the study is a random stratified proportional sample; the statistical regional division was used as a basis of the grouping of strata. The sample strata were formed in accordance with regional division and proportionally to the main group. (See Figure 4.1.) The research sample was formed proportionally to the main group that in January, 2010 was made up of 7009 families that were granted a supplement to the state family allowance for disabled children (Piemaksa pie ģimenes..., 2010).

Figure

4.1.

Description of the volume of strata sample included in the research

	Number of families with children with disability (01.01.2010).	Volume of strata proportional sample with 6% error	Number of interviewed families	Number of interviewed families (%)	Calculation of the weight of sample
Vidzeme region	938	35	39	14	0,9
Riga region	1180	43	43	16	1
Riga	1593	58	58	21	1
Zemgale region	985	36	46	18	0,8
Latgale region	1215	45	45	16	1
Kurzeme region	1098	40	41	15	0,98
Total	7009	257	272	100	

Every regional administrative unit (region or town) was sampled using the principle of mechanic selection: according to the previously arranged list every other administrative unit was chosen for the study (Socioloģisko pētījumu... 1981, 191). After selecting administrative units for the survey, the author appealed to the municipal social agencies and several societies for the people with disabilities to get in touch with the families with children with disability in their territory and offer them to participate in the study.

The study method is structured interviews. The research instruments were structured into two parts: one included the family quality of life scale developed by the international family quality of life research institution Beach Centre and the other included the family quality of life research indicators that were developed by the author based on the analysis of theoretical materials and were structured into four sections in accordance with the family quality of life domains. (See. Fig. 4.2.)

Description of the indicators used for the study of family quality of life

Area of material wellbeing	Area of social wellbeing	Area of physical wellbeing	Area of emotional wellbeing
<ul style="list-style-type: none"> • Income • Economical security • Employment • Social assistance • Possibility to satisfy the family needs 	<ul style="list-style-type: none"> • Social contacts • Attendance of cultural events • Involving in the action of the various organizations • Involving into sport, educational activities • Municipality/state support in an area of social wellbeing • Possibilities of self-realization 	<ul style="list-style-type: none"> • Housing • Education • Health care • Municipality/state support in an area of physical wellbeing • Providing with technical facilities • Availability of the transport • Free time, relaxation 	<ul style="list-style-type: none"> • Emotional stress • Municipality/state support in an area of emotional wellbeing • Attitude from others

The data obtained through the survey was processed using SPSS program, but the graphic data coverage was done using Excel data processing program. SPSS program carried out the calculations in connection with data processing. Using the Chi-square test, the author estimated the proportionally statistical significance between variables. Using the possibilities of SPSS program, the analysis of factors was performed based on the Beach Centre family quality of life scale. The factor analysis was done according to the method of the main components; as a result of it, it was possible to assess the affect of individual factors on the areas of quality of life.

The study results are disclosed within the context of living place, family structure, the highest level of education of adult family members and the type of care that matches the special needs of disabled children. While analyzing the data from the standpoint of necessary type of care, the following division of care type was developed: a child needs full care, a child needs sitting, a child needs or does not need assistance in accordance with the specifics of functional disorder. The next subdivision presents the description of family life quality in the area of material wellbeing.

4.2. Quality of life in the area of material wellbeing

The income of the families involved in the study was calculated in quartiles; as a result of it, four income groups were formed. In accordance with the family income calculations, it can be concluded that the largest group (27%) is made up of families that have monthly income of LVL 101–150 per one family member which corresponds with the third quartile, but the smallest group (21%) is made up of families with monthly income above LVL 150 per family member which corresponds with the fourth quartile. 25% are the families with monthly income below LVL 68 that corresponds with the first quartile; 26% are the families with monthly income below LVL 100 per family member which corresponds with the second income quartile. In 2008 the average monthly income per one family member was LVL 213.42 in Latvia (Mājsaimniecību...2009). It tells us that more than 70% of the interviewed families have income lower than the average in the county; so we see that the families with disabled children have limited access to the financial resources necessary to ensure the quality of life.

Latgale region and Kurzeme region have families with the lowest monthly income. Almost half of all the interviewed families from Latgale region and Kurzeme region has a monthly income does not exceed LVL 68.

Quite significant differences in the structure of family monthly income are observed in both rural and urban territories. As the research data show, families residing in urban areas have bigger monthly income per family member comparing to the families residing in rural areas. 43% of the families residing in rural areas have monthly income that corresponds with the first quartile, while 33% of the families have monthly income that corresponds with the third and fourth quartiles. But 59% of the families residing in urban area have monthly income that corresponds with the third and fourth quartiles. Income that corresponds with the fourth quartile is inherent mostly to the families residing in towns and cities. Calculating the Chi-square test, it can be concluded that place of residence affects the monthly income of families, since p-value is 0.0001. The research results show that monthly income of the families residing in cities is comparatively larger and municipalities are more easily able to support the families with low-income status since there are fewer of those families comparing to rural areas; thus, town municipalities are able to support other disadvantaged families. It shows that architects of family support policy should consider the structure of monthly income of the families residing in rural and urban areas.

As the research results show, the families residing in urban areas have more employment opportunities than the families residing in rural areas. 73% of the families residing in towns and cities and 54% of the families residing in the countryside receive their income from employment. The research data show that the families residing in the countryside would greatly benefit from the promotion of employment oriented social policies, since these families cannot use the offered employment opportunities due to the lack of transportation, the special needs of their children or the lack of necessary skills. The measures that are a part of support to low-income or disadvantages families are not able to provide long-time support to these families.

