



Universitatea  
Ștefan cel Mare  
Suceava



Erasmus+



Universitat  
de Lleida



INSTITUTO POLITÉCNICO  
DE BRAGANÇA



University of Zagreb  
Faculty of Education and  
Rehabilitation Sciences



KLAIPĖDOS  
UNIVERSITETAS



Project no. 2016-1-RO01-KA204-024504

Building Bridges: Promoting  
Social Inclusion and Wellbeing for Families  
of Children with Special Needs

**SOCIAL INCLUSION AND WELLBEING  
OF FAMILIES OF CHILDREN  
WITH SPECIAL NEEDS  
TRANSNATIONAL STUDY REPORT**

Aurora Adina Colomeischi- Romania- coordinator  
Gemma Fillella Gui- Spain  
Maria Augusta Romão da Veiga Branco- Portugal  
Sonja Alimović- Croatia  
Ingrida Baranauskiene- Lithuania  
Mine Gol-Guven - Turkey

[www.psiwell.eu](http://www.psiwell.eu)



Funded by the  
Erasmus+ Programme  
of the European Union



Universitatea  
Ștefan cel Mare  
Suceava



Universitat  
de Lleida



INSTITUTO POLITÉCNICO  
DE BRAGANÇA



University of Zagreb  
Faculty of Education and  
Rehabilitation Sciences



KLAIPĖDOS  
UNIVERSITETAS



# SOCIAL INCLUSION AND WELLBEING OF FAMILIES OF CHILDREN WITH SPECIAL NEEDS TRANSNATIONAL STUDY REPORT

Aurora Adina Colomeischi, Romania, coordinator

Gemma Fillella Guiu - Spain

Maria Augusta Romão da Veiga Branco - Portugal

Sonja Alimović - Croatia

Ingrida Baranauskiene - Lithuania

Mine Gol-Guven - Turkey



Project no. 2016-1-RO01-KA204-024504

Building Bridges: Promoting  
Social Inclusion and Wellbeing for Families  
of Children with Special Needs

## **Contributors**

### **Ștefan cel Mare University of Suceava, Romania**

Petruța Paraschiva RUSU

Marius MARICI

Diana Sinziana DUCA

### **Lleida University, Spain**

Gemma Filella Guiu

Agnès Ros Morente

Judit Teixiné Baradad

### **Polytechnic Institute Braganca, Portugal**

Maria Augusta Romão da Veiga Branco

Maria Isabel Barreiro Ribeiro;

Celeste da Cruz Meirinho Antão

### **University of Zagreb, Croatia**

Ana Wagner Jakab

Daniela Cvitković

Anamarija Žic Ralić

Jasmina Stošić

Natalija Lisak

### **Klaipeda University**

Roma Simulioniene

Regina Saveljeva

### **Bogazici University, Istanbul, Turkey**

Nalan Babur

Mine Gol Guven



Funded by the  
Erasmus+ Programme  
of the European Union

## CONTENTS

### INTRODUCTION

### BUILDING BRIDGES: PROMOTING SOCIAL INCLUSION AND WELLBEING FOR FAMILIES OF CHILDREN WITH SPECIAL NEEDS – PSI\_WELL ..... 5

#### I. GENERAL BACKGROUND INFORMATION FOR EUROPE..... 8

*I.1. Description for situation of parents of children with special needs* ..... 8

*I.2. European statistics* ..... 8

*I.3. Inclusion Policies* ..... 9

*I.4. Support programs for parents* ..... 10

*References* ..... 12

#### II. GENERAL BACKGROUND INFORMATION FOR ROMANIA ..... 13

*II.1. Description for situation of parents of children with special needs* ..... 13

*II.2. National statistics* ..... 15

*II.3. Inclusion Policies in Romania* ..... 17

*II.4. Support programs for parents in Romania* ..... 21

*References* ..... 25

#### III. GENERAL BACKGROUND INFORMATION FOR SPAIN..... 28

*III.1. Description for parents of children with special needs* ..... 28

*III.2. National statistics* ..... 29

*III.3. Inclusion policies in Spain* ..... 30

*III.4. Inclusion policies in Catalunya* ..... 31

*References* ..... 31

#### IV. GENERAL BACKGROUND INFORMATION FOR PORTUGAL..... 32

*IV.1. Description for situation of parents of children with special needs* ..... 34

