

# Psychological Characteristics of visible and invisible disabilities

Dissertation submitted to the  
Tbilisi State University  
for the degree of

Doctor of Philosophy in Psychology

Psychology

Maia Osipova-Schoeneich, Mg

Ph.D. Supervisor Prof. Tamar Gagoshidze

Department of Psychology

Tbilisi, 2009

Adolescents with Visible and invisible disabilities, Psychological Peculiarities, Self-esteem,  
Emotional and Behavioral problems, Upbringing Style, Parents' Stress Coping Responses,  
Family Social Support System



თბილისის  
უნივერსიტეტის  
გამომცემლობა

## **ACKNOWLEDGMENTS**

First, I want to thank my chairperson, Tamar Gagoshidze, for her countless hours of guidance and feedback on this study. Throughout the long six years of this study, I have received support from her.

Thanks to Tamar Abashidze in Tbilisi State University Psychology Department for her critical review.

I would like also to express my thankfulness to the headpersons of organizations for people with disabilities – Maia Bibileishvili and Irina Inasaridze for helping and supporting in recruiting participants with special needs and their families, what is not a simple deal.

I want to thank Einar Christiansen, Lillegården Resource Centre director and great professional in Special Needs Education, for the acknowledging the study as important, supporting it from Norway to be completed and insure contact with Professor Edward Befring. And lots of thanks to the Professor Edvard Befring - Department of Special Needs Education (ISP) at the University of Oslo, who could find a time for expertise and critical review of this work.

And of course I want to thank my family – my mom, my sister Shorena and my husband Martin for the love, support and patience and faith in me that I can do it.

## **ABSTRACT**

Psychological problems such as low self-esteem and emotional-behavioral problems in adolescents with disabilities are serious obstacles for the treatment and rehabilitation. On the other hand it is related to poor social adjustment, dependency on others and low level of achievement in all spheres of the life. We opposed to each other adolescents with visible and invisible disabilities to follow up the influence of conditions severity and family negative attitudes in developing such problems. Low self-esteem and emotional-behavioral problems are not related to the condition, care need and physical dependency on family members, but special attitudes of the family. In both disabilities we received the same tendencies. Several reasons were found out to influence the self-esteem and emotional-behavioral problems: usage by parents of disharmonic upbringing style, which is much more often than in case controls' group, trials to avoid the problem solving and find alternatives in society, do not tell to the child realistic prognosis for future. Difficulties also appear when parents find time for themselves or other children have guests or go for visits. It happens, because parents spend most of time for "family", but not for the child. At the same time parents, who expect negative prognosis for a child, often seek support outside the family. Siblings of adolescents with disabilities have lower impression about their sibling with disability then those about themselves. But despite of it, siblings attitude do not influence the development of problem. For prevention of the problems parents should inform their child about his condition and perspectives and find the time not only for care, but for relationships.

# Table Of Contents

Acknowledgements .....	ii
Abstract .....	iii
Table of Contents .....	iv
Introduction .....	1
Definitions of terms .....	1
1. Psychological problems in disabilities .....	1
2. Definitions of cerebral palsy (visible disability) and epilepsy (invisible disability) ...	2
3. Psychological peculiarities in puberty related to disability .....	2
Self-competence .....	2
Behavioral and emotional problems .....	5
4. The role of family factors in influencing psychological peculiarities .....	6
4.1. Stress .....	7
4.2. Upbringing .....	8
4.3. Siblings' attitudes .....	9
5. Relation between Stress coping and Upbringing style .....	9
Study .....	10
Statement of the Problem .....	10
Hypothesis .....	10
Methods .....	11
Participants .....	11
Procedure .....	12
Results .....	15
Sample Characteristics .....	15
Behavioral and Emotional problems .....	16
Self-esteem .....	20

Stress coping strategies .....	24
Upbringing Style .....	27
Correlations between Stress Coping Strategies and Upbringing Styles .....	29
Demographic and social data .....	29
Awareness of diseases .....	31
Discussion .....	32
General discussion and Conclusions .....	37
Recommendations .....	40
References .....	41

## **Introduction**

Self-esteem and emotional-behavioral problems of adolescents in different kinds of chronic diseases has already been a focus of investigators for a long time. Epilepsy and cerebral palsy are conditions which are wide spread in the population and treated like most stigmatizing conditions. Self-esteem and emotional-behavioral problems in children with disabilities were explored from different perspectives: attitudes of society and family, upbringing style and severity of disability. In the years 1970's it was discovered that families of persons with disabilities tended to execute different styles of disharmonic upbringing. Latest research is focused on issue of emotional challenges of families of persons with disabilities and has proven that those stress level differ from the families without disabilities. Though there is opposing data, which confirms that stress levels do not differ from those of other families. The problem of coping strategies in families of persons with disabilities are poorly investigated, only little research exists. The relationship between stress coping strategies and the upbringing style of parents have not been yet investigated. Innovative work consists of comparing psycho-emotional conditions and self-esteem of adolescents with visible and invisible disabilities in their family perspective and in this way finding out the family contribution and influence in forming these characteristics. Two characteristics are supposed to influence adolescents' self-esteem and emotional-behavioral problems and to be opposed to each other – severity of condition, care need and physical dependency on others versus family attitude – upbringing style and stress coping responses of parents and attitudes of sisters and brothers, how they estimate their siblings with disabilities. Results of work can be useful for professionals who work in the area of psychological rehabilitation for families of persons with disabilities.

## **Definitions of terms**

### **1. Psychological problems in disabilities**

Having disability status regardless of the visibility or invisibility of it, often related to psychological peculiarities. These peculiarities can contain low self-competence and behavioral-emotional problems (Urtaikin, Komarova, 1996). In the case of physical disability several factors appear in formation of functional impairment (disturbance): on one hand it is objective physical condition, discomfort related to this condition, care need and on the other hand inadequate family influence – inability to solve the problem, trials to infantilize the disabled member of family. It is difficult to accept a person with disability as for society so for family (Batshaw,

Perret, 1996). Cerebral palsy and epilepsy are in the list of mostly stigmatizing conditions (Igor, 1992). This fact is strengthens resignation of diagnose and child by family.

## **2. Definitions of cerebral palsy (visible disability) and epilepsy (invisible disability)**

**Epilepsy:** In accordance with statistics of different countries epilepsy is quite frequent in the population. Per every 1000 infants (newborn baby) there are 3-5 cases of epilepsy (Carr, 1999).

The International League against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE): Epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, **cognitive, psychological, and social consequences of this condition**. The definition of epilepsy requires the occurrence of at least one epileptic seizure (Fisher, Van Emde Boas, Blume, Elger, Genton, Lee, Engel, 2005).

**Cerebral palsy:** Based on different data for every 1 000 infants there are 3-5 children born with cerebral palsy. Within the male and female population there is the same frequency of cerebral palsy (Carr, 1999). Cerebral palsy (CP) is an umbrella term for a group of disorders affecting body movement, balance, and posture. Loosely translated, cerebral palsy means “brain paralysis.” Cerebral palsy is caused by abnormal development or damage in one or more parts of the brain that control muscle tone and motor activity (movement). Common to all individuals with cerebral palsy is the difficulty to control and coordinate muscles. Mental retardation, seizures, breathing problems, learning disabilities, bladder and bowel control problems, skeletal deformities, eating difficulties, dental problems, digestive problems, and hearing and vision problems are often linked to cerebral palsy (Ratanawongsa, 2005).

Several outputs of personality can be impacted by having chronically illness or disability. These are: 1. Cognition (Self-esteem); 2. Emotions; 3. Behavior.

## **3. Psychological peculiarities in puberty related to disability**

### **Self-competence**

Puberty is a risk-factor for the onset of depression in many kinds of chronic diseases by the reason of being different from peers, because conformity is important in this period. **We should underline certain differences between visible and invisible disabilities in this period.** McCoy (1982, p. 159) states: “Defects, deviations, disability or chronic disease can cause strong

emotional influence on adolescent and often causes deficient (inferior) self-perception and depression”. In accordance with one point of view persons with visible disabilities have more depression and self-esteem problems, than persons with invisible disability. Offer, Oslov and Howard (1984) found out that adolescents with cystic fibrosis have many more problems with self-esteem, than adolescents with cancer or asthma, because fibrosis influences physical grow and sexual development (Boice, 1998).

There is also opposing data: Goffman (1963) distinguishes visible and compromising conditions. The last one allows the person with the disability to pretend that he is not ill. The reason for this anxiety is fear that friends and strangers will notice this condition. Thompson and Gustafson (1996, p. 35) suggest that “visualization is very important in relationship with peers, because difference often determines reaction in surrounding... It is a paradox, but children with normal appearance often have bad adjustment skills”.

*Researches related to self-esteem of adolescents with chronic diseases mostly cover epilepsy. There are only a few investigations about cerebral palsy (PubMed 1985-2006). Researchers of self-esteem and self-confidence discuss two different opinions: one of them states that self-conception of adolescents with disabilities are not distinguished from the ones without disabilities. One of them proves that disability does not cause different self-esteem. Another opinion suggests that persons with disabilities have lower self-esteem than those without disabilities, especially girls with regards to physical self-esteem. Other researchers found out that persons with disabilities have higher self-esteem in social and cognitive spheres than population without disabilities.*

1. Shields, Murdoch, Loy, Dodd, Taylor (2006) analyzed data of 1355 researches and found out that though disabled girls have lower self-esteem on features like physical appearance, social acceptance, athletic abilities and academic achievement, researchers suppose that these girls only represent a **risk group**, because there are no evidences which can prove that girls with cerebral palsy have lower self-esteem than others. Teplin, Howard, O'Connor (1981) investigated self-conception and self-esteem of pupils in inclusive classes and state that there is no negative influence on those pupils' self-esteem by class-mates and teachers attitudes.

2. Another group of researchers suggests that there is **different data for adolescents with and without disabilities**. Appleton, Minchom, Ellis, Elliott, Boll, Jones (1994): Adolescents with disabilities estimate themselves less competent in the following spheres: academic, athletic and social competences and **less supported by class-mates** than their other

peers. Girls with disabilities give importance to physical appearance, which is most tightly related to self-esteem. King, Shultz, Steel, Gilpin, Cathers (1993) research concerning cerebral palsy, spine bifida indicated problems in the same areas and additionally found out that **social competence** is very important for stability and independence formation for **physically disabled, who are dependent on others**.

Research of Magill, Hurlbut (1991) about adolescents with cerebral palsy showed that girls with cerebral palsy have lower self-esteem than boys with cerebral palsy, also in relation to girls and boys without disability.

Margalit, Heiman (1983) compared 20 anxiety levels and self-conception of adolescents with epilepsy with adolescents without epilepsy and those with learning disabilities. Adolescents with epilepsy showed higher level of anxiety and self-disappointment than the other two groups.

Stafstrom, Havlena (2003): patients with epilepsy expressed themselves in pictures and researchers did not find out the existence of **depression**. Research of Adamson (2003) showed the opposite: disabled adolescents demonstrated higher self-esteem and self-image than those without disabilities. In study of Armstrong, Rosenbaum, King (1992) children with visible physical disabilities were considered to be a risk-group in relation to **emotional-behavioral problems**. They indicated lower rates on physical competence than those without disabilities. Though they didn't perceive themselves less competent in social and cognitive spheres, they had less friends and in sociometric scale received lower rates than healthy children (Mean of children with disabilities=2.06, without disability Mean=2.39,  $p=0.01$ ).

*Some studies relate inadequate self-esteem and self-competence to the severity of the disease and suggest that those characteristics are lower for the population with disabilities in comparison to the population without disabilities.* Collings (1990) suggests that **self-perception** and own condition perception of people with epilepsy is tightly related to general well-being and seizure frequency. In the study of Raty, Soderfeldt, Larsson, Larsson (2004) **disease severances** are significantly related to self-conception: severe disease related to less awareness and low self-esteem and negative attitude toward epilepsy.

*In accordance with some investigations low self-confidence and self-esteem are related to poor social competences.* Allan Colver and SPARCLE group's study (2006) of 8-12 adolescents with disabilities in 8 European regions highlighted low self-esteem and **communicational problems**. Magill-Evans, Restall (1991) longitudinal study did not find significant differences between persons with cerebral palsy and without disability in adolescence

and adulthood. There were differences between girls' self-esteem in adolescence, but not in adulthood. Demographic data analysis showed that subjects with disabilities indicate **relationships and experience** like reasons for change.

### **Behavioral and emotional problems**

*Having behavioral disturbances in persons with disabilities is an issue for discussion. One group of researchers supposes that there are more behavioral problems in persons with disabilities rather than in those without disabilities. Other studies prove opposite data. We should take into consideration different triggers for behavioral problems.*

*1. The first approach acknowledges a difference in behavioral problems between persons with and without disabilities and states a special importance of social and especially family support network.* Dodrill, Breyer, Diamond, Dubinsky, Geary (1984) found out in their study in the US that the main problems for persons with epilepsy were emotional, interpersonal and financial support. The epilepsy study by Kurokawa, Matsuo, Yoshida, Takaki (1983) in Japan highlighted almost all kinds of problems: emotional, communicational and daily activities. Research of McDermott, Coker, Mani, Krishnaswami, Nagle, Barnett-Queen, Wuori (1996) showed that children without family and society support have more behavioral problems than children with disabilities. In accordance with Bjornaes study (1988), emotional (anxiety) problems are rising as a consequence of neglect by society. Appleton, Ellis, Minchom, Lawson, Boll, Jones (1997) found out that besides low self-acceptance and depression, persons with spina bifida are a **suicide-risk group**. Suris, Parera and Puig (1996) also proved emotional problems, upset (negative mood), sadness, pessimism, suicidal thoughts and personal problems of girls with a chronic form of the disease. Molteno, Molteno, Finchilescu, Dawes (2001) in Capetown (south Africa) analyzed 355 children with disability and found out more **behavioral** (antisocial, deviant) problems with boys than girls and frequency was higher in epilepsy in comparison to those with cerebral palsy. Those who had ambulatory treatment indicated a higher level of **antisocial behavior** than those in a clinic who were expressing anxiety.