The study tells that the higher the education level, the bigger the chances for both parents to be employed. 87% of fathers and 69% of mothers with higher education are involved in employment relationships. The smallest percentage of employment is shown by parents with secondary or elementary education. The given results do not indicate of absolute affect of education on the employment and family income; they only point out the tendency in the area, since the factors that affect both employment and the size of family income can be diverse and education is just one of them. As the study shows, the special needs of disabled children most strongly affect the employment chances of those mothers whose children need full care. The mothers of these children believe that it is almost impossible to get involved in the labour market, since hired labour is not compatible with child-care; also they believe that due to the long-term child care they have lost skills and experience. Similar views are expressed by 44% of mothers whose children need continues sitting. Another factor that interferes with the employment of mothers is employers' insensitivity towards employees after finding out about a disabled child. It can be concluded that the need to meet the special needs of disabled children is one of the factors affection mothers' employment chances; it is also justified by Chi-square test, since its p-value is 0, 01.

Not always families can live on the available income and meet their needs; besides, the need to meet special need of disabled children is always associated with additional financial means. Almost all families with a monthly income with the first quartile confirm that current resources are not sufficient to meet family's needs; the same applies to families with the monthly income up to second quartile. The sufficiency of the family monthly income is greatly affected by the care type the child needs involving the specifics of meeting his or her special needs. Adequacy of monthly income available to families is affected by the type of child care in connection with the special needs of disabled child. The study shows that families with children that need full care have more expenses than the families whose children need sitting or do not need any assistance. The families with children who need full care expressed their need of adequate physiotherapy because the physiotherapy provided by the state is not sufficient for the improvement of child's health while additional therapy costs starting with LVL 20 per one visit to the specialist. Families would also like to be able to take their children to the specialists abroad.

Families face a lack of financial means regardless of their income in all areas of their life; nevertheless, it is possible to single out areas where it is more difficult for the low-income families to meet their needs: usually it has to do with the basic needs, for example food, clothing and footwear, health-care for adult family members, housing repair and purchase of household items, including electrical appliances, furniture, and also attendance of cultural events. Families with average income up to second and third quartiles have problems in the area of utilities. More than 90% of the interviewed families face financial difficulties in the area of health care. For example, 98% of the families residing in Riga believe that they are not able to provide all necessary health services for their family members.

Even though the amounts of state support are not big, they promote economic safety for 79% of the interviewed families. When analyzing the influence of the satisfying the special needs of disabled children on the financial safety provided by the state, it can be concluded that the support provided by the state is more essential for the families with children who need full care or continuous sitting and promotes their safety than for the families with children who do not need or need a help.

The meeting of child's special needs mostly limits the families with children who needs full care and, as the study shows, there are families that are not affected by the meeting of child's special needs because they have very little finances and do not spend much money on meeting child's special need; or there are some families that can afford anything they need. It tells us that the field of family social policy that concerns children with disability should re-evaluate and consider both the specifics of child's special needs and the type of necessary care, and the material support must be designed according to it.

A bit more than half of the interviewed families with the income less than LVL 90 has obtained a needy family status but in 47% of cases, municipalities have denied granting the low-income status to the families, or families do not know that their income fits the requirements for granting the low-income status and have not applied for it in social services. The largest number of families whose income meets the requirements for getting a needy family status is in Latgale region – it is 86% of all the interviewed families from Latgale region; the needy status was granted to 45% of these families. There is also large number of families in Kurzeme region and Riga region with a monthly income under LVL 90: it is 76% of all interviewed families of these regions. The needy status has been granted to 47% of these families in Riga region and to 54% of these families in Kurzeme region. The largest numbers of the families whose income meets the requirements and who has actually received needy family status reside in Riga.

The types of material support for families in all regions of Latvia are housing relief, GMI allowance, allowance for medical services and free lunches; there are some other types, for example, Christmas allowance for disabled children and extraordinary allowance for special cases. As the study shows, transport recompense and care benefit are usually received by the families residing in Riga. The rest of allowances are given by other municipalities; nevertheless, Riga has taken the leading position in the area of providing material support; it tells us that Riga has the most means for providing material support for the population.

As the study results show, the families residing in Riga are the most satisfied with their financial situation in comparison to all other regions; it is not surprising since these families have the highest income comparing to all other regions. (See. Fig. 4.3.) The second region where the residing families consider their financial situation to be fairly good is Vidzeme region. But the families residing in Latgale region, Kurzeme region and Zemgale region consider their financial situation to be bad. In all of the regions, large percentage of families assess their financial situation as satisfactory, which tells us that they have resigned to the situation and have learned to meet their needs with the resources available to them and are satisfied with their situation. Large amount of respondents are satisfied with their financial situation; that shows that families are learned to satisfy the needs with disposable financial resources.