*IV.2. National statistics* ..... 34

*IV.3. Inclusion policies in Portugal* ..... 36

*IV.4. Support programs for parents in Portugal* ..... 39

*References* ..... 41

<b>V. GENERAL BACKGROUND INFORMATION FOR CROATIA .....</b>	<b>44</b>
<i>V.1. Description for situation of parents of children with special needs .....</i>	<i>44</i>
<i>V.2. National statistics .....</i>	<i>46</i>
<i>V.3. Inclusion policies in Croatia .....</i>	<i>47</i>
<i>V.4. Support programs for parents in Croatia .....</i>	<i>49</i>
<i>References .....</i>	<i>50</i>
<b>VI. GENERAL BACKGROUND INFORMATION FOR LITHUANIA.....</b>	<b>52</b>
<i>VI.1. Description for situation of parents of children with special needs .....</i>	<i>52</i>
<i>VI.2. National statistics .....</i>	<i>53</i>
<i>VI.3. Inclusion Policies in Lithuania .....</i>	<i>56</i>
<i>References .....</i>	<i>62</i>
<b>VII. GENERAL BACKGROUND INFORMATION FOR TURKEY .....</b>	<b>63</b>
<i>VII.1. Description for situation of parents of children with special needs .....</i>	<i>63</i>
<i>VII.2. National statistics .....</i>	<i>64</i>
<i>VII.3. Inclusion policies in Turkey .....</i>	<i>65</i>
<i>VII.4. Support programs for parents in Turkey .....</i>	<i>66</i>
<i>References .....</i>	<i>67</i>
<b>STRESS, COPING AND WELL BEING FOR PARENTS OF CHILDREN WITH SPECIAL NEEDS: A CROSS-CULTURAL RESEARCH STUDY .....</b>	<b>68</b>
<i>Introduction .....</i>	<i>68</i>
<i>Method .....</i>	<i>69</i>
<i>Procedure .....</i>	<i>70</i>
<i>Measures .....</i>	<i>71</i>
<i>Results.....</i>	<i>72</i>
<i>Discussion.....</i>	<i>88</i>
<i>References .....</i>	<i>90</i>

## **INTRODUCTION**

### **BUILDING BRIDGES: PROMOTING SOCIAL INCLUSION AND WELLBEING FOR FAMILIES OF CHILDREN WITH SPECIAL NEEDS – PSI\_WELL**

The project entitled Building Bridges: Promoting Social Inclusion and Wellbeing for Families of Children with Special Needs (PSI\_WELL) proposes an innovative approach aimed to facilitate social inclusion and wellbeing for families confronting with disabled children through adult education for parents. The project is addressing to the specific needs of families parenting children with special needs (SN) and it is designed to help parents to improve their coping strategies and to enhance their parenting skills in order

to foster their social inclusion and wellbeing. The first aim of our project is to assess the wellbeing, stress related factors and couple relationship of parents of children with special needs. The second aim is to enhance personal resources (such as individual coping, emotion regulation), family resources (such as dyadic coping) and social support for parents of a child with special needs through development, implementing and validating a psycho-educational and social intervention program. The general aim of the project is promoting social inclusion, equity and wellbeing for risk families in Europe through an intervention program for parents of children with special needs. This will be reached through objectives:

(1) Diagnose the level of social inclusion, stress and wellbeing of 1500 families parenting children with special needs through a cross-sectional and cross-national research;

(2) Developing a psychoeducational & social intervention program for fostering wellbeing for families of children with SN;

(3) Validating the psychoeducational & social intervention program for risk families through the implementation with 360 parents from European countries of partnership;

(4) Raising the awareness of the communities regarding the specific needs for social inclusion of risk families and disadvantaged parents of children with special needs

through conducting an information campaign; (5) Developing a psychoeducational kit comprising two working tools for trainers specialized in working with disadvantaged parents by the end of the project;