Breslau, Marshall (1985) observed higher levels of aggression stability and duration of children with cerebral palsy, cystic fibrosis and other multiple physical anomalies in comparison to healthy children. Kim (1991) stated that people with epilepsy are a psychiatric risk-group compared with adolescents with other chronic diseases, because 1 from 3 adolescents indicates

academic, emotional, behavioral and family problems. In a study by Clench-Aas, Roy, Mowinckel, Gjerstad (2006) adolescents with epilepsy showed a **high level of psychiatric symptoms** in comparison to the normal population. Keene, Manion, Whiting, Belanger, Brennan, Jacob, Humphreys's (2005) study highlighted problem behavior of 6-18 year old children with epilepsy, related to **learning difficulties** in comparison to children without disabilities. Hoare, Mann (1994) investigated the relationship between self-esteem and behavioral adjustment in two groups of children with chronic disease, one with epilepsy and the other diabetes (Harter and Achenbach Questionnaires) and found that children with epilepsy showed more **behavioral problems and lower self-esteem** than those with diabetes.

*2. The second approach did not find differences between adolescents with chronic disease and ones without disease.* Investigation of Lewis, Tonge, Mowat, Einfeld, Siddons, Rees (2000) showed that adolescents with mental delay and epilepsy do not demonstrate a higher rate of psychopathology in comparison to other adolescents.

#### **4. The role of family factors in influencing psychological peculiarities**

*One approach estimated behavioral and emotional problems in parent-child perspective.* In the study of Austin, Dunn, Johnson, Perkins (2004) if a family has any doubt about the child's discipline improvement, it increases the child's behavioral problems and vice-versa: parent's distraction grows together with the increased child's emotional-behavioral problems. Komender (1989): On the basis of these investigations it was found that epilepsy in children had an influence on the functioning of the child and its family. This vicious circle mechanism was found in several cases. The child's disorder caused negative reactions by family members, which in turn unfavorably influenced the child's functioning and behavior. According to the author these statements are of great importance for psycho-social therapy. Sbarra, Rimm-Kaufman, Pianta, Dodrill, Beier, Kasparick, Tacke, Tacke, Tan (2002): Psychosocial problems in a groups of adults with epilepsy from Canada, Finland, Germany, and the United States were evaluated by the Washington Psychosocial Seizure Inventory. At the forefront for each group were emotional problems, followed by concerns pertaining to adjustment to the seizures themselves. In all cases, few problems were found in matters pertaining to family relationships and medical care.

## 4.1. Stress

Recent studies have highlighted families of children with disabilities experience more stress than other families. However, there are opposite investigations: Thompson and Gustafson (1996) found that those families do not have more stress in general, but more everyday stress. In accordance with Rudolf H. Moos (1993), author of the CRI, new negative life events can change a person's coping strategies.

Parents of children with disabilities do not have different coping strategies; part of researchers state approach strategies, and another part is proving an avoidance strategy. However, there are no systematic investigations on cerebral palsy and epilepsy issues. Parents of children with myelomeningocele (spinal cord structure anomaly) prefer to use the response "Believe in God" (praying), which is an avoidance response (Samuelson, Foltz, Foxall, 1992). By Hodgkinson, Lester (2002) state in their investigation, that the main challenge for mothers of children with disabilities was to take responsibility for caring, awareness of the genetic nature of it. At the same time, their major response is seeking guidance and support (SG). Cayse (1994) emphasize approach responses of fathers who have children with cancer.

**Family-based conception of Stress and coping.** 260 families were observed during 12 months and it was revealed that mothers while expressing higher level of functional disturbance use mostly avoiding strategies. But at the same time it was observed that women are more influenced by ongoing events rather than by primary coping strategies. In men coping strategies were determined not by events, but by a priority coping style. So, women's coping changes according to the situation whilst men's coping styles stay stable despite the situation. The people's functioning can change live context and can be expressed in new negative events, which change coping responses and influence further adjustment (Moos, 1993).

In a study by Hryshko-Mullen and Dobow (1992) mothers of preschool age children who do not follow approach strategies refer to more severe upbringing methods.

The study of Hodgkinson et al. (2002) suggests that major stresses for many mothers of children with Cystic fibrosis (CF) are felt in the middle in terms of decision-making particularly concerning the genetic implications of CF, the burden of responsibility for parenting a child with a chronic disease, and coming to terms with a personal change in identity. The most commonly used coping strategy was seeking support from others including nursing professionals.

The purpose of the Cayse (1994) study was to identify the stressors and coping strategies of fathers of children diagnosed with cancer. The fathers reported that their most common

concern was their "child's future", followed by their "child's health." The most common coping strategy was "to pray", a strategy that was also reported as being the most helpful. The next most common strategies were "to get information", "look at options", and "to weigh up choices". These strategies are problem-oriented and are consistent with the research findings of others. No planned comparisons were statistically significant at the 0.05 level nor were any additional differences detected.

Samuelson, Foltz, Foxall (1992): This pilot study examined parents of children with myelomeningocele (MMC). Help related to play was the most frequent need among mothers. Having faith in God was the coping strategy mentioned most often by both parents.

## 4.2. Upbringing

Upbringing is one of the important family functions. Like several studies highlighted (Dodrill, Beier, Kasparick, Tacke, Tacke, Tan 1984), mostly excessive care is conducted given to children with acute and chronic diseases. These diseases make children more valuable for parents. In families of children with disabilities were found pathological features of upbringing (Kiseliova, Akimova, 2001). For the majority of families of children with disabilities it is typical to have different disharmonic upbringing styles, which are accompanied by a low level of communication (Bocharova, Kazarina, Sidorov, Soloviov, 2000). These families have specific features, which often characterizes as a hyper-protection and hyper-inclusiveness of family members in the lives of each other. In accordance with Ratter (1970) there are two disharmonic upbringing styles, which influence children's **self-esteem** and cause a formation of personality with **poor adjustment competences**. Those can be: Hyper-protection or Resignation upbringing. In our previous investigation (Osipova, 2006) on family upbringing style was dominating "compliant hyper-protection". Levi in the past 20<sup>th</sup> century stated that when parents reinforce the child's infantile behavior, restrict his social contacts and do not involve them in the household, those children have problems in communication with peers, are slow to adjust innovations and are passive and dependent on others. Often children with **emotional and behavioral problems** are weak and unprotected out of house, because they get everything they want without any obstacle at home and their **problem solving competence is very poor** (Kondrashenko, Donskoy, Igumnov, 1999, p. 13-14).

Systematic evaluation showed that children with chronic diseases often have **emotional and behavioral disturbances**. It is not a result of disease, but related to special relationships within the family that cause a lack of certain competences such as: social and cognitive

competence. It can be the result of hyper-protective or resignation upbringing (Dodrill et al., 1984). Adolescents in the US feel lonely which is caused by poor social competences (Zullig, Valois and Drane, 1997).

*Having certain disabilities makes the person with disability weaker than his peers. Lack of surrounding accessibility maintains this complicated condition for persons with functional anomalies. Eastern upbringing style should be also taken into consideration. According to it, parent-child affiliation is maximally prolonged. But the most severe burdening factor for the child's helplessness is an exaggerated perception of his condition* (Boice, 1992).

### **4.3. Siblings' attitudes**

Children follow their parents' example. If parents treat their child with a disability as unimportant, so do the siblings without disability and vice-versa: if parents are proud of their child with a disability, another child is also proud of his sibling.

Children without disability are disrupted between the protections of the sibling with disability and need to be accepted by peers, because peers often make fun of the sibling with disability. Such attitudes of society often can be reflected in the same attitude of siblings: children without disability can believe their siblings are inferior or disabled (Finnie, 1997).

## **5. Relation between Stress coping and Upbringing style**

There are almost no evaluations revealing a relationship between stress coping strategies and upbringing styles. Within research of the last 15 years we found only one on this issue. We should also underline that this investigation is not about cerebral palsy or epilepsy, but autism. Sivberg (2002): this study focused on the coping strategies of parents' with children with autistic spectrum disorders (ASD) and the relation between these strategies and parenting styles. Main results distinguished significant ( $p < 0.001$  to  $0.003$ ) differences between autistic children's parents and the control groups. The M level of coping strategy was much higher for the CG than for the EG. SOC showed a stress-reducing effect in both the EG and CG. PIL-R explained 50% of the variance in SOC for the EG and 33% for the CG. *The only significant gender difference in the EG was on SOC indicating a higher sense of coherence among the fathers and probably an indicator of a stronger burnout effect of the mothers.*

# Study

## *Statement of the Problem*

Psychological peculiarities related to disabilities such as behavioral-emotional problems and self-esteem for a long time is in a focus of investigators. Those issues became especially important since psycho-social rehabilitation programs for children and adolescents with different kinds of disabilities are widely spread around. Though most of the theories prove that rehabilitation of children should be conducted in family environment, parents should be involved in early rehabilitation programs, much work is still required to improve conceptualization and definitions of rehabilitation-prevention. This rehabilitation-prevention process needs to address family issues because a great part of child psychological problems are inseparable from family functioning.

An important point is to know what influences the formation of psychological problems: physical restrictions, care needs, dependence on others or special relationships and attitudes in the family.

One approach gives us clear information on psychological problems of children with disabilities, which are caused by disharmonic upbringing styles – hyper-protective, resignation or in “perspective of disease”. Such upbringings cause a feeling of helplessness, physical dependence on family members and inability to make decisions independently. Mechanisms of disharmonic style in children with visible and invisible disabilities and their relationship with real physical restrictions and intensive care needs were not purposefully investigated.

In accordance with Moos (1993), author of CRI (Coping Responses Inventory), new negative life events can change our coping strategies.

There is no empirical evidence which has documented the correlation between stress coping, upbringing style of parents and psychological problems of child with disability. There are no investigations either, which study parents’ stress coping responses influence on the child with disability.

***Hypothesis:*** Psychological problems in adolescents with disabilities are not impacted by physical restrictions related to disability and intensive care need, but by special attitudes and influences of the family, poor social support network and lack of awareness about the condition (disease).

## **METHODS**

*The goal of the investigation* was to research impact of family attitudes, upbringing style and parents' stress coping responses, social support network and awareness about condition on self-esteem and emotional-behavioral problems in adolescents with visible and invisible disabilities.

### ***Investigation objectives:***

1. Study personal and family characteristics and social-demographic data in control group (adolescents without disability):
  - study adolescents' behavioral and emotional issues using Achenbach's Scale.
  - study adolescents' self-esteem using a questionnaire created by us.
  - study how adolescents are perceived by their siblings using the same questionnaire.
  - study parents' upbringing style using Varga and Stolin's check-list.
  - study parents' stress coping strategies using Moos's Inventory.
  - study social relationships using a questionnaire created by us.
2. Conduct the same spheres research in groups of adolescents with visible and invisible disabilities – cerebral palsy and epilepsy. Study the awareness level using a questionnaire created by us.
3. Compare the data collected from adolescents with cerebral palsy and their families with those from adolescents with epilepsy and their families; compare the data of adolescents with disabilities and their families with those of without disabilities and their families.

### ***Participants:***

The study was conducted in Georgia. 12-16 years old adolescents, their parents or primary care-givers and siblings were recruited. The sampling frame (experimental group) for the study included cerebral palsy and epilepsy groups' respondents, who were members of different organizations of/for disabled. In study participated 106 adolescents with disabilities – 64 with visible and 42 with invisible disabilities. Adolescents without disabilities were 62. The experimental group included 132 parents: 82 mothers and 50 fathers of adolescents with disabilities (55 mothers and 35 fathers of adolescents with visible disability; 27 mothers and 15 fathers of adolescents with invisible disability); the control group included 111 participants: 61

mothers and 50 fathers of adolescents without disabilities. 30 siblings of adolescents with disabilities and 42 of those without disability were recruited.

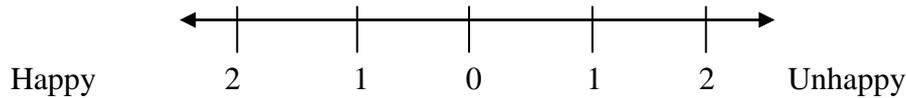
	<b>Experimental group</b>		<b>Case Controls</b>
	<i>Cerebral Palsy</i>	<i>Epilepsy</i>	
<b>Girls</b>	29	22	30
<b>Boys</b>	35	20	32
<b>mothers</b>	55	27	61
<b>fathers</b>	35	15	50
<b>siblings</b>	31		43

### ***Procedure***

Parents of experimental group were chosen in daycare centers and in a week-end school in nongovernmental organizations as well as, in schools with inclusive education. They filled out questionnaires and tests at the center or took them home. Some were visited at their home places and filled the questionnaires together with the investigator. Control groups were chosen in schools. The investigator explained the administration the goal of the investigation and then teachers gave explanations to parents at parents’ meetings. Participation in the investigation in both experimental and control groups was voluntary and participants did not receive any financial compensation. The given tests were confidential; the only features to be marked were gender, education and age of the parent, also child’s gender, siblings’ gender and age. The tests were completed by respondents of control group in their homes and returned.

### **The investigation inventory included:**

**1. Adolescent’s self-esteem** was measured by using the questionnaire created by us which included 15 antonym couples. Each couple contained positive and negative features. The positive was situated at left side, the negative – at right. In the middle were gradations of these features and neutral estimation. Assessment was conducted on 5-scores rating scale, where measures varied from “Very Poor” (number 1), to “Excellent” (number 5) rating scales. Statistical measures were done from left side: number 5 – strongly expressed positive feature, number 4 – averagely expressed positive feature, number 3 – neutral, number 2 – averagely expressed negative feature, number 1 – strongly expressed negative feature. For simplifying procedure for adolescents, we marked number 5 at visual questionnaire as 2, 4 as 1, 3 as 0, 2 as 2 and 1 as 1.