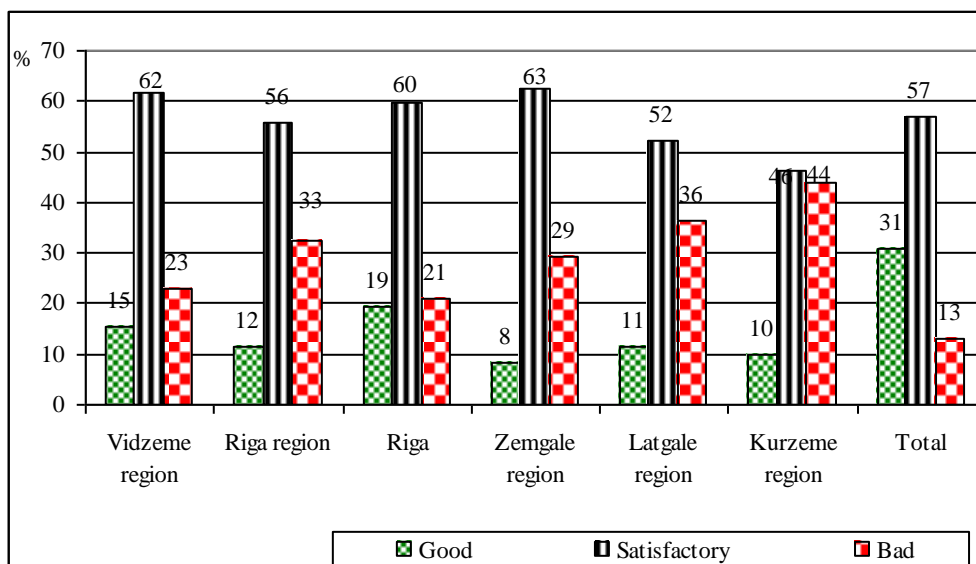


Figure 4.3. Satisfaction with family' financial situation in regions (%)

The conclusion then is that the material wellbeing of the families is affected by many factors that often do not depend on the families alone; they depend on the socio-economic situation in the country, living place, as well as the specifics of special needs of disabled children.

4.3. Quality of life in the area of social wellbeing

Involvement of the families with children with disability in cultural activities is affected by many factors that are associated not just with financial opportunities, but also child care, lack of time, as well as environment accessibility and lack of transportation. As the study shows, attendance of cultural events are most affected by the lack of financial means, since the families with limited financial resources first need to meet their basic needs and only then can meet the other needs.

The largest number of families (58%) whose adult members do not remember when they attended some cultural event has income that fits in the first quartile, but the largest number of families whose adult members have attended some cultural event during the last month has income that fits in the fourth quartile. It tells us that the financial status of families affects the attendance of cultural events; yet when viewing calculations of Chi-square test (p-value is 1.29) it can be concluded that the monthly income of families is not the factors that has significant impact on the attendance of cultural events by adult family members. Possibly, adults from the families with lower income do not have any desire to attend cultural events.

The study shows that lack of time, a distance to the place where events take place as well as interest in the event are the factors affecting the attendance of cultural events by families regardless of the specifics of disabled children. The special needs of disabled children also affect involvement into cultural activities since children often are not able to sit and concentrate for a long time; also they get agitated seeing multitudes of strange people. Some families mark out difficulties in the area of transportation. More than a third of the adults in Kurzeme region do not remember when the last time they attended a cultural event was. Also, in Vidzeme region, adults are very passive in getting involved in cultural activities. The most active are the adult family members from Riga city and Riga region. Obviously, the most important factor in the area of attending juvenile cultural events is personal interest and motivation to attend cultural events and to get the children involved as well. They are the least likely to attend cultural events; nevertheless, 17% of families with disabled children

that need full care parents do not remember when their children attended some kind of cultural event. 22% of the parents of these children have attended some cultural event during the last or previous two years. Calculating the statistical significance of percentage difference (p-value), the conclusion is that the specifics connected with the special needs of disabled children do not affect the activity of families in cultural area. It indicates that attendance of cultural events largely depends on the personal interest of parents to get involved in cultural life and not on the special needs of disabled children and the ability to meet them.

Family quality of life is largely affected by the social contacts. Families mostly choose those social contacts that match up to their needs and interests: in a wider variety of social contracts there is a greater opportunity for these families to find support when it is the most needed. Families with disabled children mostly contact their friends and relatives; they rarely contact neighbours, colleagues and other people, for example, workers of different organizations.

Families form their social wellbeing not only with the help of friends and relatives, but also through getting involved in different self-improvement and self-realization activities. As the study shows, children are more likely to get involved in sports activities than the adult family members. Families in Vidzeme region and Kurzeme region are more active in getting their children involved in sport: it is more than a half of all families from Kurzeme region and Vidzeme region. The smallest numbers of children involved in sport activities reside in Riga, Zemgale region and Latgale region. In turn, the adult family members from Riga city and Vidzeme region are the most active in the area of sport activities. The most passive in that sense reside in Zemgale and Riga region. Yet adult family members are more active in getting involved in the activities of different organizations than sport activities. The most active are the ones residing in Riga city, Zemgale region and Riga region.

As the study shows, the families residing in Zemgale region, Latgale region and Kurzeme region are the most active in getting their children involved in different activities of self-development and self-improvement. The families residing in Vidzeme region are the most passive in encouraging their children's involvement in different activities; it indicates that this region lacks activities that fit the needs of these families. The adult family members are the most active in this sense in Riga region; they are the most passive in Kurzeme region. The social wellbeing of these families is also described by the accessibility of different education opportunities for disabled children, since the satisfaction of the family needs is subject to the satisfaction of the special needs of disabled children that often is associated with education.

Quite often the parents experience difficulties in choosing the most adequate way to obtain education, because, for example, in order for a child who needs full care to be able to obtain education that matches his abilities, parents often are forced to take their child far away from home and leave in a special school for a week or even longer, because there are no homeschooling or inclusive education options available at their place of residence. The study indicates that homeschooling as a type of training for the children with disability is not practised in Kurzeme region and not often practised in Riga city and Vidzeme region for the children that need full care; it tells us that these regions force families with children that need full care to send them away from home and leave them in specialized schools or use training opportunities in mainstream schools.