(6) Improving parenting skills and parent-child relationships through developing an integrative handbook for parents by the end of the project. The target group comprises 360 parents from six European countries who will be involved in training activities and social network in order to enhance their personal and parental skills for a better social inclusion. The activities describe specific interventions such as a cross-national research on social inclusion, stress and wellbeing of families of children with SN to diagnose the level of stress and wellbeing of parents and the implications for adult education; designing and validating of a Psycho-Educational & Social Intervention (PESI) Program for enhancing social inclusion and wellbeing of families of children with special needs; developing specific and comprehensive tools to sustain the intervention program (such as: a handbook for parents of children with special needs; a psycho-educational kit for social-emotional learning training for parents of children with SN, comprising the trainer's manual and the trainee's workbook), developing and implementing a training course for trainers; delivering the training program for parents; creating a network of support groups for parents of children with special needs in order to facilitate knowledge and experiences sharing, fostering social inclusion as well; dissemination of project's activities and results; sharing the project's deliverables through website, workshops, symposium, conferences.

The expected impact on target groups is twofold: on the one hand is expected a personal development process and on the other hand is expected acquiring specific parenting skills (the results will consist in 360 parents of children with SN more resilient and enabled to practice different parenting strategies in order to respond exactly to their children growing and development needs; they will overcome the social exclusion becoming active involved in the process of raising and supporting their own children with SN).

The project expect a community more inclusive and sensitive to the specific needs of families with children with SN and the university will be recognized as an important resource for quality knowledge and experience (provider of an evidence-based program). At the national and international level is expected raising the awareness of the political deciders regarding the specific needs of families of persons with SN. The

research conducted within the project draws some implications for family's life within social environment and it will propose some solutions for intervention to enhance the life quality of these families and their social inclusion, so that the results of the project could serve as a base for developing an educational policy for parents and families of children with SN.

Strategic partnership KA2

Stefan cel Mare University of Suceava, Romania - coordinator

Lleida University, Spain

Politechnik Institute Braganca, Portugal

Zagreb University, Faculty of Education and Rehabilitation Sciences, Croatia

Klaipeda University, Lithuania

Bogazici University, Turkey

## **I. GENERAL BACKGROUND INFORMATION FOR EUROPE**

### ***1.1. Description for situation of parents of children with special needs***

A study, on a sample of 11 countries, from Europe, found that parents with special needs children struggle more difficulties as compared with a sample of parents without special needs children. Parents with special needs children are often unstable, have a low economic status, show more often traditional gender role arrangements, have a lower health condition, their wellbeing is definitely lower, mothers have lower rates of social contact and fathers have significantly lower emotional exchanges. Overall, these parents face more often solitude, isolation and social marginalization. (Paola Di Giulio, Dimiter Philipov, and Ina Jaschinski, 2014)

In addition, the social and mental condition of these parents is further shaped by the precarious health system, underfunded programs aiming at helping the recognition, prevention and care services of disabled children, frequent cuts in national health budget, instability in the political policy, dramatic local, regional or European crisis.

### ***1.2. European statistics***

It is estimated that about 15% of people worldwide suffer from a form of disability, whether severe or easy, and probably 5,1% of children live with a severe or a moderate form of disability (EFA Global Monitoring Report 2013/4)

In Europe it is estimated that about 15 million children have special educational needs (European Commission). According to the World Report on Disability (2011), in Europe there were recorded the following statistics on disability:

- 0,9 percent of boys between 0 and 14 years old, suffer of severe disability and 0,8% of girls
- moderate severity was recorded in case of 4,4 percent of boys between 0 and 14 years old, and 4,0% in case of girls.

A survey with a sample of 40620 families from Europe, aged between 18 and 84 years old, found that the sample mean for families with disabled children being 1,80% (Paola Di Giulio, Dimiter Philipov, & Ina Jaschinski). Some other studies show that the average percent rate of disabled children in Europe is 2,5 (The UNICEF Innocenti

Research Centre, 2005). The same study found that in Eastern Europe some countries such as Bulgaria, Russia, Georgia, Hungary, Romania and Poland recorder a higher rate regarding child disability than the other countries in the sample.