Adolescents had to estimate themselves only with one feature in each couple. At the picture is given example of visualization of the antonyms. The instruction was: “Mark at the left or right side number 2 if feature strongly characterizes you, number 1 if averagely characterizes; number 0 is neutral”. So, for each feature number 5 means very high self-esteem, 4 – high, 3 – average, 2 – low, 1 – very low. The Average self-esteem of every adolescent was the Mean of their all 15 estimations. The antonyms were:

1. Happy – Unhappy;
2. Lucky – Unlucky;
3. Smart – Foolish;
4. Beautiful – Unbeautiful;
5. Plodding – Lazy;
6. Strong – Weak;
7. Healthy – Ill;
8. Loving – Distant;
9. Independent – Dependent;
10. Open-hearted - Reserved;
11. Attentive – Inattentive;
12. Fair – Unfair;
13. Communicative – Uncommunicative;
14. Brave – Shy;
15. Quiet – Nervous (anxious).

**2. Adolescent’s problem behavior was measured by Achenbach’s Standard Test:** CBCL 4/18 – Child Behavior checklist, Parents’ frame. CBCL consists from 2 scales – competence and problems. We used only the problem scale, which contains 118 statements and gives information on any problem for a certain age and gender of child. The scale contains 3 ranges, which gives opportunity to reveal problems intensity and frequency.

Summarizing of scores for concrete statements gives information on certain problems: 1. Withdrawn. 2. Somatic complaints. 3. Anxious/depressed. 4. Social problems. 5. Thought problems. 6. Attention problems. 7. Delinquent behavior. 8. Aggressive behavior. Combination of 8 scales provides the total score for behavior. Internal problems consist from summarizing of

I, II and III scales, external problems – VII and VIII. So, internal problems are kind of emotional problems and external – behavioral problems. T scores 60-63 are borderline clinical range, above 63 – clinical range. We did not explore concrete problems on 8 scores, but total internal and external problems.

**3. Estimating demographical and social data:** the questionnaire created by us includes the following characteristics: 1. Who completes the form (mother, father, grandmother, etc.); 2. Child's gender; 3. Family average monthly income.

Family social relationships: 4. How often do you go for visits (everyday, 3-4 times a week, once a week, once during 2 weeks, once a month or rarely); 5. How often do you have guests (everyday, 3-4 times a week, once a week, once during 2 weeks, once a month or rarely); 6. What for do you spend the major time during the day (open question. Answers were categorized in according with frequencies); 7. Do you have free time for yourself (rarely, moderately, often); 8. Do you have time for relationships with another child (rarely, moderately, often); 9. Do you (parents) have time for each other (rarely, moderately, often); 10. Housing place (in square meters).

**4. Estimating related to diagnose awareness level and needs.** Included the following open-ended questions: 1. Child's diagnosis; 2. What do you know about the disease? 3. What are course, treatment and prognosis of disease? 4. Where do you receive information about it from? 5. Do you use medical service and how often (averagely a year)? 6. Did you benefit from governmental social programs and how many times? Who gave you information about it? 7. What kind of support should exist for such children and their families?

**5. The Coping Responses Inventory – Adult form (CRI -Adult)** (Rudolf H. Moos, PH.D, 1993) measures eight different types of coping responses to stressful life circumstances. For these responses it uses eight scales: Logical Analyses (LA), Positive Reappraisal (PR), Seeking Guidance and Support (SG), Problem Solving (PS), Cognitive Avoidance (CA), Acceptance of Resignation (AR), Seeking Alternative Rewards (SR) and Emotional Discharge (ED). The first four scales measure approach coping; the second set of four scales measures avoidance coping. The first two scales in each set measure cognitive coping strategies; the third and fourth scales in each set measure behavioral coping strategies. The significant T-score ranges and appropriate interpretive statements for each are the following:

≤ 34 – Considerably below average

35-40 – Well below average

41-45 – Somewhat below average

46-54 – Average

55-59 – Somewhat above average

≥ 66 – Considerably above average

**6. Parents' Attitudes Checklist** (Varga, Stolin, 1999). In accordance with Stolin and Varga, there are 5 styles of upbringing, which are based on different attitude systems. 1) Resignation (negation), which expresses in abusing the child; 2) "Hyper-protective attitude", which is resonating in "Authoritarian hyper-socialization" and imply restrictions of child's rights, opinions, behavior and independence; 3) Cooperation – "Behavior Social Desirability" is respecting child and supporting his independence; 4) Symbiosis – trial to infantilize the child, stick him to him/herself and increase anxiety, when the child tries to separate from his parents. In this case the child is treated like weak and helpless; 5) "Disabling" style, also named "Little Failure", when the parent tries to present his own child like incompetent, socially and personally weak, unprotected, limiting his rights and efforts to protect him from the surrounding. The only harmonic style is "Behavior Social Desirability", the four others belong to disharmonic styles.

**Statistical methods:** Data were analyzed by using SPSS for Windows version 12 (statistical package for social sciences). For correlation analyze was used Pearson's correlation coefficient (r). To examine variations between groups, tests with significance were made with  $\chi^2$  for categorical variables, for the statistical significance of the difference between two samples mean Student's t-distribution.

## Results

### *Sample Characteristics*

The focus of interest was to follow up the process of formation of psychological problems in adolescents with disabilities. For this target we made comparative studies of visible and invisible disabilities. For assessing patterns of psychological problems we tested behavioral and emotional problems, also self-esteem of the adolescents. In order to find out if psychological disturbances are due to physical restriction or to attitudes pertaining to family, we assessed the adolescents' estimation by siblings and parents' upbringing style. In accordance with our hypothesis, psychological peculiarities of adolescents with disabilities are influenced not by physical condition, but by family's special attitudes. We supposed that such characteristics of parents like upbringing style and coping should correlate with each other. We

investigated parents' coping strategies in social contexts: we collected information on frequency of social contacts with society and with own children. We considered awareness level of disease and inclusiveness to social and medical care like most important variables. Afterwards data of adolescents with visible and invisible disabilities as well as of their families were opposed to each other and to data of those without disabilities.

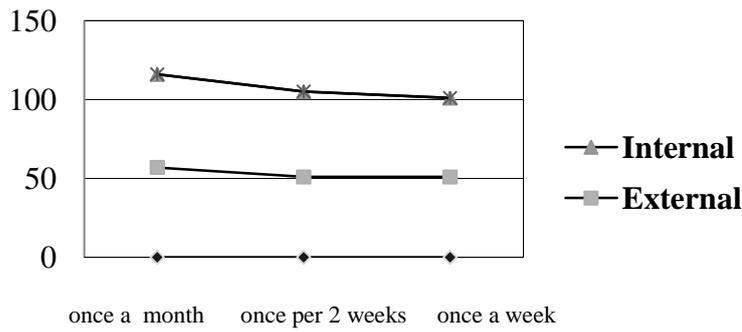
### ***Behavioral and Emotional problems***

Adolescents with disabilities showed a high level of affiliation with parents and the anxiety level is rising, when parents are not by their side. This occurs despite of the fact that parents do not leave their children for visiting friends and have guests also quite rarely in comparison to parents of adolescents without disabilities: parents of children without disabilities go out mostly once a week (Valid Percent=42.7) and parents of children with disabilities once per two weeks (Valid Percent=74.8). Parents of children with disabilities showed that have guests mostly once a week (Valid Percent=31.1). Parents of children without disabilities also have mostly guests once a week, but with higher frequency (Valid Percent=42.5).

In adolescents with disabilities external (M=74, SD=0) and internal (M=76, SD=0) problematic behaviors are above clinical range in those adolescents, who's **parents go out** every day (60% of cases). In the group of adolescents without disabilities we have the opposite tendency: there is no relation between absence of parents and problematic behavior (the score does not reach a clinical range threshold when they are going out), but the level is rising proportionally with parents' presence frequency rising at home. Table 1 and Diagram 1 are showing internal and external problems' Mean scores for 54.1% of adolescents without disabilities in accordance with frequencies of outgoing of parents.

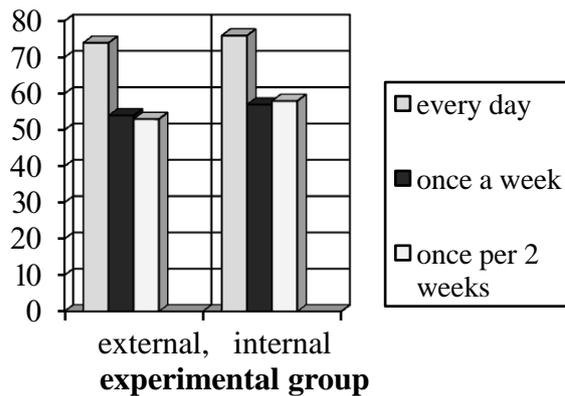
		<b>External problems</b>	<b>Internal problems</b>
<b>Once a week</b>	Mean	50.7059	50.1176
	N	17	17
	Std. Deviation	9.73887	9.92398
<b>Once per 2 weeks</b>	Mean	51.3333	53.6667
	N	36	36
	Std. Deviation	10.29840	7.23089
<b>Once a month or less</b>	Mean	57.0000	59.0000
	N	1	1
	Std. Deviation	.	.

**Table 1.** Control group. Problems related to frequency of outgoing of parents.

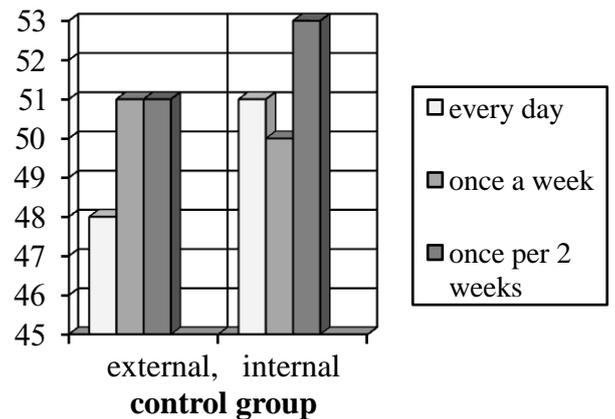


**Diagram 1.** Control group. Problems related to frequency of outgoing of parents.

Diagram 2 and 3 show comparative picture of experimental and control groups related to outgoing of parents.



*Diagram 2.*



*Diagram 3.*

There is almost the same score of internal problems for adolescents with disabilities, whose families **have guests** very rarely (once a month or less,  $M=67.7$ ,  $SD=7.92$ ) or very often (3-4 times a week,  $M=65.3$ ,  $SD=5.03$ ). In control group internal problems level for 54.1% of the adolescents is rising up to clinical level ( $M=63.75$ ,  $SD=8.5$ ) when they have guests very rarely – once a month or less. Diagrams 4 and 5 show internal and external comparative picture in experiment and control groups.

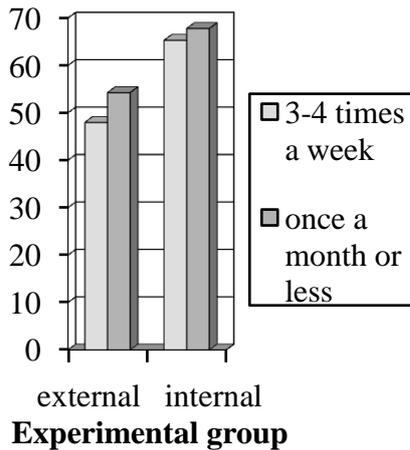


Diagram 4.

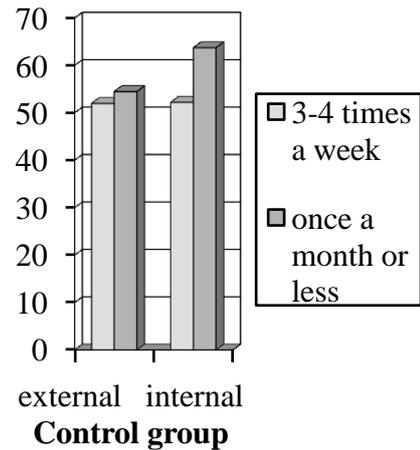


Diagram 5.

Problem behavior of adolescents with disabilities appear (internal problems  $M=59.1$ ) when their parents use the major time for family; but as internal ( $M=71$ ), so external ( $M=73$ ) problems are at a clinical range, when parents use their time mostly for children's upbringing. In adolescents without disabilities external problematic behavior is also at a borderline clinical area, when parents use major time for child's upbringing ( $M=62$ ). We did not find significant difference between adolescents with and without disabilities in external behavior. Diagrams 6 and 7 show internal and external problems in experiment and control groups related to priorities for spending time by parents.

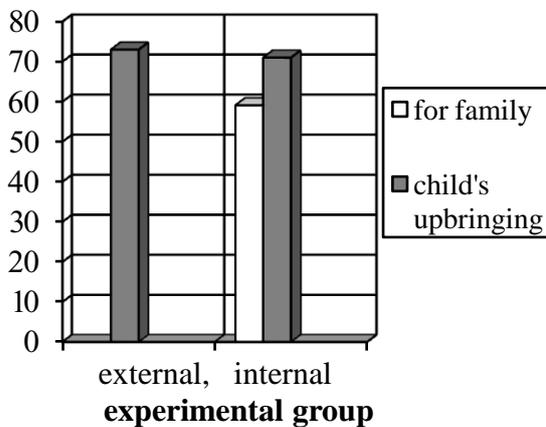


Diagram 6.

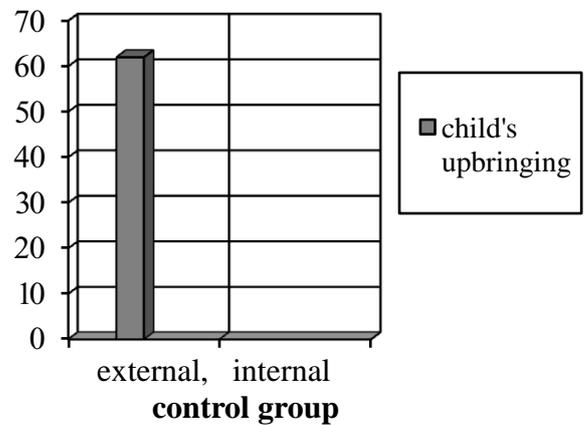


Diagram 7.