Altogether families assess educational opportunities as good or satisfactory, yet 23% of the respondents are not satisfied; it signifies that there is a lack of opportunities for children with disability to obtain adequate education. 38% of families with children that need full care and 20% of families with children that need sitting assess educational opportunities for the children with disability as bad. Parents' opinion of the education provided by specialized schools varied: some parents expressed their displeasure with having to leave their children at school overnight, because to their mind it created psychological trauma not only to children, but to parents as well; also some parents pointed out to challenging contingent in these schools; yet there was also different opinion: some argued they were pleased with being able to leave the children at school for a week or longer because that was the only way for parents to rest from having to continually take care of their children.

4.4. Quality of life in the area of emotional and physical wellbeing

Physical wellbeing is a prerequisite of the provision of quality of life for children with disability, since physical wellbeing includes such areas as suitability of housing and environment to the family needs, also mobility and accessibility of health care. As the study shows, majority of the families live in residences with dwelling space of less than 15 m² on a family member. According to the statistical data, in 2009 average floor space on 1 person was 27.2 m² (LR Centrālā..., 2010). It signifies that families with disabled children live in dwellings that are smaller than average. As the study shows, most of the interviewed families live in two-room lodgings; even larger number of families live in a single-room lodgings, for example, in Riga city and Riga region; it indicates that these families do not have real opportunity to have rest and that children with disability do not have their own room.

The family quality of life is affected by amenities in the housing, especially if there is a need to satisfy special needs of children that need full care. The study indicates that largest number of families with housing with all amenities reside in Riga and Riga region. A little than third of families in Kurzeme region occupy housing without any amenities; it means that their lodging does not fit the special needs of disabled children. The families there are not able to take a shower or a bath; there is no hot water and central heating in the lodging, also the toilets often are located outside. Proportionally large number of the interviewed families has such lodgings in Latgale region and Zemgale region. As the study data show, families than live in urban areas have dwelling with amenities more often than the ones living in rural areas. Only 8 % of the interviewed families that live in towns have dwelling with no amenities, for example, the source of water and the toilets are outside; there is no hot water inside and no chance to have a wash. In comparison, 30% of the interviewed families from rural areas face the same problem. There are quite many families in all regions of Latvia that occupy housing with partial amenities: these places are without central heating and sometimes no hot water, - almost half of the families from rural areas and 21% of the families from towns same the problem.

Housing amenities have a lot to do with the opportunity to satisfy the special needs of disabled children, but housing amenities alone do not create adequate environment to satisfy the special needs of children that need full care. These children need the lodging to be adapted to the specifics of their needs that requires reconstruction of housing and special equipping to provide a way for the children to move around in wheelchairs, take showers or baths, have a room for exercise units and a special type of bed. As the study shows, the majority (72%) of the interviewed families with disabled children that need special adaptation of housing to their special needs do not occupy that type of housing. Situation is the worst in Latgale region; 82% of the families with disabled children do not occupy housing adapted for their special needs.

The study results show that majority of the interviewed families are generally satisfied with their lodging and consider it to be satisfactory or good; yet 25% of the families residing in Latgale region, Zemgale region and Kurzeme region believe their housing to be inadequate. Usually they substantiate this opinion by the lack of amenities, as well as bad condition of the dwelling. The highest assessment to their dwelling was given by the families from Riga city and Riga region.

As a result of the health care reform, the families from the most remote areas experience difficulties in the area of accessibility of health care services, especially if a family does not own a personal vehicle. The study shows that the families from all regions face various difficulties in the area of health care, for example, financial difficulties, inaccessibility of specialists and experts, remote location of health service providers, as well as low quality of health care and indifferent attitude from doctors. It is especially Latgale region and Kurzeme region where the families experience the inaccessibility of necessary specialists; also health care service providers are located a long way from their residence. Low quality of health care services is an issue that the families from Riga and Vidzeme region are the most concerned about.

Most families believe the health care to be acceptable; yet it can be concluded that almost 25% of the families from Latgale region consider the health care available to them to be bad. The calculations of statistical significance of

percentage differences indicate that the assessment of health care is affected by the type of care the disabled children need (p-value is 0, 00044). Significant differences are observed among the families with children that need full care and the families whose children need little or no assistance.

The families whose children need full care face different problems that could be reduced by an opportunity to have an assistant. As the study shows, families from all regions equally feel the lack of professional assistance. This lack is felt the most by the families in Riga city and Zemgale region; and it is felt the least in Kurzeme region, which indicate that the families from these regions have resigned to the situation and have gotten used to difficulties.

One-parent families feel smaller need for an assistant than nuclear families. As it is stated by the families, they are used to the difficulties and can manage daily duties; most of the mothers that take care of their children believe no-one can do a better job.

One of the main difficulties the families face in the area of physical wellbeing is the lack of personal vehicle; for these families, many places are totally out of reach. The main problem caused by a lack of a personal vehicle is inability to get to the necessary places, especially at the moments when it is the most important, since there are still areas in Latvia with not public transportation. It significantly aggravates the quality of life of these families. In general 56% of the interviewed families has access to the adequate transport to get to the necessary places.

The quality of life of the families with disabled children is largely affected by the availability of technical aids. The lack of technical aids for disabled children denies them the opportunity to move; also available technical aids do not always match the special needs of disabled children, for example, orthopaedic braces or wheelchairs are too small or low-grade. The study shows that the greatest lack of technical aids is experienced by the families from Kurzeme region and Latgale region. The smallest numbers of families whose children experience the lack of necessary technical aids reside in Riga and Vidzeme region. It can be concluded that the families face this problem in all regions and it tells of the gaps in social policy.