### ***1.3. Inclusion Policies***

One of the most mentioned documents regarding special needs education is “The Salamanca Statement and Framework for Action on Special Needs Education”. The document came into being at the World Conference on Special Needs Education: Access and Quality (UNESCO), in 1994, in Salamanca, Spain. The document points out the importance of several directions of actions regarding special needs children.

Education should be for everybody – children with special needs should have access to regular schools, and discrimination in case of special needs children can be addressed the best by inclusion in regular schools.

The Salamanca Statement is also a call to action for governments which are guided to adopt the “highest policy and budgetary priority”, to “adopt as a matter of law or policy the principle of inclusion education”, develop preschool and vocational strategies, develop projects and partnerships between countries, involve different partners in education to help organize special needs people...

Another important aspect of the Statement is the initiative to develop inclusive schooling and stimulate the creation of education programs for special needs children, prepare teachers in the field, develop research projects on the topic, fund various initiatives in the educational field.

In addition, equalization of opportunity must be a priority. Countries should create inclusive schools, not special schools, and scientifically based methods should be incorporated into educational programs (The Salamanca Statement, 1994).

In the Salamanca Statement, which contains 50 pages, the words “parent” or “parents” are mentioned only 22 times, and in most cases parents are mentions as *partners* along with other education agents. In addition, the statement underlines the fact that parents have *rights* and their *relationship* with their children is an important aspect, or that parents should be supported and helped to be efficient. Looking back to this statement and to its policy, it is clear why today we there are so few programs to aim parental socio-emotional health and parenting training.

#### ***1.4. Support programs for parents***

Regarding the special needs children there are two main intervention pathways: either children are the target of institutional interventions or parents are targeted as providers of care and nurturing for their special needs children. Obviously, when both sides are developed, family can benefit much more as the intervention becomes holistic. Unfortunately, parents of children with special needs are often overlooked regarding psycho-educational interventions. For example, the site entitled European Agency for Special Needs and Inclusive Education (European Agency) scarcely has any information about intervention programs for parents. The same situation could be found in case of other reports or documents, which mention parents in the context of child inclusion, or cooperation between school, parents and specialists.

European funds such as PHARE<sup>1</sup> or PETI<sup>2</sup>, or Norwegian funds (EEA), created a context for other publications. The main strategy was to reach the key people who could influence these special needs children the most, and they were decision makers such as teachers, principals, specialists in social sciences, teachers at university or anyone-else who could virtually provide specialized care to these children. Although there were few interventions, aimed at directly educating parents, most efforts were made to focus on children, and parents were considered partners or collaborates.

All these efforts target especially children and educators, and their tutors or parents are actually secondary beneficiaries of education and care. Most parents learn about their child's disability from internet sites or they pay on their own courses, in order to find out information and learn techniques which might help their children. Dealing with the needs of such a child comes from the realm of the expert or university area and only parents who attend such courses have access to the qualification to help their children.

There are a few attempts in Europe, to help parents through programs such as:

- „*Vaimupuudega Laste Vanemate Ühing*“, in Estonia, which motivates parents with children with intellectual disability (Association of Parents of Children with Intellectual Disabilities).

---

<sup>1</sup> Poland and Hungary: Assistance for Restructuring their Economies

<sup>2</sup> Project for Inclusive Early Education

- “Parent Know How”, online, UK, which is a program for parents launched in 2008, and which offers support and advice for parents in need, through a variety of means on different topics of interest.

- Side by Side, EU, a program providing training for families online, in Portugal (World Health Organization, 2010)

- Early Bird Programme, UK, a program which helps parents integrate small children in school, manage behavior and communication, and good practices (National Autistic Society).