60% in the group of adolescents with disabilities were found out that internal problems are at a borderline clinical range, when parents have often time for themselves ( $M=62.6$ ,  $SD=8.44$ ) as well as when they have time for themselves rarely ( $M=62.5$ ,  $SD=9.4$ ). In controls, external problems are mostly expressed, when parents do not have a time for themselves, but the data is in normal range ( $M=55.7$ ,  $SD=9.7$ ).

We found out that adolescents with disabilities show significantly low level of external problems, when **parents have rarely time for each other** (M=47.7, SD=10.7), but borderline clinical level of internal problems, when they have time for each other often (M=61.7, SD=8.7). In the control group internal (emotional) problems occur (M=55, SD=5.3) when parents have time for each other rarely.

When parents of adolescents with disabilities treat the child's disease as a major problem, this does not cause problematic behavior of adolescents. 35% of parents indicated as the basic problem the child's disease and adolescents' internal (M=56) and external (M=58) problems are in the normal range. Financial problems is in second position indicated by parents, despite the fact that majority of parents of children with disabilities (32%) prefer financial support. But when parents indicated **financial** like basic **problem** which is given in 13% of parents, adolescents internal problems scores are in a borderline clinical range (M=63). The internal problems of adolescents with disabilities rise during **family conflicts** (M=71), which we could observe in 25% of cases.

In families of children without disabilities 22% of parents indicated a **financial problem**, but adolescents' behavior are not in a borderline clinical area. Diagrams 8 and 9 present major problems of parents in experiment and control groups.

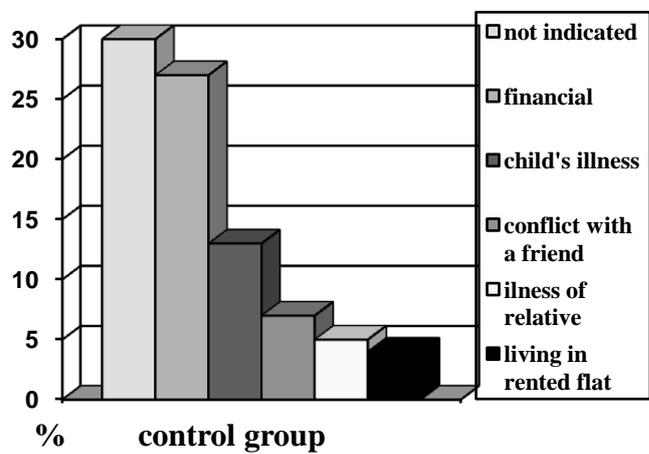


Diagramm 8

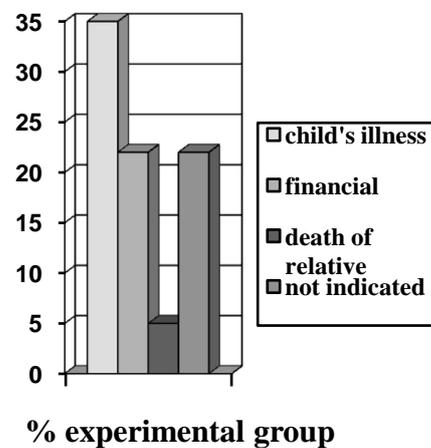
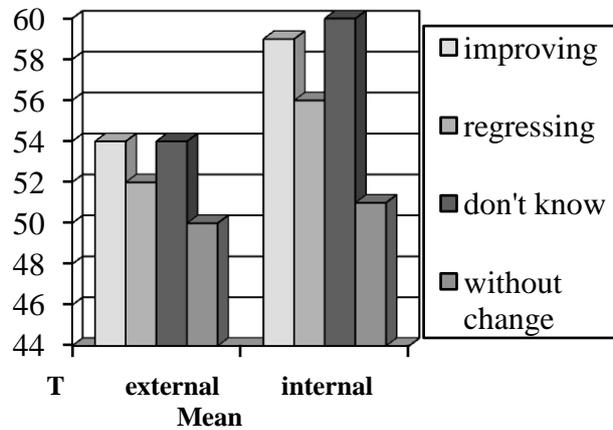


Diagramm 9

It was found that 32% of parents of children with disabilities treat their children's condition as progressing towards better condition, but their children's behavior is nearby borderline of clinical area (M=58.76). 17% of parents suppose that the condition is improving and children' internal behavior cannot be treated like clinical (M=56.63). **Overall, unclerness**

about child's prognosis or improving promise cause emotional problems (M=60). Data are given at Diagram 10.

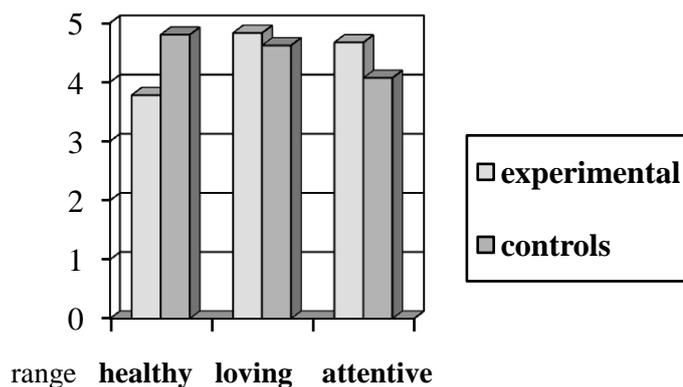


**Diagram 10.** Experimental group. Adolescents internal and external problems related to expectations of parents towards children' condition.

### *Self-esteem*

We did not find out a statistically significant difference between data of adolescents with visible and invisible disabilities, gender and between sisters' and brothers' perceptions.

Between adolescents with and without disabilities were indicated the following differences: adolescents without disabilities treat themselves as healthy (on 5 scores scale average score is 4.8) rather than adolescents with disabilities (average score is 3.78), difference is statistically valid ( $p=0.000$ ). Adolescents with disabilities are higher in assessing themselves in feature "loving" (4.83) while those without disabilities esteem themselves with lower score (4.62), statistical validity is  $p=0.000$  and more attentive (4.67, controls – 4.07,  $p=0.000$ ). Data are presented at Diagram 11. It's meaningful that there were insignificant scores of **negative self-esteem** in both groups.



*Diagram 11.* Differences in self-esteem in experimental and control groups.

Ratter (1970) states that **self-esteem strongly influences the behavior**. The child who is self-assured about own abilities has a great chance to obtain successes in his life. This attitude influences his decision.

Though in our investigation there are difficulties in interpreting of direction – if low self-esteem influences emotional-behavioral problems or vice-versa. Adolescents with disabilities, who have **emotional** (internal) **problems**, characterize themselves with features: ill, unhappy and dependent, but the ones, who have behavioral problems, estimate themselves as unfair. It is interesting, that adolescents without disabilities while having behavioral (external) problems, estimating themselves with features: strong, but neurotic, while internal problems – strong and communicative (see tables 2 and 3). We can suppose, that having external (behavioral) problems means externalization of negative feelings, that’s why they feel neurotic, but strong. Emotional problems are cumulated internally and cause such self-perception like unhappy and weak. So, emotional problems cause negative self-esteem more, than behavioral. Though as we stated, the interpreting of the self-esteem peculiarities in adolescents with emotional problems seems to be complicated. **So, in adolescents with disabilities as emotional, so behavioral problems can be related to low and negative self-esteem and this distinguishes those ones from case controls.**

**Correlation between self-esteem and income:** adolescents with disabilities indicate the feature “quiet” when their family has high economical income. Those without disabilities in such cases characterize themselves “communicative” and “brave”. High income makes the adolescent more self-assured. So, according to income and parents’ presence-absence at home with psychological well-being, we can see how much well-being of children with disabilities is influenced by their parents.

Correlations					
		<b>Happy - unhappy</b>	<b>Healthy – ill</b>	<b>Independent – dependent</b>	<b>Fair - unfair</b>
<b>External behavior</b>	Pearson Correlation				-0,34815
<b>Intrenal behavior</b>	Pearson Correlation	-0,42993	-0,38267	-0,33288	

**Table 2.** Correlations between problematic emotional-behavioral problems and self-esteem in experimental group.

Correlations				
		<b>Strong - weak</b>	<b>Communicative - uncommunicative</b>	<b>Quiet - nervous</b>
<b>External behavior</b>	Pearson Correlation	0,315017		-0,42618
<b>Intrenal behavior</b>	Pearson Correlation	0,327147	0,397288	

**Table 3.** Correlations between problematic emotional-behavioral problems and self-esteem in control group.

Differences in estimation of respondents by siblings in experimental and control groups were not found out. But the interesting data was observed within the group of adolescents with visible disabilities. Those, who use wheelchair estimate themselves much competent rather their siblings (See table 4 and diagram 12). But we should acknowledge that the only statistically significant difference is in feature “Brave” ( $t < 0.01$ ). But this data demonstrates the need of further investigations in this direction.

	<b>smart</b>	<b>beautiful</b>	<b>attentive</b>	<b>brave</b>
<b>Adolescents using wheelchair</b>	4.75	4.56	4.94	4.43
<b>Siblings</b>	4	3	3	1

*Table 4*

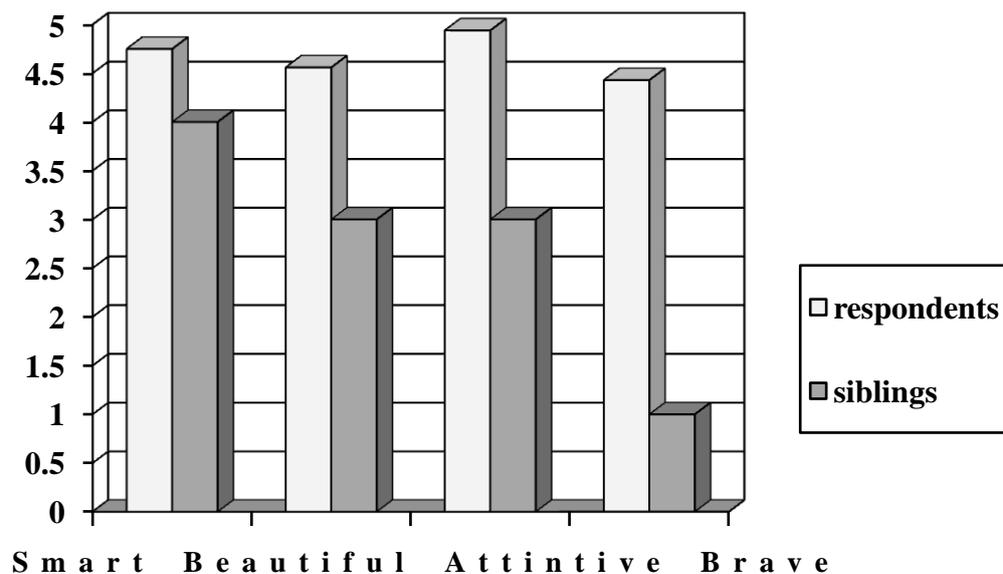


Diagram 12

When parents use **disharmonic upbringing styles**, such as “**Acceptance-resignation**” (psychological resignation of the child), **self-esteem** of adolescents with disabilities includes the following features: **beautiful** (Pearson correlation  $r=0,328489$ , Correlation is significant at the 0.05 level (2-tailed)) and **attentive** ( $r=223$ , Correlation is significant at the 0.05 level (2-tailed)); “**Little failure**” (disabling style) is related to such features as **beautiful** ( $r=0.275$ , Correlation is significant at the 0.05 level (2-tailed)), but at the same time **distant** (Pearson correlation  $r=-.327$ , Correlation is significant at the 0.01 level (2-tailed)). “**Authoritarian Hyper-socialization**” also related to feature **beautiful** ( $r=.230$ , Correlation is significant at the 0.05 level (2-tailed)), also to **strong** ( $r=.265$ , Correlation is significant at the 0.05 level (2-tailed)). It is interesting that upbringing style “**Symbiosis**” causes such feature like **liar** ( $r=.244$ , Correlation is significant at the 0.05 level (2-tailed)). Harmonic upbringing style “**Behavior Social Desirability**” related to the following features: **brave** ( $r=.235$ , Correlation is significant at the 0.05 level (2-tailed)) and **quiet** ( $r=.340$ , Correlation is significant at the 0.01 level (2-tailed)).

In adolescents without disabilities “**Symbiosis**” related to features **happy** ( $r=.241$ , Correlation is significant at the 0.05 level (2-tailed)). The style “**Authoritarian Hyper-socialization**” - **brave** ( $r=-.237$ , Correlation is significant at the 0.05 level (2-tailed)) and **happy** ( $r=.284$ , Correlation is significant at the 0.01 level (2-tailed)). “**Desirability of Social Behavior**” causes features **unbeautiful** ( $r=-.283$ , Correlation is significant at the 0.01 level (2-tailed)). “**Resignation**” – **unbeautiful** ( $r=-.208$ , Correlation is significant at the 0.05 level (2-tailed)).

We can see that upbringing style does not determine self-esteem of adolescents, correlation is not so strong. But we can suppose that for adolescents with disabilities disharmonic upbringing style causes rising of personal features and decreasing of social, for adolescents without disability it is vice-versa.