The quality of life of the families is largely affected by their emotional wellbeing that is characterized by the emotional state of the family members and the opportunities to improve it. The study shows that half of the interviewed families experience emotional tension. Nuclear families face a bit more emotional tension than extended or one-parent families. Yet, as the calculation show, there are no substantial differences between the variables that describe family structure, since p-value is 0.92. The families with disabled children often experience emotional tension due to satisfaction of their special needs. More than a half of the families with children who need full care or sitting experience emotional tension; little less than a half of the families with children who need little or no assistance experience lower level of emotional tension. It indicates that the families with disabled children need to be provided various activities that lessen emotional tension. The study shows that the majority of the interviewed families use the help of their friends, relatives, neighbours and other family members to relieve the tension and only a small percentage (16%) seek help with the professionals.

Social agencies provide not only psychological support, but also in-house care and other services. In-house care is the least used service, - during the last year it was used by only 5% of the interviewed families; this service wasn't used by any of the families from Kurzeme, Latgale and Vidzeme regions which indicates that this service is not offered in these regions or that the families lack the necessary information about it. During the last year day care centres have been used by 14% of the interviewed families; most of them reside in Latgale region. Also rehabilitation in day care centres is practised in all regions, even though families are really passive in using this service – only 20% of the interviewed families have used it. This service is the most popular among the families in Riga, but the least popular in Zemgale and Kurzeme region.

Describing their experience with obtaining the support from municipal social services, families mentioned both positive and negative attitude of the social workers. Among the negative experiences were insensitivity, dishonesty and humiliation they felt from social workers. Families, mostly in rural areas, mentioned some cases when social workers were

providing the support not to the families in need, but to their friends and acquaintances. Families admitted they lack information about the types of support from municipalities and the terms of obtaining it. It is mostly connected to the fact that families do not have access to the Internet and the only source of information about the types of support is social service. Nevertheless, as the study results show, not always social services present precise information about the terms of this support. Some of the families pointed out that social workers do not respect the principle of confidentiality. But it must be said that 67 % of the families assess the support provided by municipalities as good and satisfactory.

4.5. Factors that affect quality of life of families with disabled children and its assessment

The family quality of life is chiefly affected by material provision that is expressed by the adequacy of available financial resources to the family needs. As a result of the factor analysis, two factors were singled out that feature **material provision** of the families: the material provision designed to meet all family needs; that is designed to meet all of the family needs characterize the financial resources of the families that satisfy not only basic needs, but also social and spiritual needs; they allow families to attend cultural events, visit friends, cover health expenses and other expenses and make families believe that they are financially secured; and the material provision designed to meet basic family needs characterize those financial resources that only help satisfy elementary needs, such as needs for food, clothing and footwear, and housing. The factors that have been singled out as a result of factor analysis allow assessing the influence of the material provision of the families on their quality of life in all of its areas.

The factor analysis shows that family quality of life is affected by such factors as material provision, conditions that ensure physical wellbeing, closeness and unity of the family members, as well as **social contacts**. In order to analyse the influence of social contacts on different areas of quality of life , the author singled out three factors that feature social contacts of the families: community based social contacts that include friends, common acquaintances, neighbours and colleagues; formal type of social contacts that include contacts within different areas of interest, different institutions, as well as accessibility of the necessary information; kinship based social contacts that mostly include communication among relatives.

The factors that feature social contacts of the families reflect not just the specifics of the relationships that form their social contacts, but also explain the ways of obtaining the necessary information which greatly affects family quality of life.

Physical wellbeing is mostly associated with environment where the family quality of life is formed and that affects other areas of quality of life; environment is reflected by the conditions that form it. As a result of factor analysis, the author singled out two *factors that reflect the conditions necessary for the satisfaction of family needs* : conditions adequate to meet basic needs; that includes home and community environment characterized by the conditions that are necessary for the families to meet basic needs; they include a safe, warm and light lodging, as well as healthy nutrition and safe surroundings; and conditions necessary for recreation and self-realization points out to the conditions that ensure the environment that is good not just adequate for basic needs, but also for recreation and self-realization: that would be sufficiently large housing that provides opportunities for all family members to rest and time for self-realization.

Emotional wellbeing of the families is largely characterized by emotional intimacy and unity. So the author will give an analysis of the factors affecting quality of life in the area of emotional wellbeing based on two factors: emotional intimacy featuring emotional wellbeing of the families reflect emotional intimacy among family members that implies mutual support and care, as well as openness between family members and unity within the family; that talks about the unity that expressed in form of common friends, attendance of the same events, the time spent together with the family.

This chapter proceeds with the analysis of the family quality of life based on the factors marked out as a result of factor analysis.

As the study shows, quality of life of disabled children is affected by such factors as material provision, social interaction, family unity, income security, as well as conditions necessary for meeting their needs. (See figure 4.2)