Education plays a significant role in child development and parent-child interactions. Children with special needs and their parents often fall behind, skip classes, miss vaccinations, go innumerable times to health specialists, have lower quality relationships, do not have enough opportunities to learn efficiently, all such hardships being rather supported and felt by parents to the same extent (Filmer, 2008)

Policy makers should take into account the need of these parents for personal resources and skills to face successfully such problems, and also a positive environment in which they might feel safe and protected. In addition, parents of children with special needs do not have access, at all, to courses and training at a lower price or for free, which puts additional psychological pressure upon them. A research funded by European Union, studying “Families with disabled children in different European countries” states in its conclusions the following: „The promotion of programs directed at the psychological support of the parents and at improving and managing their emotional resources seem to be a crucial point.” (Paola Di Giulio, Dimiter Philipov, & Ina Jaschinski, 2014). Most European countries lacks efficient and specialized intervention programs for parents, all the responsibility being in the hands of the helpless parents. On the other hand, special needs children own problems that are often seen as very serious and any intervention should be led by trained specialists. On the other hand, intervention programs for parents should aim at fortifying parental resources and building appropriate skills necessary for managing special and difficult child situations.

## References

1. Paola Di Giulio, Dimiter Philipov, and Ina Jaschinski, (2014) Families with disabled children in different European countries, <http://www.familiesandsocieties.eu/wp-content/uploads/2014/12/WP23GiulioEtAl.pdf>
2. EFA Global Monitoring Report 2013/4: Teaching and Learning: achieving quality for all.
3. European Commission, [http://europa.eu/rapid/press-release\\_IP-12-761\\_en.htm](http://europa.eu/rapid/press-release_IP-12-761_en.htm)
4. World Report on Disability, World Health Organization, (2011) [https://www.unicef.org/protection/World\\_report\\_on\\_disability\\_eng.pdf](https://www.unicef.org/protection/World_report_on_disability_eng.pdf)
5. The UNICEF Innocenti Research Centre. (2005). Children and disability in transition in CEE/CIS and Baltic states. Retrieved from <http://www.unicef.org/ceecis/Disabilityeng.pdf>.
6. THE SALAMANCA STATEMENT AND FRAMEWORK FOR ACTION ON SPECIAL NEEDS EDUCATION, 1994, <http://unesdoc.unesco.org/images/0009/000984/098427eo.pdf>
7. European Agency, <https://www.european-agency.org/>
8. Association of Parents of Children with Intellectual Disabilities
9. World Health Organization (2010).
10. National Autistic Society, Early Interventions training: Early Bird. As of 30 March 2013: <http://www.autism.org.uk/our-services/residential-community-and-social-support/parent-and-familytraining-and-support/early-intervention-training/earlybird.aspx>
11. Filmer, D. (2008). Disability, poverty, and schooling in developing countries: results from 14 household surveys. *The World Bank Economic Review*, 22:141-163.
12. Paola Di Giulio, Dimiter Philipov, and Ina Jaschinski, (2014) Families with disabled children in different European countries, <http://www.familiesandsocieties.eu/wp-content/uploads/2014/12/WP23GiulioEtAl.pdf>

## II. GENERAL BACKGROUND INFORMATION FOR ROMANIA

Romania (is a sovereign state located in Southeastern Europe. It has an area of 238,397 square kilometres and almost 20 million inhabitants. The country is the seventh most populous member state of the European Union. Capital city of Romaia is Bucharest.

In October 2011, Romanians made up 88.9% of the population. The largest ethnic minorities are the Hungarians, 6.1% of the population, and the Roma, 3.0% of the population. Hungarians constitute a majority in the counties of Harghita and Covasna. Other minorities include Ukrainians, Germans, Turks, Lipovans, Aromanians, Tatars and Serbs.

After the Romanian Revolution of 1989, a significant number of Romanians emigrated to other European countries, North America or Australia. For example, in 1990, 96,919 Romanians permanently settled abroad.