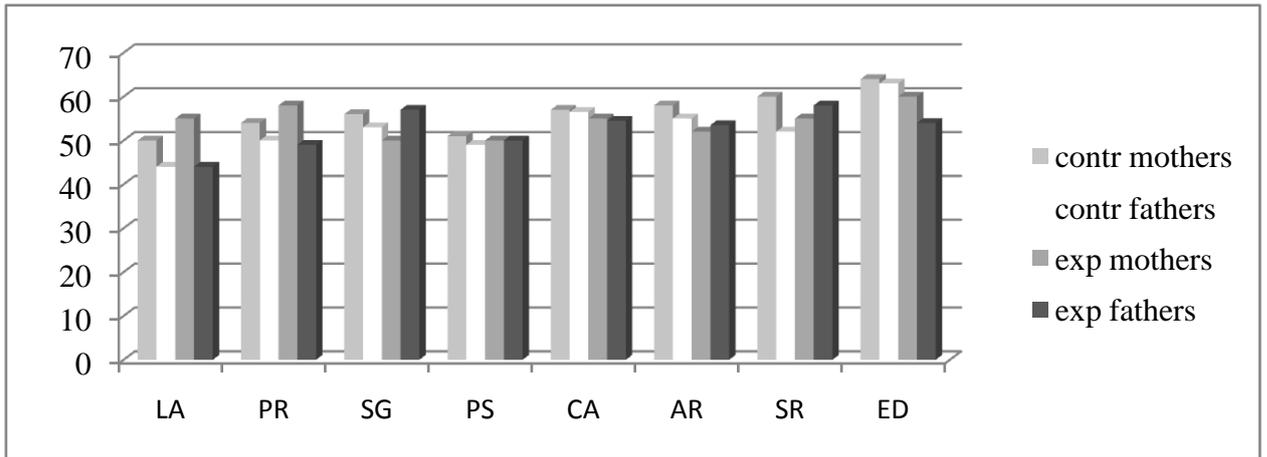
It is important that in adolescents with disabilities a disharmonic upbringing style related to both self-esteem and emotional-behavioral problems: high level of upbringing style “Acceptance-Resignation”, what means strong resignation is related to external ( $r=.437$ , Correlation is significant at the 0.01 level (2-tailed)) and internal problems ( $r=.310$ , Correlation is significant at the 0.05 level (2-tailed)); upbringing style “Little failure” causes external problems ( $r=.288$ , Correlation is significant at the 0.05 level (2-tailed)), but correlation is not so strong like in case of “Acceptance-Resignation” style. For persons without disabilities disharmonic upbringing related only to self-esteem changes, we did not find correlations between upbringing styles and problem behaviors.

### *Stress coping strategies*

As we found out, there are differences between major problems in families of children with and without disabilities: parents of children with disabilities most frequently indicate the child’s illness as a main problem, for parents of children without disabilities the most frequent indication is financial problems.

We didn’t find statistically significant differences between visible and invisible disabilities in stress coping responses. As we can see from diagram 13, mothers of children without disabilities express higher scores as on approach coping as well, as on avoidance responses. But in this case when can talk about the only one statistically valid data - difference was found out in mothers’ data - in the level of Logical analyze, which is  $T=50$  for control group mothers ( $SD=12.13$ ) and  $T=44$  for experimental groups ( $SD=10.12$ ) ( $\chi^2=4.11$ ,  $p<0.001$ ).

Fathers of children with disabilities follow more Seeking Guidance and support (SG), Acceptance of Resignation (AR) and Seeking Alternative Rewards (SR) responses, but this is only a tendency, which is not statistically proved.



**Diagram 13.** Stress coping strategies of mothers and fathers of children with and without disabilities.

We found a certain correlation between **self-esteem of adolescents with disabilities and parents' stress coping responses**. When parents mostly use avoidance strategies, children treat themselves as unhappy, foolish, lazy, ill and distant. When parents use approach responses, adolescents estimate themselves lucky, fair, communicative, and quiet. It is interesting that when parents use *Social ways of Approach* responses such as Seeking Guidance and Support, adolescents feel unlucky and reserved. Results are given in Table 5. Overall, we can conclude that *self-esteem of adolescents with disabilities depends not so much on whether parents try to solve the problem or not, but how they try to solve it – socially or independently*. The less a social way is used, less problems it causes. But as correlations are not high, we can just suppose about it.

In families of children without disabilities coping strategies do not influence adolescents' self-esteem, positive and negative features are mixed.

Afterwards, there is a different situation between family influence on adolescents in families of disabled and without disabilities. In families of adolescents without disabilities there is no precise tendency in adolescents' self-esteems when parents use approach or avoiding coping strategies.

*Overall, adolescents with disabilities perceive themselves from a negative perspective, feel ill and unhappy, when their parents try to avoid problems. We did not find such a tendency in adolescents without disabilities.*

<i>Features of Self-esteem</i>	<b>Approach responses</b>				<b>Avoidance responses</b>			
	Logical Analysis (LA)	Positive Reappraisal (PR),	Seeking Guidance and Support (SG)	Problem Solving (PS)	Cognitive Avoidance (CA)	Acceptance or Resignation (AR)	Seeking Alternative Rewards (SR)	Emotional Discharge (ED)
Happy – unhappy								-.385(**)
Lucky – unlucky	.285(**)		-.329(**)					
Smart – foolish						-.221(*)		
Beautiful – unbeautiful								
Plodding – lazy						-.247(*)		
Healthy – ill							-.252(*)	-.228(*)
Loving – distant						-.246(*)		
open-hearted – reserved			-.230(*)					
Fair – unfair	.250(*)	.350(**)		.246(*)				
Communicative – uncommunicative	.243(*)							
Quiet – nervous (anxious)	.219(*)							

\*\* Correlation is significant at the 0.01 level (2-tailed).

\* Correlation is significant at the 0.05 level (2-tailed).

**Table 5.** Correlation between self-esteem of adolescents and parents' stress coping responses in experiment group.

We found out an interesting relation between stress coping responses and frequency of social contacts. These parents of children with disabilities, who have high score **in socially determined stress coping responses**, have **frequent social contacts**: those, who have a score considerably above average in Seeking Alternative rewards, go for visits every day (Mean=69, SD=0.000); who have a score considerably above average in Emotional discharge, go out 3-4 times a week (M=72, SD=0.00). We did not find such a tendency in control group.

An important factor is also **financial well-being**: parents of children without disabilities indicate financial like a major problem, low income related to coping responses “**Acceptance or resignation**” (r=-.247; Correlation is significant at the 0.05 level (2-tailed).) or “**Emotional discharge**” (r=-.238; Correlation is significant at the 0.05 level (2-tailed) – both avoidance strategies. We did not find out the same tendency in families of children with disabilities.

There is a certain relationship between stress coping responses and **prognosis of Child's condition**. The more pessimistic parents' attitudes are towards children's condition's outcomes, the more they are seeking guidance and support and use emotional discharge. Parents, who have the attitude that the condition is regressing or are not aware of the future, are characterized with higher score of stress coping response "Seeking Guidance and Support" (M=69, SD=0 and M=55.6, SD=11.5) rather than those, who believe in an improvement of the condition (M=59.3, SD=9.6). Emotional discharge is also higher in those, who expect worth outcome (M=69, SD=0) rather, than in those who are not aware of future (M=59.6, SD=10.78) or expect improvement (M=60.8, SD=12.27). Differences between sample means are significant ( $p \leq 0.001$ ).

Nor in experimental, nor in control groups we did find out a clear relation between stress coping responses and upbringing styles: as an approach, so avoidance responses are used during both harmonic and disharmonic upbringings.

In families of adolescents with disabilities we also found that when parents use approach **strategies**, adolescents do not show **behavioral**, nor **emotional problems** (Pearson correlation coefficient is negative: between Logical analyze and external problems is  $r = -0,4119$ , between Problem solving and internal problems is  $r = -0,39916$ ; between Logical analyze and internal problems is  $r = -0,35305$ ), but when parents use avoidance strategies, adolescents show emotional problems (Pearson correlation coefficient between Emotional discharge and internal problems is  $r = 0,375163$ ; Correlations are significant at the 0.01 level (2-tailed)). In control group we did not find any correlation between stress coping responses and behavioral or emotional problems. So, we can see that adolescents with disabilities are influenced by parents' stress coping strategies.

### ***Upbringing Style***

Our research proved already existed data about disharmonic upbringing style in families of disabled.

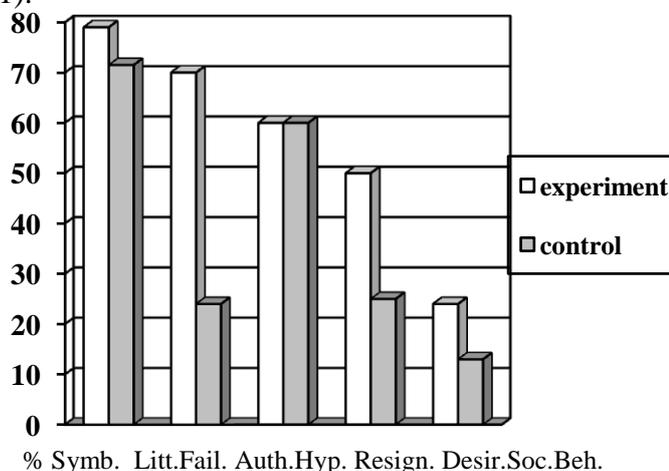
Both in families of children with and without disabilities the mostly spread upbringing style was "Symbiosis" (see diagram 14). We also found out significant differences between mothers' and fathers' data:

1. In both experimental and control group disharmonic style "Symbiosis" was expressed more by fathers, rather than by mothers and this difference is statistically significant (control groups: mothers – 44.1 %, fathers – 75 %,  $\chi^2 = 8.05$ ,  $p < 0.001$ ; experimental group: mothers – 40%, fathers – 85%,  $\chi^2 = 11.5$ ,  $p < 0.001$ ).

2. In the group of children without disabilities this style is mostly used toward daughters (girls' fathers – 55%, boys' fathers – 25%.  $\chi^2=12.7$ ,  $p<0.001$ ).

3. Disharmonic style “Symbiosis” is more peculiar for parents of children without rather than with disabilities ( $\chi^2=14.9$ ,  $p=0.001$ ).

Diagram 14.



We did not find significant differences between results of parents of adolescents with visible and invisible disabilities. But we found out statistically significant differences between control and experimental groups. The “Disabling” style - “**Little Failure**” was revealed mostly in parents of adolescents with disabilities (significance for Means difference in control and experimental  $p<0.001$ ). **Resignation** level is also significantly higher in parents of children with disabilities (significance for Means difference  $p<0.0001$ ). But at the same time, we observed contradictive data – these parents are more tolerant toward their children’s behavior, they treat it as more socially accepted rather than parents of children without disabilities and use “**Behavior Social Desirability**” significantly more often (significance for Means difference  $p<0.0001$ ).

We found out that upbringing style “Little failure” in adolescents without disabilities mostly used towards girls as by fathers (girls  $M=66.45$ , boys  $M=52.11$ ,  $p<0.0001$ ), so by mothers (girls  $M=67.29$ , boys  $M=58.4$ ,  $p=0.05$ ) Upbringing style “Symbiosis” mostly used by fathers towards girls (girls  $M=85.69$ , boys  $M=65.08$ ,  $p<0.0001$ ). Mothers of adolescents with disabilities express positive attitudes and use upbringing style “Desirability of Social behavior” mostly towards girls (girls  $M=31.29$ , boys  $M=17.69$ ,  $p=0.002$ ).

We did not find a significant difference between experimental and control groups, neither between mothers’ and fathers’ data in relation of frequency of social contacts (within and out of family) and upbringing styles.

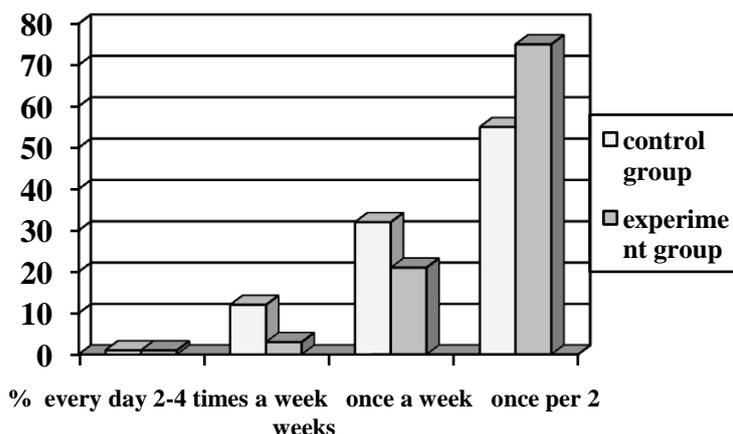
Disharmonic upbringing style influences emotional and behavioral problems only in families of the adolescents with disabilities. **Resignation upbringing style** causes **emotional problems** – internal problematic behavior (correlation coefficient  $r=0.31$ ,  $p=0.05$ ) and external **behavioral problems** ( $r=0.437$ ,  $p=0.01$ ), and disabling upbringing style – “**Little failure**” is related to external behavioral problems ( $r=0.28$ ,  $p=0.05$ ).

### *Correlations between Stress Coping Strategies and Upbringing Styles*

We found out a correlation between stress coping responses and upbringing style only in the experimental group, thus - parents of children with disabilities. In opposite to our hypothesis, avoiding coping not related only to a disharmonic upbringing style, but also to harmonic and vice-versa, avoidance coping can be in negative correlations with disharmonic upbringing style: “Seeking Alternative Rewards” (avoidance response) is in correlations with “Desirability of social behavior” (harmonic upbringing style) ( $r=0.386$ ,  $p<0.001$ ). Problem solving is also related to “Desirability of social behavior” ( $r=0.301$ ,  $p<0.001$ ). Cognitive Avoidance is in negative correlation with “Acceptance-resignation” ( $r= - 0.241$ ,  $p<0.001$ ), this means that our hypothesis was not proved: avoidance coping is not necessarily related to disharmonic upbringing style.