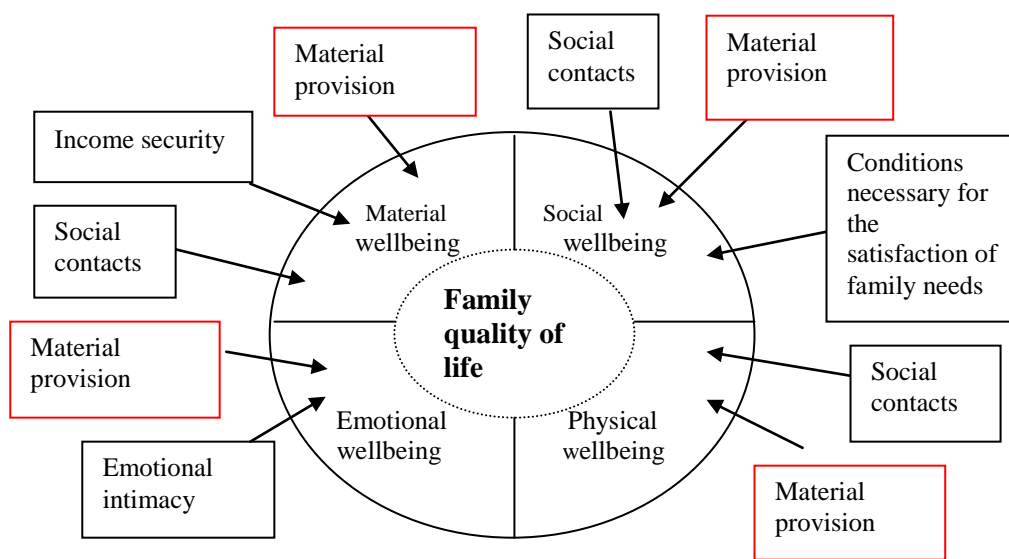


Figure 4.2. Factors that affect quality of life of families with disabled children and its assessment
Source: author's created figure

Material wellbeing of the families is affected by *material provision*: not just the ability of the families with disabled children to satisfy their needs, but also security of income gained not just through hired work, but also through the material support provided by the state and local governments. As it is shown by the study results, additional resources necessary to meet the special needs of disabled children mostly affect the ability of families to purchase necessary household items and attend cultural events and visit friends and relatives. The second indicator that describes material wellbeing is the safety of family income which can be affected by material provision. The higher the material provision, the less secure family feel about their income; it can be explained by the fact that higher material provision is typical for families that have well-paid jobs since there is no guarantee that some socio-economic crises won't cause the loss of it. Lower material provision is associated with higher security of income.

Material wellbeing of the families is affected also by *social contacts*, for example, in the areas of employment and social assistance. The calculations of significance of percentage differences indicate that social contacts have serious influence on employment. The opportunities for families to enter the labour market are bigger when families use not only kinship and community based, but also formal social contacts. Material wellbeing is largely affected by the opportunity of the families to receive material support from the state and municipality which in turn is affected by social contacts of the families.

Social wellbeing of the families is affected by such factors as material provision, social contacts, and everyday living conditions that provide physical wellbeing, as well as intimacy and unity within the family. Participation of the families in cultural life is affected by what social contacts are used by the families on a daily basis. As the study shows, if social contacts of the families are based not just on kinship and community, but also on formal relationships, the families are a lot more active in participating in cultural life; they also are more active in introducing their children to the cultural life. The calculations show that in a wider variety of social contacts families more likely attend cultural events; social contacts that are kinship and community based do not encourage participation of the families in the cultural life. Social

contacts largely affect also the participation of the families in the activities of different interest groups and organizations, self-development and sport activities. Social contacts affect family's chances to receive support from friends when it is the most necessary. For example, the families with only kinship or community based relationships have fewer chances to make friends who would be able to give support adequate to the family needs when it is the most needed.

The assessment of the difficulties families face when attending cultural events indicates that material provision affects not only family's decision to attend cultural events in remote locations that need transportation, but also commercial cultural events; for example, quite often the families talked about attending circus, but could not afford it.

Material provision does not largely affect the formation of social contacts, except contacts with neighbours; it is interesting that this type of contacts is affected by material provision that is justified by the calculations of the statistical significance of percentage differences. The families that want to keep in touch with friends, colleagues and other individuals, are not limited by their material status. The calculations done during the study indicate that material provision does affect the opportunities of adult family members to get involved in sport activities and functioning of different organizations, but it does not affect participation in other types of activities, for example, self-improvement activities. In the same way material provision does not significantly affect the participation of children in different activities.

The study calculations indicate that social wellbeing of the families is affected by conditions that determine physical wellbeing. For example, *everyday living conditions* that usually match the satisfaction of basic needs, encourage the forming of contacts with other families more than the everyday living conditions that match not only the satisfaction of basic needs, but also of the needs for rest and self-realization. The tendency is that the families whose everyday living conditions are sufficient for both recreation and self-realization tend to avoid contacts with other families, because they have time and favourable conditions to get involved in different activities of self-improvement. Everyday living conditions also greatly affect the opportunities of the families to receive the support from the friends when it is the most necessary; as the study shows, *everyday living conditions* that are sufficient not just to meet basic needs, but also the needs for recreation and self-realization, increase their chances to receive friends' support when it is the most needed. The study shows that social wellbeing of the families is not affected by the *unity* and *emotional intimacy* within the family.

It can be seen in the study that *material provision* significantly affects emotional wellbeing of the families, since the lack of material resources is one of the main causes of emotional tension. The calculations indicate that the families that have sufficient material provision for meeting both basic and other family needs are in a lower risk of emotional tension. The calculations indicate that the families that have sufficient material provision for meeting both basic and other family needs are in a lower risk of emotional tension. Emotional wellbeing of the families is affected also by family unity; as the calculations show, families that lack unity also lack friends who could give necessary support in a time of need. As a result of calculations, we see that emotional wellbeing of the families is affected by neither *material provision*, nor *everyday living conditions* and *the type of social contacts*.

Physical wellbeing of the families is largely affected by *material provision*. Material provision influences not just the chances of the families to obtain the resources necessary for meeting their needs, but also largely influence the conditions necessary for meeting the family needs. . The calculations show that material provision affects the chances of the families to upgrade their housing: the higher the material provision, the bigger the chances to upgrade the housing. Material provision designed to meet the basic needs of the families is not sufficient for the families to upgrade their housing. Material provision mostly affects the chances of the families to live in housing with all amenities; - the calculations provide grounds for this conclusion. The study shows that material provision mostly affect the chances of the families to remodel the housing and install in it all necessary amenities, for example, in-house toilet, bathroom, laundry machine or exchange a housing in critical condition for a better one.

Material provision affects availability of the doctors in the areas of specialists and the distance. When assessing the affect of material provision on physical wellbeing of the families, the conclusion is that not all difficulties in connection

with provision of quality of life can be solved through material provision; yet material provision increases the chances to form conditions adequate for meeting the family needs.

Physical wellbeing is affected by *social contacts* of the families, since the families with disabled children need the support of friends and relatives more than they need material provision. For example, the availability of technical aids is largely affected by social contacts. The study calculations show that the families whose social contacts are not just community or kinship based, but also have the formal component have bigger chances of obtaining the necessary technical aids; it indicates that formal social contacts are necessary for meeting of the special needs of disabled children.

It appears from the analysis of the factors affecting family quality of life that family quality of life is a multidimensional phenomenon that is affected by both structural conditions formed by the society and the involvement of these families in improving of their quality of life, based on the experience of quality of life gained through the socialization process. For example, the families whose experience of quality of life is associated with difficulties quite often get used to these difficulties and do not desire to change their different living conditions. Conclusions made as a result of the study of family quality of life are substantiated by the subjective assessment of family quality of life (See Fig. 4.3.) The study results show that more than a half of the interviewed families from all the regions of Latvia consider their quality of life to be either satisfactory or good. For example, almost a third of the interviewed families from Kurzeme region reside in lodgings without basic amenities; yet 86% of these families consider their quality of life to be good and satisfactory.

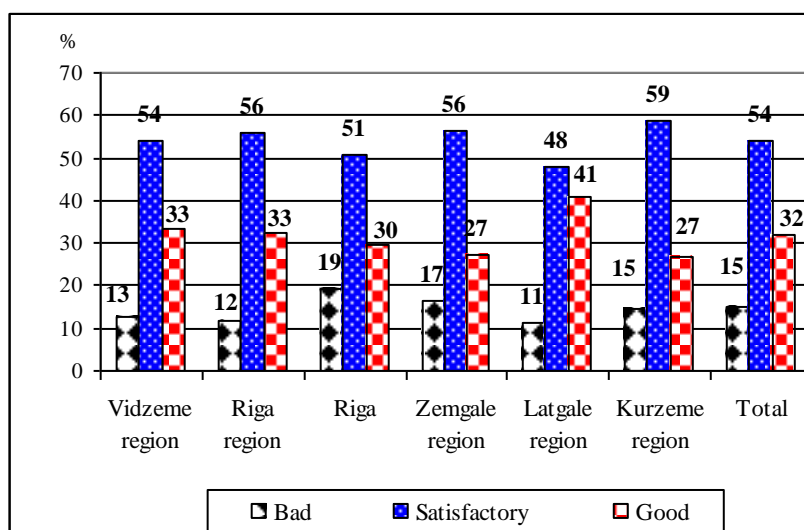


Figure 4.3. Assessment of subjective wellbeing of families by regions (%)

Assessment of subjective family quality of life by the type of care does not significantly differ among families with children who need different types of care to meet their needs. The factors affecting family quality of life impact not only quality of life, but also the assessment of quality of life.

Material provision that is designed to meet all family needs increase the chances that family will assess their quality of life as being good or very good by 2.5 times. Material provision that is designed to meet the basic family needs increases the chance that family quality of life would be considered to be bad or very bad by 2.4 times. Also, formal social contacts increase the chances that family quality of life will be assessed as good or very good by 2.1 times. The regression analysis shows that the factor featuring conditions adequate for family relaxation and self-realization increase family quality of life assessment by 2 times. Yet family quality of life is not impacted by such factors as community based and kinship based social contacts, unity and intimacy within the family, and living conditions sufficient for meeting the basic needs. Only one factor significantly affects the assessment of the quality of life: it is the factor of material provision

designed for meeting all of the family needs. It indicates that the families whose material provision allows them to sufficiently meet all of the family needs tend to assess their quality of life as satisfactory. The analysis reflects that if the material provision is designed to meet not just the basic needs, but also all the other needs, then the probability that under the influence of this factor the families would give positive assessment of their quality of life would be sixteen times bigger than with all the other factors.

CONCLUSIONS

- The quality of life is described by individuals' satisfaction with the current life conditions that meet the needs in all the areas affecting their everyday life. Family quality of life reflects the conditions through which family needs are met and family members have opportunity to do what is important to them. Family quality of life is characterized by the areas as emotional, physical, financial and social wellbeing.

- According to Anthony Giddens, in order to ensure sufficient family quality of life, family members need to get involved in numerous social practices that are connected with the provision of financial, emotional, social and physical wellbeing. Based on Jurgen Habermass' theoretical findings, family life is carried out within a particular life space that is affected by the structures and systems formed by society, as well as cultural values and individuals' ability to use resources. Along to Anthony Giddens, Pierre Bourdieu argues that quality of life is affected by individuals' capacity or their social baggage, as well as the resources at their disposal and the area that determines the rules of conduct.

- Family quality of life with disabled children is affected by the availability of resources necessary to meet their needs. The resources necessary to meet their special needs depend on the type of child's functional disorder and the suitable care. This paper describes children's special needs and the suitable care by dividing families into three groups: families with children that need full care, families with children that need an sitting and families with children that may or may not need any help.