### *Demographic and social data:*

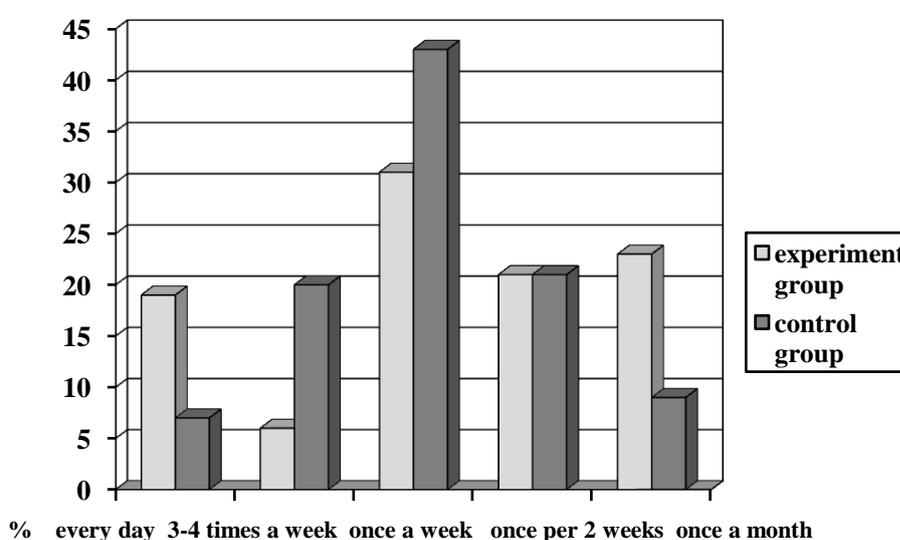
We found out that parents of children without disabilities visit their friends mostly 2-4 times a week or at least once a week. Parents of children with disabilities mostly go out once per 2 weeks ( $\chi^2=9.23$ ,  $p=0.001$ ). Results are given in Diagram 15.



*Diagram 15*

In both groups – families of adolescents with and without disabilities have guests the most frequently once a week. But there is a significant difference between those groups: only 30% of families of children with disabilities have guests once a week and 42.3% families of children without disabilities ( $\chi^2=4.22$ ,  $p<0.05$ ). Results are shown in Diagram 16.

There is a difference between parents groups in accordance with spent time: it was found that parents (41%) of children with disabilities spend major time on household, the second is time spent at working place 21.7%) and care after children is only the third priority (17%). 37% of parents of children without disabilities spent most time at working place and only 24.3% at family and only 7.2% for child’s upbringing.



**Diagram 16.** Frequencies of having guests in experiment and control groups.

Time for themselves have the parents in control group on the average (valid percent=45.5) in experiment group averagely (valid percent=47.6) and rarely (valid percent=46.7) are presented equally.

In both groups parents can find on the average time for each other (valid percent for experiment group=48.5, for control=54.5).

Only 37.5% of parents of children with disabilities can find time often for a relationship with other children. For the families of children without disabilities it’s 59.2%. ( $\chi^2=9.03$ ,  $p<0.01$ ). 47.9% of parents of children with disabilities find time for other children on average.

## *Awareness of diseases*

There is a low level of awareness of disease:

The medical definition of disease can be given only by 32% of parents children with disabilities, 11% do not know exactly, what is disease, 9.5% still suppose that the idea about birth trauma as reason for physical condition is right, 9.5 % only describe symptoms of disease.

About **course of disease and prognosis** there are different points of view: 30.8% of parents think that the disease trends are to recover. 17.3% of parents prove that it stable condition and 15.4% do not know the outcome. 12.5% think that the condition is not progressive.

Parents receive **information about the disease** mostly from doctors (46.2%), another group (12.5%) partly from doctors and partly from medical literature and a few part (10.6%) receives it from other parents of children with disabilities or does not receive it at all.

There is a lack of information about **free governmental services** for persons with disabilities: a significant part (46.7%) had never used these programs, 31.4% had used it only from 1 to 3 times, 10.5% use these programs only in summer.

Those parents, who have information about free governmental services, receive it from following **sources**: 13.7% - from ministry of health, 12.7% - from other parents, 10.8% - from the executive organizations, but the major part – 42.2% do not receive information at all.

**What kind of support** should exist for people with disabilities and their families: a majority (32.4%) thinks that this support should be financial or facilities (subsidies). 11.8% suggests it should be moral support (attention and empathy), 10.8% - physical and medical support, 4.9% think that parents like primary care-givers should have a salary.

Regular medical services are used by a small group of people with disabilities: 20.2% visit a physician once a year, 18.3% - 2-3 times a year, 10.6% only say that they visit doctor often and 48.1% do not use medical services at all.

As we mentioned above, parents' awareness of disease (condition) and expectations of the future influence adolescents' emotional-behavioral problems and self-esteem. But we did not find out a relation between usage of free governmental and medical services and parents' or adolescents characteristics.

## Discussion

There is a lot of discussion around the psychological characteristics of adolescents with disabilities. Despite a lot of research, it is still unclear what influences the development of these kinds of problems in persons with disabilities – physical dependences on others and care needs or the special attitude toward those persons within the family. There is a lot of research investigating such problems as behavioral-emotional condition, self-esteem, and upbringing style. But there are only a few assessments on parents' stress coping strategies. We found out only several and a huge amount of work in this area still needs to be done. There are no researches studying family stress influence on the psychological condition of the child with disability.

In our research we compared those psychological characteristics in visible (cerebral palsy) and invisible (epilepsy) disabilities. Comparing gave us an opportunity to distinguish factors, which could have an impact on forming psychological problems: 1. Objective need of care and 2. Subjective attitudes such as upbringing style, parents' coping responses, awareness about conditions and hopes, siblings' attitudes. Then we concluded how those factors can influence behavioral-emotional condition and self-esteem of the person with disability.

There are contradictory approaches towards psychological problems in disability: one proves that in different disabilities the psychological impairment appears in different ways, another one suggests that despite disability type, during chronic disease impairment is expressed the same way (Shields et al., 2006; Perrin et al., 1984; Carroll et al., 1983). **In our research we did not find out significant differences in internal or external behavior independently from family factors between adolescents with disabilities (visible, invisible) and without disability.** But the interesting results were in self-esteem: adolescents with disabilities mostly perceive themselves in a social perspective, mentioned such features as loving and attentive, other adolescents (without disabilities) describe themselves as healthy. We should underline that negative self-esteem is very rare in both groups. The pattern of results indicates negative self-esteem in girls without disabilities, towards those who used disharmonic disabling upbringing style – “little failure” and “symbiosis” both by mothers and fathers. Because of such respect adolescents often perceive themselves as “smart” and “beautiful”, but at the same time as “distant” and “reserved”. In general, in both groups: families of children with and without disabilities more spread are symbiotic and hyper-protective upbringing styles.

Though we did not observe statistically valid differences in estimation by siblings in experimental and control groups, some differences exist within the group of adolescents with visible disabilities, those who use wheel-chairs and who do not. We should emphasize that other differences between adolescents who use wheelchair and those who do not use were not found. So, participants using wheelchair were not identified as heteronym group. **Adolescents using wheelchairs estimate themselves more competent rather than their siblings do** in a feature brave. Though this data is very few for stating that siblings' attitudes do not influence self-esteem of adolescents with disabilities, so farther investigations are still ahead.

We find the same tendencies in experiment and control groups concerning **upbringing style**. Most spread style "Symbiosis", but "**Little failure**" is given also in families of children without disabilities. There are adolescents' gender differences of usage of it in experiment and control groups: in families of children with disabilities it's mostly boys and in families without disabilities – girls. So, we should also take into consideration eastern style of upbringing, which causes strong level of "Symbiosis", especially towards girls. Concerning this issue, **families of children with disability have the opposite position – they are more loyal towards girls, rather than towards boys**. But we should also emphasize that style "Little failure" is much stronger in families of children with disabilities.

In accordance with different investigations (Armstrong et al., 1992; Shields et al. 2006; King et.al., 1993; Appleton et al., 1994), girls with cerebral palsy are lower in self-esteem than boys with cerebral palsy and both genders of adolescents without disabilities and develop lower self-acceptance, what is also related to severances of disease. But in our research we did not indicate the same results.

**We did not find out a significant difference between stress coping strategies in parents of children with visible and invisible disabilities. Though there are some differences and tendencies between groups of parents of children with and without disabilities:**

Some researchers proved that families of children with disabilities do not experience more stress in general than other families, but more everyday stress (Seligman and Darling, 1989, page 104). In our investigation **stress coping strategies of parents** in families of children with and without disabilities differ only in mothers: those of adolescents with disabilities show significantly low results in approach strategy "logical analyze" that in accordance with Moos's (1993) model of coping can be a risk-factor for developing depression. These results are

contradictive to a family based model, which proves that women tend to adjust to the changing environment and men stay more stable. There are also differences **how the coping strategy influences child's self-esteem**: when parents use avoiding responses or any behavioral response (approach or avoiding), the child with disability feels unhappy and ill and appears to have emotional (internal) problems. In adolescents without disabilities we did not observe such data. Coping behavioral responses can be treated such as stress solving social way and means people's participation in it in comparison to cognitive responses, which is an abstract approach and does not necessarily mean society participation. A precise link between parents' coping strategies and upbringing style exists not in approach-avoiding perspective, but behavioral and cognitive presences.

We should also underline another important factor for stress coping – frequency of **social relationships** as within the family, so out of the family. Despite of the fact that parents of children without disabilities go to visit friends, have time for themselves, spouses and other children, the reason for behavioral problems happen when parents decrease contacts within and out of the family and have more time for the children. In adolescents with disabilities we found out the opposite situation: their anxiety rises with decreasing parents' time for adolescents with disabilities and find more time for contacts, even with siblings of the adolescent or another parent. But if we analyze the timetable of parents of children with disabilities, we can see that most time is used for household and working time, when parents of children without disabilities divide their time for work and upbringing equally. So, adolescents with disabilities need more time and without disabilities – more freedom, what is quite consequent in present situation.

**Awareness of condition** also influences **stress coping strategies**. As parents are better informed about their children's condition and have hope for improving it, they use approach responses. But if parents do not have hope for improving or do not know what expect in future, adolescents with disabilities appear emotional (internal) problems. There are the same results in other investigations, which prove that lack of awareness of disease prognosis can cause behavioral and emotional problems of children with disabilities (Collings, 1990; Goffman, 1963). However, emotional problems appear, when parents have hope for improvement. So, farther investigations about relation of stress coping responses and social contacts in parents of children with disabilities and are still ahead.

**Link between problems, indicated by parents and behavioral and emotional problems of adolescents exists**: parents of children with disabilities mostly indicate their child's

disease as a main problem. Parents of children without disabilities indicate financial problem or do not indicate at all. In adolescents with disabilities appear behavioral problems when parents treat their child's disease as the primary problem and emotional problems while parents indicate financial problems. It's interesting that in control group as behavioral, so emotional problems appear when parents indicate as a primary problem relatives' illness. **So, we can conclude that problems in adolescents mostly are linked to relatives' or their own disease.**

An important factor is also **financial well-being**: when parents of children without disabilities indicate financial like a major problem, low income related to coping responses **“Acceptance or resignation”** or **“Emotional discharge”**– both avoidance strategies. Adolescents with disabilities characterize themselves as “quiet” when their family has high economic income. It can be related to the need of treatment and rehabilitation. These results are due to already existed investigation on epilepsy. In this one emotional problems of persons with disabilities were related to financial problems. In accordance with Goffman (1963), expensive treatment is related to hard psychological stress.

**Awareness of condition** (What is condition, source of information about condition): most parents of children with disabilities indicates physician as a main source of information about the disease, condition and given medical definition of it. But what we could already see, despite of the fact of being aware of condition, children of those parents have a lack of information or unrealistic hope of recovering, which are related to strong emotional problems.

In accordance with different investigations, fathers of children with chronic disease use problem approach strategies and more consequent **upbringing** than mothers (Cayse, 1994). In our research we did not find any significant difference between results of mothers and fathers. Though disharmonic upbringing styles (resignation and disabling) are mostly used in families of children with disabilities, in families of children without disabilities these styles are mostly used towards girls, in families with disabled – mostly towards boys (resignation). At the same time, upbringing influences behavioral problems only in adolescents with disabilities. Resignation upbringing linked to behavioral-emotional problems; disabling style to behavioral problems.

We did not find a significant **relation between frequency of social contacts and stress coping strategies or upbringing styles**. We found out that stress coping responses influence frequency of social contacts and emotional-behavioral problems and self-esteem of adolescents with disabilities, but more important is the direction of coping towards social and cognitive ways, rather than approach-avoiding. For adolescents with disabilities coping social responses

are related to emotional problems and for adolescents without disabilities lack of social responses is causes behavioral problems.

**It's interesting that adolescents with disabilities who have behavioral problems (delinquent or aggressive behavior) perceive themselves in social terms: "unfair" and while having emotional problems, prevailed features characterizing personal condition: unhappy, ill, dependent. In adolescents without disabilities as emotional, so behavioral problems are accompanied by positive self-esteem, which can be treated like compensation.**

We can link it to **self-esteem features, which accompany emotional and behavioral problems**. In adolescents with disabilities who have emotional problems they are mostly negative. Adolescents without disabilities, who have behavioral problems, are higher in their self-esteem than those with disabilities. Aggressive and delinquent behavior normally relates to emotional discharge, but depression, withdrawal and somatization are results of an accumulation of negative emotions.

Thus, normal adjustment in persons with disabilities is not linked to real physical restrictions, but influenced by society and first of all to micro-society – the family. Parents stress coping responses are related to their choice – support child's independence and development of mature person or add to somatic or physical disability psychological problems. This choice is reflected in self-esteem and problematic behavior, which is also influenced by siblings. Coping responses are seen in a frequency of social contacts and the ways, in which parents try to decrease the stress.

Afterwards, we see that psychological problems are not related to the severity of the condition and care needs: we did not identify differences between adolescents with physical restrictions and with a hidden disease. The same tendencies were peculiar for the parents of adolescents of both kinds of disabilities. So, we can conclude, that psychological impairment is caused by social-psychological issues in families.