- Satisfaction of children's special needs affects family quality of life in all areas regardless of the care type needed; yet it especially affects the quality of life of those families that have the children that need full care or sitting.

- **The hypothesis of this paper is not conformed**, because the support to the families with disabled children provided by the state social policy recompenses the effect of the special need of disabled children on family quality of life in the area of **material wellbeing**, as the results of this study show.

- More than 70% of the interviewed families have income below the average income per one household member in the country (in 2009 – LVL 213.42). The financial support from the state promotes the economic security of 79% of the respondents; also 97% of the families that have been granted low-income status receive financial support from the local government. Besides, the families with children that need full care or serious sitting receive more substantial support from the state, which promotes the financial security of these families more than the families with disabled children that may or may not need help.

- These are the types of material support that the families receive from the local government in all regions of Latvia: housing allowance, GMI allowance, medial service allowance and free lunches. Care allowance and transportation recompense (from the municipality) is provided to the families residing in Riga. Also the families residing in Riga can rely on the allowance for meeting the special need of the disabled children, since other municipalities mostly provide the allowance for the needy families, regardless of the needs.

- The special need of the disabled children especially affect the employment of the mothers that need to provide full care to their children; as a result these mothers lose their professional skills; with every passing year their chances to return to labor market grow smaller. Neither state nor municipal support can changed, since the guiding principles of state social

policy do not provide for promotion of employment for the parents with disabled children; municipalities also do not provide any support in this area.

- The support in the areas of emotional, physical and social wellbeing does not recompense the influence of special needs of the disabled children on family quality of life, since available support is either suitable to the family needs or these families face different obstacles in receiving the necessary support.

- In the area of emotional support, 50% of the families experience emotional tension, and neither state nor municipal support is able to lessen it. This tension is mostly caused by the satisfaction of special needs of a disabled child. The interviews with the families show that not all municipalities provide the consultations with a psychologist; in case when a municipality does provide such opportunity, families are passive in using it due to lack of information and certain prejudice.

- In the area of social wellbeing, parents are overall satisfied with children's education; yet they point to several faults, for example, indifference of teachers towards the quality of education and the fact that adequate education for the children with disability is not obtainable at the place of residence (town or village).

- Neither state nor municipality helps families with disabled children to attend cultural, sports and other events and create social networks. Families with children that need full care experience difficulties in attending cultural events mostly due to lack of financial resources, transportation, as well as lack of care assistance.

- In the area of physical wellbeing, state provides children with disability necessary technical aids; yet 51 % of families do not have access to these aids. Besides, technical means provided by the state sometimes do not match the need; for example, orthosis and/or wheelchair is too small and of bad quality. 71% of families have not received support for accommodating the dwelling to the special needs of children. The situation is the worst in Latgale region; 82% of dwellings are not accommodated to the special needs of children.

- Even though the health care services for children under the age of 18 are free, more than a half of the interviewed families face the problems with the accessibility of medical doctors and lack of finances. Families' with the children that need full care assessment of medical care is lower than that of the other families; it tells us that in the country families face problems with diagnostics and treatment of specific diseases.

- As the research shows, family quality of life is characterized not by objective life condition, but by subjective satisfaction of families with their living conditions; so often families are used to 'bad' living conditions and assess their quality of life as satisfactory or even good. And vice versa; some families enjoy fairly good living conditions, yet they are not satisfied with their quality of life as not matching their needs and desires. It is told by the families that in order to meet their needs and improve their quality of life, they would need qualified assistance, personal transportation, housing with amenities, more financial resources, personally owned, not rented dwelling, as well as positive attitude and consideration from the people.

- As a result of the factor analysis, the following factors were highlighted as the ones that describe the quality of life of the families with children with disability and reflect the areas affecting their quality of life.

- The research shows that family quality of life in the area of material wellbeing is affected by financial security of the families, income security, and social networking.

- Emotional wellbeing is affecting by financial security and the unity of family members.

- Social wellbeing of the families is affected by financial security and social networking, as well as necessary conditions for meeting family needs.

- Family quality of life in the area of physical wellbeing is affected mostly by financial provision and the factor of social networking.

- Besides the factors mentioned above, the quality of life of the families with disabled children is affected by the place of residence (urban or rural area), the specifics of their needs and family structure.

- The assessment of quality of life is mostly affected by the factor of material provision, which signifies of the fact that family quality of life is mainly affected by the material provision.

- As a result of this promotional work, it was possible to draw several conclusions that point to the gaps in the area of state social policy that degrades family quality of life.

- The research reflects the gap in accessing of information about social assistance opportunities and social services provided by municipalities. The lack of information prevents families to use the material support provided by the municipalities, mostly to poor families; this degrades their quality of life in all areas. It also prevents them from using social services that at times is even more necessary than material support, for example, psychological support in the area of emotional wellbeing.

- During the research the author discovered cases when both state allowance for a disabled child and care allowance were listed as declared income, which is against the law; as a result of it these families were prevented from receiving social assistance provided by the municipality which degraded the quality of life of these families.

- The research results show that quality of life of families with disabled children is to a great extent affected by emotional tension caused by meeting their special needs; so it would be necessary not only offer social assistance to these families, but also social services, for example, psychological consultations or rehabilitation. Quite often social assistance to these families is given mechanically without going into the causes of the problems.

- According to the Cabinet Regulations on granting a person or a family low-income status, this status can be granted only to the families whose members are either unemployed or job seekers. It leads to the situation when families of working parents whose monthly income is very low and meet the standard of low-income status are not entitled to receive this status and cannot ask for municipal support; this degrades the quality of life of these families in all areas that comprise the quality of life.

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