But still other important conclusions can be made: further investigation on stress coping responses and its relation to upbringing style are still possible. In our research we found that mothers of children with disabilities have a higher risk of depression; other significant differences between parents of children with and without disabilities were not proven. We affirmed that disharmonic upbringing styles are stronger in families of children with disabilities,

but these styles are also used in families of children without disabilities, especially towards girls. Parents of children with disabilities showed more loyalty towards girls than towards boys.

Self-esteem is not lower in adolescents with disabilities, but they are lower in personal features and higher in social. Behavioral-emotional problems are not higher in adolescents with disabilities, but are closely related to parents and depend on them: parents' problems, frequency of social contacts, upbringing style. Adolescents without disabilities are not impacted by parents in these contexts.

## **General discussion and Conclusions**

Following our research we can make general conclusions about psychological peculiarities of adolescents with visible and invisible disabilities in family context and their difference from peers without disabilities:

In our research we did not find out differences in psychological peculiarities of adolescents with visible and invisible disabilities. Despite of different nature of care and everyday needs, the same kind of psychological characteristics appear in both kinds of disabilities. We observed an important data in those adolescents in family context, which proves our hypothesis that psychological problems of adolescents with disabilities are tightly related to family attitudes and awareness of children's conditions.

We should acknowledge that the most frequent upbringing styles in both families of adolescents with and without disabilities are "Symbiosis" and "Hyper-protection". Both belong to disharmonic upbringing styles. Despite of this fact, the upbringing "Resignation" and "Little failure" much more spread in families of adolescents with disabilities. This related to both emotional-behavioral problems and negative self-esteem of adolescents. In families of children without disabilities these styles are mostly used towards girls, in families with disabled – mostly towards boys. When towards girls without disabilities used upbringing styles "little failure" and "symbiosis" both by mothers and fathers, those estimate themselves as "smart" and "beautiful", but at the

same time as “distant” and “reserved”. So, in adolescents without disabilities disharmonic upbringing styles are related only to self-esteem and not to emotional or behavioral problems. It is interesting data that mothers of adolescents with disabilities are more tolerant towards girls than in other families. **Thus, we can see that disharmonic upbringing styles influence adolescents as with, so without disabilities, but in adolescents with disabilities it is related to more psychological problems.**

1. Emotional and behavioral problems in adolescent with disabilities do not differ from those in adolescents without disabilities. The differences appear in relation to family influence factors such as upbringing, stress coping responses of parents, frequency of social relationships, financial well-being and attitude of family towards prognosis of the condition.
2. Stress coping strategies of parents in families of children with and without disabilities differ in mothers: those of adolescents with disabilities show significantly low results in approach strategy “logical analyze” that can be a risk-factor for developing depression.  
**Only adolescents with disabilities are influenced by parents’ stress coping responses.** Self-esteem and emotional problems of adolescents with disabilities is influenced by parents’ stress coping responses. When parents avoid problem solving or try to solve it in a social way, when parents’ contacts rise, the adolescents with disability feel unhappy and ill and appear to have emotional (internal) problems.
3. **Emotional-behavioral problems of both adolescents with and without disabilities are impacted by frequency of relationships with parents:**  
Though parents of adolescents with disabilities indicate child’s disease as a major problem, their time mostly used for the household and job. Parents of children without disabilities share their time for the job and children’s upbringing equally. We can link it to problems when problems of adolescents with disabilities increase with decreasing of parents’ time for them and problems of adolescents without disabilities grow with increasing time for them. So, problems of adolescents with disability appear because of lack of parents’ time for them and in adolescents without disabilities because of excess of time.
4. **Emotional problems of adolescents with disabilities are related to parents’ awareness level of children’s conditions and their expectations towards prognosis.**

When parents are not aware of it or expect improvement of condition, appear emotional problems of adolescents.

5. An important factor is also **financial well-being**: when parents of children without disabilities indicate financial as a major problem, low income related to coping avoidance responses “Acceptance or resignation” or “Emotional discharge” Adolescents with disabilities indicate the feature “quiet” when their family has high economical income. Those without disabilities in such cases characterize themselves “communicative” and “brave”. So, in this case we can see that emotional conditions of adolescents with disabilities are tightly related to parents’ problems. In group of adolescents without disabilities self-esteem characterized with socially features. However we can suggest that for adolescents with disabilities it is very important to me maintained financially because of great deal of expenses related to their treatment and rehabilitation.
6. In adolescents with disabilities **behavioral-emotional problems and self-esteem are linked to each other**. Mostly those, who have emotional or behavioral problems, characterize themselves also in negative terms. In adolescents without disabilities such phenomenon was not observed.
7. **Adolescents with and without disabilities differ in self-esteem**. Those with disabilities mostly perceive themselves in a social perspective, mentioned such features as loving and attentive, adolescents without disabilities describe themselves as healthy.

Overall, we can see that difference in self-esteem and factors influencing emotional-behavioral problems in adolescents with and without disabilities exist. Upbringing styles and stress coping strategies between parents of adolescents with and without disabilities also differ. Responses of parents of adolescents with disabilities are influenced by social factors such as financial well-being, also awareness of child’s condition. However those parents indicate child’s problems as the major problem, they do not spend enough time with their children with disabilities. Disabling upbringing style and resignation of the child also more frequent for them. All the given peculiarities of parents have an impact on adolescents’ psychological problems. Afterwards, we can conclude that psychological problems of adolescents are related not to physical restrictions or care need, but parents’ special attitudes towards them.

## **Several recommendations can be made:**

1. Hiding of diagnosis, objective prognosis from adolescent with disability are maintaining formation of low self-esteem, low self-acceptance and emotional problems. Thus, **awareness of condition with positive and negative prognosis, speaking about it openly with adolescent with disability could be a measure for prevention anxiety and inadequate self-esteem.**

2. When parents prefer to solve their problems in social way or get rid of it in society, their child with disability feels unhappy and ill. Possibly acknowledgement of the problem (involving cognitive strategy), verbalization of it could be helpful for improving well-being for the child. It's possible to link this recommendation to the first one: when parents hide their child's condition, do not speak about it and try to discharge negative emotions in indirect – social way, the adolescent with a disability feels lonely, unhappy, ill and unaccepted in their surroundings. **So, an awareness of one's own condition and speaking about it is essential for preventing stigmatization caused by own condition and rising self-esteem.**

3. When parents are not aware of child's condition and expect positive outcome, it causes in adolescent anxiety and other emotional problems. **Thus, condition's and prognosis's presenting should be realistic for child.**

4. In families of adolescents with disabilities the time spent on children's upbringing is at third place after the time spent on family and job. In accordance with the results emotional and behavioral problems of adolescents proportionally increase when parents spend more time for relationships without the family. Therefore, **adolescents with disabilities need not only care, but upbringing.**

**Cultural issues:** eastern Upbringing style, which is using disabling and hyper-protective methods is quite challenging also for the population without disabilities. We found two categories for stigmatizing: gender (girls) and disability.

## References

- Adamashvili Nino (2002). *Genesis of self-identity*. Course of lectures. Tbilisi. Tape recording.
- Adamson L. (2003 Sep-Oct). *Self-image, adolescence, and disability*. *Am J Occup Ther.*; 57 (5):578-81.
- Appleton PL, Minchom PE, Ellis NC, Elliott CE, Boll V, Jones P. (1994. Mar). *The self-concept of young people with spina bifida: a population-based study*. *Dev Med Child Neurol.*; 36(3):198-215.
- Appleton PL, Ellis NC, Minchom PE, Lawson V, Boll V, Jones P. (1997 Oct). *Depressive symptoms and self-concept in young people with spina bifida*. *J Pediatr. Psychol.*; 22 (5):707-22.
- Armstrong RW, Rosenbaum PL, King S. (1992 Feb). *Self-perceived social function among disabled children regular classrooms*. *J Dev Behav. Pediatr.*; 13 (1):11.
- Arnston P, Droge D, Norton R, Murray E. (1986). *The perceived psychosocial consequences of having epilepsy*. New York, NY: Oxford University Press: 143-161
- Austin JK, Dunn DW, Johnson CS, Perkins SM. (2004 Oct). *Behavioral issues involving children and adolescents with epilepsy and the impact of their families: recent research data*. *Epilepsy Behav.*; 5 Suppl 3:S33-41.
- Batshaw M.L., Perret Y.M. Caring and Coping. The Family of a child with Disabilities. With Symme W. Trachtenberg. *Children with disabilities*. Paul Brookes Publishing Co. Baltimore. London. Toronto. Sydney. 1996
- Batshaw M.L., Perret Y.M. (1996). Caring and Coping. Cerebral palsy. With Symme W. Trachtenberg. *Children with disabilities*. Paul Brookes Publishing Co. Baltimore. London. Toronto. Sydney.
- Batshaw M.L., Perret Y.M. (1996). Caring and Coping. Epilepsy. With Symme W. Trachtenberg. *Children with disabilities*. Paul Brookes Publishing Co. Baltimore. London. Toronto. Sydney.
- Bibileishvili M., Laghidze A. (2005). *Child with disability and parent*. Tbilisi: Children' Studio "ADC".

- Bjornaes H. (1988). *Consequences of severe epilepsy: psychosocial aspects*. Acta Neurol Scand Suppl.; 117: 28-33.
- Blum, R. W. (1992). *Chronic illness and disability in adolescence*. Journal of Adolescent Health, 13, 364-368.
- Bocharova E.A., Kazarina E.V., Sidorov P.I., Soloviov E.G. (May 23-25. 2000). *Working Frames with families of children with developmental disturbances*. Present problems and development perspectives of child complex help. Digest of international scientific-practical conference. Arkhangelsk.
- Boice M.M. (1998). *Chronic illness in Adolescence*. Retrieved Winter 1998, from LookSmart's FindArticles. Web site: [http://findarticles.com/p/articles/mi\\_m2248/is\\_132\\_33/ai\\_53870307](http://findarticles.com/p/articles/mi_m2248/is_132_33/ai_53870307)
- Boldirev A.I. (1984). *Epilepsy in adults*. Moscow: Medicina.
- Breslau N, Marshall IA. (1985 Jun). *Psychological disturbance in children with physical disabilities: continuity and change in a 5-year follow-up*. J Abnorm Child Psychol.; 13 (2):199-21.
- Bronfenbrenner U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Cambridge, MA: Harvard University Press. ISBN 0-674-22457-4
- Carr A. A (1999). *Child and Adolescent Clinical Psychology. An Contextual Approach*. London. N.Y.
- Carroll, G., Massarelli, E., & Opzoomer, A. (1983). *Adolescents with chronic disease: Are they receiving comprehensive health care?* Adolescent Health Care, 4, 261.
- Carter Elizabeth A., McGoldrick Monica. (October 8, 1980). *Family Life Cycle*. Hardcover. Wiley, John Sons: 468 pp
- Cayse LN. (1994 Jul). *Fathers of children with cancer: a descriptive study of their stressors and coping strategies*. J Pediatr Oncol Nurs.; 11 (3):102-8.
- Chabashvili M. (editor)( 1974). *Defining dictionary of foreign words*. Tbilisi: Ganatleba: 479.
- Chaves V.S. (1993). *Social-psychological peculiarities of family upbringing of child with Cerebral Palsy*. Moscow: SPB.

- Child with disability and his family. Advices to parents* (2003). Tbilisi: Fund "First Step".
- Clench-Aas J, Roy BV, Mowinckel P, Gjerstad L. (2006 Aug 4). *Psychiatric symptoms in adolescents with epilepsy in junior high school in Norway: A population survey*. *Epilepsy Behav.*
- Collings JA. (1990 Jul-Aug). Psychosocial well-being and epilepsy: an empirical study. *Epilepsia.*; 31(4):418-26.
- Colver Allan and the SPARCLE group; European study of the relationship of environment to participation and quality of life in children with cerebral palsy. *BMC Public Health.* 2006; 6: 105. Retrieved 2006 April 25 from <http://creativecommons.org/licenses/by/2.0>
- Davis B.H. (1987). *Disability and grief. Social Casework.* *Journal of Counseling and Development .* 68: 352-357.
- Dgebuadze Ch., Abesadze L. (editors) (1988). *Lathin-Russian-Georgian medical dictionary.* Tbilisi: Ganatleba: 327
- Diagnostic and Statistical Manual of Mental Disorders (DSM IV TR). The Diagnostic and Statistical Manual of Mental Disorders in the News. *Psychiatry Online.com*, accessed 2008; available from <http://www.psych.org/MainMenu/Research/DSMIV.aspx>. Internet.
- Dodrill CB, Breyer DN, Diamond MB, Dubinsky BL, Geary BB. (1984 Apr). *Psychosocial problems in adults with epilepsy: comparison of findings from four countries.* *Epilepsia.*; 25(2):168-75.
- Dodrill CB, Beier R, Kasparick M, Tacke I, Tacke U, Tan SY. (1984 Apr). *Psychosocial problems among adults with epilepsy.* *Epilepsia.*; 25(2):176-83.
- Eiser C. (1993). *Growing up with a chronic disease: The impact on children and their families.* London: Kingsley.
- Finnie N. R. (1997). FCSP. *Handling the Young Child with Cerebral Palsy at Home.* Butterworth Heinemann.
- Fisher Robert, Van Emde Boas Walter; Blume Warren; Elger Christian; Genton Pierre; Lee Phillip; Engel Jerome JR (2005); *Epilepsia* ISSN 0013-9580 CODEN EPILAK., vol. 46, n<sup>o</sup>4, pp. 470-472 [3 page(s) (article)] (2 ref.)). Blackwell,

Malden, MA, ETATS-UNIS (1909) (Revue), accessed 2005; available from <http://cat.inist.fr/aModele=afficheN&cpsidt=16684434>. Internet.

Gagoshidze Tamar (2000). *Neuropsychology Guide*. Tbilisi. Tape recording: Page 109.

Garrison W.T., McQuiston S. (1989). *Chronic Illness During Childhood and Adolescence: Psychological Aspects*. SAGE, Newbury Park CA.

Gerrig, R.J. & Zimbardo, P. *Psychology and Life* 16-th edition. Ellyn and Bacon. 2002.

Goffman E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.

Gogichaishvili Tamaz (1996). *Psychology*. Tbilisi: Tsisnami..

Goshadze G. (2003) *Investigation of disabled children families in Georgia*. Tbilisi: Fund "First Step".

Grant Igor (1992). *The Social Environment and Neurological Disease in Interface between Neurology and Psychiatry*. Ed. M.R Trimble: 27-44

Hanscomb A. and Hughes L. in association with the National Society For Epilepsy (1999). *Epilepsy*. Word Lock.

Hinrichsen G. A., Emery E. E. (2004). *Interpersonal Factors and Late-Life Depression*  
Retrieved May 24, 2005 from  
<http://www3.interscience.wiley.com/journal/118706655/abstract>

Hirst M. (1989 Jan). *Patterns of impairment and disability related to social handicap in young People with cerebral palsy and spina bifida*. J Biosoc Sci.; 21(1):1-12.

Hodgkinson R, Lester H. (2002 Aug). *Stresses and coping strategies of mothers living with a child with cystic fibrosis: implications for nursing professionals*. J Adv Nurs.; 39(4): 377-83.

Hoare P, Mann H (1994 Nov). *Self-esteem and behavioural adjustment in children with epilepsy and children with diabetes*. J Psychosom Res.; 38(8): 859-69.

- Horowitz M.J. and Cohen F.M. (1968). *Temporal lobe epilepsy. Effects of Lobectomy on Psychosocial Functioning*. Epilepsy-9. Elsevier Publishing Company, Amsterdam.: 23-41.
- Hryshko-Mullen Ann S. (1992). *Examination of a Model of the Relations Among Parenting Stress, Parenting Resources, Parenting Behavior, and Child Adjustment*. Bowling Green State University.
- Iivanainen M., Uutela A. and Vikkumaa (1980). *Public Awareness and attitudes toward epilepsy in Finland*. Epilepsya, 21; New York: 413-423.
- Inasaridze K. (1999). *Society attitude towards people with epilepsy*. Tbilisi: Georgian Psychological Journal. N 1: 61-76
- International Statistical Classification of Diseases and Related Health Problems*. 10th Revision (ICD 10). Version for 2007 [book online]. WHO & DIMDI (German Institute of Medical Documentation and Information), accessed 2007; available from: <http://www.who.int/classifications/apps/icd/icd10online/>. Internet.
- Ivanova S.N. (May 23-25 2000). *Family role in upbringing of child with disabilities*. Present problems and development perspectives of child complex help. Digest of international scientific-practical conference. Arkhangelsk.
- Jenkins R.L. (1960). *Psychiatric syndromes in children and their relation to family background*. – *American journal of Orthopsychiatry*, vol.3: 450-457.
- Keene DL, Manion I, Whiting S, Belanger E, Brennan R, Jacob P, Humphreys P. (2005 Apr 26). A survey of behavior problems in children with epilepsy. *Epilepsy Behav*. 2005 Jun; 6(4):581-6. Epub.
- Kim WJ. (1991 Nov). *Psychiatric aspects of epileptic children and adolescents*. *J Am Acad.Child. Adolesc.Psychiatry.*; 30(6):874-86.
- King GA, Shultz IZ, Steel K, Gilpin M, Cathers T.( 1993 Feb). *Self-evaluation and self-concept of adolescents with physical disabilities*. *Am J. Occup. Ther.*; 47 (2):132-40.
- Kinne Susan, PhD, Donald L. Patrick, PhD, MSPH, and Debra Lochner Doyle, MS, CGC (2004 March). *Prevalence of Secondary Conditions Among People With Disabilities*. *Am J Public Health*; 94(3): 443–445.

- Kiseliova T.G., Akimova L.A. (2001). *Conclusions: investigation comparative analyze of disabled children families*. Culture and recreation in families of disabled children. Articles Review on materials of Russian regions sociological investigation. Moscow.
- Komender J. (1989 Mar-Apr). *Psychosocial problems of epileptic children and their families*. Psychiatr. Pol.; 23 (2):104-10.
- Kondrashencko V.T., Donskoy D.I., Igumnov S.A. (1999). *General Psychotherapy*. Minsk: Visheishia Shkola.
- Krementz J. (1989). *How it feels to fight for your life*. Boston: Little, Brown
- Kübler-Ross E. (1969). *Five stages of grief*. Retrieved 2006.8 from web site [http://www.businessballs.com/elisabeth\\_kubler\\_ross\\_five\\_stages\\_of\\_grief.htm](http://www.businessballs.com/elisabeth_kubler_ross_five_stages_of_grief.htm)
- Kurokawa T, Matsuo M, Yoshida K, Takaki S, Goya N. (1983). *Behavioral disorders in Japanese epileptic children*. Folia Psychiatr. Neurol. Jpn.; 37(3): 259-65.
- Lewis JN, Tonge BJ, Mowat DR, Einfeld SL, Siddons HM, Rees VW (2000 Apr). *Epilepsy and associated psychopathology in young people with intellectual disability*. J Pediatr. Child Health.; 36(2):172-5.
- Magill J, Hurlbut N (1986 Jun). *The self-esteem of adolescents with cerebral palsy*. Am J Occup. Ther.; 40(6): 402-7.
- Magill-Evans JE, Restall G. (1991 Sep). *Self-esteem of persons with cerebral palsy: from adolescence to adulthood*. Am J Occup. Ther.; 45(9): 819-25.
- Margalit M, Heiman T (1983 Autumn). *Anxiety and self-dissatisfaction in epileptic children*. Int. J Soc Psychiatry.; 29 (3): 220-4.
- Mastiukova E.M., Moskovkina A.G (2004). *Family upbringing of children with developmental disturbances*. Moscow: Vlados.
- McCoy K. (1982). *Coping with teenage depression*. New York: New American Library.  
Retrieved from Web Site:  
[http://findarticles.com/p/articles/mi\\_m2248/is\\_132\\_33/ai\\_53870307/pg\\_9](http://findarticles.com/p/articles/mi_m2248/is_132_33/ai_53870307/pg_9)

- McDermott S, Coker AL, Mani S, Krishnaswami S, Nagle RJ, Barnett-Queen LL, Wuori DF (1996 Jun). *A population-based analysis of behavior problems in children with cerebral palsy*. *J Pediatr Psychol.*; 21 (3):447-63.
- Millstein, S. G., & Irwin, I. F. (1990). *Adolescent health*. In S. S. Feldman & G. R. Elliott (Eds.), *At the threshold: The developing adolescent* (pp. 431-617). Cambridge: Harvard University Press.
- Minuchin, S. (1974). *Families and family therapy*. Cambridge: Harvard University Press.
- Molteno G, Molteno CD, Finchilescu G, Dawes AR (2001 Dec). *Behavioral and emotional problems in children with intellectual disability attending special schools in Cape Town, South Africa*. *J. Intellect Disabil Res.*; 45(Pt 6): 515-20.
- Morgan Laura, Ruth Chambers (October 2004). *Enabling Disabled Doctors - Scoping Exercise*. Faculty of Health and Science Staffordshire University.
- Moos Rudolf H. (1993). *Coping Responses Inventory. Adult Form*. Professional Manual. Psychological Assessment Resources. Inc. P.O. Box. 998/Odessa, Florida.
- Nadirashvili Sh. (1995). *Social Psychology of Person*. Tbilisi University Press.
- Naneishvili G. (1998). *Psychiatry short course*. Tbilisi: Metsniereba: 243
- Nelson & Ellenberg (1986). *Antecedents of Cerebral Palsy: Multivariate analysis of risk*. *The New England Journal of Medicine*, 315: 81-86.
- Nesterova G.F. (May 23-24, 2000). *Problems of family upbringing of children with disabilities*. Present problems and development perspectives of child complex help. Digest of international scientific-practical conference. Arkhangelsk.
- Offer D., Ostrov E. & Howard K. I. (1984). *Body image, self perception and chronic illness in adolescence*. In R. W. Blum (Ed.), *Chronic illness and disabilities in childhood and adolescence* (pp. 59-73). Orlando, FL: Grune & Stratton.
- Osipova M., Gagoshidze T. (2006). *Influence of Upbringing peculiarities on self-esteem of child with disability*. *Journal Intelqti* .Tbilisi Technical University Scientific Journal N 1/24: 357-360.

- Osipova M. (2006). *Family role in creation of independent personality of child with disability*. Journal Intelekti .Tbilisi Technical University Scientific Journal N 2/25: 358-360.
- Osipova M. (2006). *Parents Stress Coping Strategies influence on problem behavior of child with disability*. Journal Intelekti .Tbilisi Technical University Scientific Journal N 2/25: 361-364.
- Ounsted C. (1955). *The hyperkinetic syndrome in epileptic children*. Journal of Neurology, Neurosurgery & Psychiatry. Retrieved 1 Dec 2000.; 2: 303- 311. [Context Link]. 5. From Web Site: [www.pt.wkhealth.com/pt/re/jnnp/fulltext.00005069-200012010-00009.htm](http://www.pt.wkhealth.com/pt/re/jnnp/fulltext.00005069-200012010-00009.htm))
- Paneth N. (1986). *Etiologic factors in cerebral palsy*. Pediatric Annals, 15: 191, 194-195, 197, 201.
- Perrin J. M. & Gerrity P. (1984). *Development of children with chronic illness*. Pediatric Clinics of North America, 31, 19. Retrieved from Web Site: [http://findarticles.com/p/articles/mi\\_m2248/is\\_132\\_33/ai\\_53870307/pg\\_9](http://findarticles.com/p/articles/mi_m2248/is_132_33/ai_53870307/pg_9)
- Pidcock FS, Graziani LJ, Stanley C, Mitchell DG, Merton D. (1990). *Neurosonographic features of periventricular echodensities associated with cerebral palsy in preterm infants*. J Pediatr; 116: 417-422.
- Ratter M. (1970). *Helping troubled children*. London: Penguin Books.
- Ratanawongsa Boosara, *Cerebral Palsy Overview [book on-line], Last Editorial Review: 10/31/2005, accessed 15 November, 2008; available from [http://www.emedicinehealth.com/cerebral\\_palsy/article\\_em.htm#Cerebral Palsy Overview](http://www.emedicinehealth.com/cerebral_palsy/article_em.htm#Cerebral_Palsy_Overview). Internet*
- Raty LK, Soderfeldt BA, Larsson G, Larsson BM. (. 2004 Sep). *The relationship between illness severity, sociodemographic factors, general self-concept, and illness-specific attitude in Swedish adolescents with epilepsy*. Seizure; 13 (6): 375-82.
- Reingold, A. L., & Krishnan, S. (2002). *The study of potentially stigmatizing conditions: an epidemiologic perspective*. Paper presented at the International Conference on Stigma and Global Health: Developing a Research Agenda. Bethesda, MD, accessed January 8, 2008; available from <http://www.stigmaconference.nih.gov/ReingoldPaper.htm>.
- Rogov E.I. (1999). *Handbook of practical psychologist*. Moscow: Vlados.

- Russman B.S., & Gage, J.R. (1989). *Cerebral palsy. Current problems in Pediatrics*.
- Samuelson JJ, Foltz J, Foxall MJ. (1992 Oct). *Stress and coping in families of children with myelomeningocele*. Arch. Psychiatr Nurs.; 6(5): 287-95.
- Sbarra DA, Rimm-Kaufman SE, Pianta RC (2002 Aug). *The behavioral and emotional correlates of epilepsy in adolescence: a 7-year follow-up study*. Epilepsy Behav.; 3 (4): 358-367.
- Scambler G., Hopkins A. (1986). *Being Epileptic: Coming to terms with stigma*. Sociology of Health & Illness, 8 , 26-43.
- Seligman M. & Darling R. B. (1989). *Ordinary families, special children*. New York: Guilford Press.
- Shetty T., Trimble M. (1997) *The Bear Fedio Inventory: Twenty years on*. Epilepsy: 10: 254-262.
- Shields N, Murdoch A, Loy Y, Dodd KJ, Taylor NF. (2006 Feb). *A systematic review of the self-concept of children with cerebral palsy compared with children without disability*. Dev. Med Child Neurol.; 48(2):151-7.
- Sivberg B. (2002). *Coping strategies and parental attitudes, a comparison of parents with children with autistic spectrum disorders and parents with non-autistic children*. Int. J. Circumpolar Health.; 61 Suppl. 2: 36-50.
- Stafstrom CE, Havlena J. (2003 Feb.) *Seizure drawings: insight into the self-image of children with epilepsy*. Epilepsy Behav.; 4 (1):43-56.
- Suris JC, Parera N, Puig C. (1996 Aug). *Chronic illness and emotional distress in adolescence*. J Adolesc Health.; 19(2):153-6.
- Teplin SW, Howard JA, O'Connor (1981 Dec). *Self-concept of young children with cerebral palsy*. MJ Dev Med Child Neurol.; 23(6):730-8.
- The impact of epilepsy on family life – in Psychiatric co-morbidity in epilepsy* (1999); Epilepsy: 73-93.
- The psychopathic or antisocial personality*. The Journal of Nervous and Mental Disease, 1960. 131(4): 318.

- Thompson R. J. & Gustafson K. E. (1996). *Adaptation to chronic childhood illness*. Washington, DC: American Psychological Association.
- Urtaikin V.V., Komarova O.G (1996). *Family and child with "special needs"*. Moscow: Shkola Zdorovia. Volume 3.
- Uzdnadze D. (1974). *Transacts*. Volume 6. Tbilisi: Metsniereba.
- Vetrova I.U. (1994). "*Know to...*" Samara: Association "Destnica".
- Wallander J.L. & Siegel L. J. (1995). *Appraisal, coping, and adjustment in adolescentys with a physical disability*. Adolescent health: Behavioral perspectives. New York: Guilford.
- Zullig Keith J, Robert F Valois and J Wanzer Drane (1997. Dec). *Adolescent distinctions between quality of life and self-rated health in quality of life research*. Dev Med Child Neurol.; 23(6): 730-8.