### ***II.1. Description for situation of parents of children with special needs***

Researchers have posited that families of a child diagnosed with a disability are negatively impacted and therefore experience more instability and dysfunction than „typical“ families (Watson, Hayes & Radford-Paz, 2011; Hayes & Watson, 2013). When parents learn that their child has a disability or a chronic illness, they begin a journey that takes them into a life that is often filled with strong emotion, difficult choices, interactions with many different professionals and specialists, and an ongoing need for information and services. Initially, parents may feel isolated and alone, and not know where to begin their search for information, assistance, understanding, and support (ND20, 3<sup>rd</sup> Edition, 2003).

Looking after a child with disability is challenging both physically and psychosocially given that it usually spans the course of a child's life, exceeding typical child development needs and that parents as well as families are not at all prepared for it (Ceylan & Aral, 2007; McCubbin & McCubbin, 1987). As a part of the care giving responsibility, parents encounter a variety of challenges such as overcoming the disappointments attendant to the original diagnosis and the need to coordinate the child's multifaceted medical, educational, and developmental interventions while

balancing competing family needs (Silver, Westbrook & Stein, 1998). Furthermore, caring for a child with disability often requires additional physical, emotional, social, and financial resources (Murphy, Christian, Caplin & Young, 2007). Parents fear social stigma, often have a lack of understanding of their child's needs and some live in poverty. They are given very little or no support in parenting children with disabilities. As a result children with special needs are vulnerable and at high risk of being put into state institutions. Institutional state care further delays the development of children with special needs as often children develop associated disabilities. Children who develop in state institutions are not integrated into society. These children will often require long term nursing care, which ironically results in significantly higher social efforts and costs (<http://www.childrenontheedge.org/romania-early-intervention-for-children-with-special-needs.html>). It is also noted that having a child with disabilities affects not only the parents, but also siblings and the relationships among the family members (Harris, 1994).

Parents of children with disabilities live more intensely the experience of school commencement, because insufficient information or inconsistent support from state institutions make them feel helpless. Most of these parents want mainstreaming school integration and support for them as parents but also as first educators (Gliga & Popa, 2010). The lack of access to education was considered as one of the most significant infringements of the rights of children with disabilities. The *Country Report on Romania for the Study on Member States' Policies for Children with Disabilities* (2013) shows that children with disabilities face several impediments to access the educational system:

- (1) refusal of the schools to register a child with disabilities, particularly with intellectual disabilities;
- (2) expelling children with disabilities from schools in the course of the school year (in this case children with intellectual disabilities also represent a more vulnerable segment);
- (3) difficulty in the formal participation to the educational system. Even if children with disabilities are included in a mainstream class, no particular attention is paid to them (Deteseanu, Ballesteros & Meurens, 2013).

The school authorities justify the non-registration or expulsion arguing that the educational management becomes particularly difficult if a child with disabilities is included in the educational community due to the lack of adapted curricula, personal

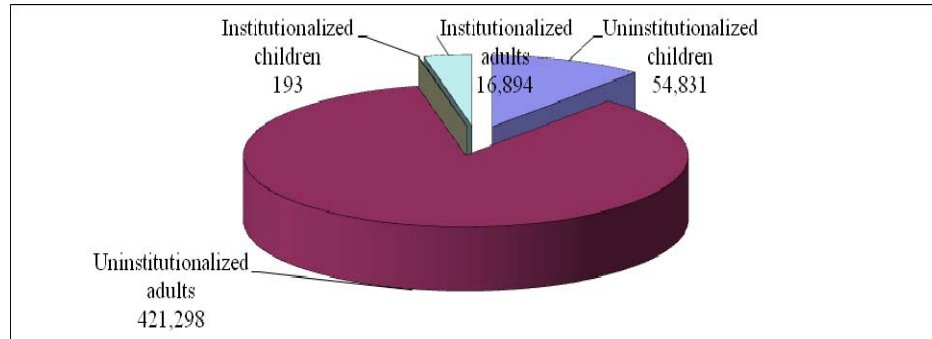
reluctance of other children or parents, and a lack of information. In principle, abusive exclusion of a child from school can be appealed in front of the courts of law, but usually the procedures are lengthy, therefore the practical efficiency of such step can be very low (Deteseanu, Ballesteros & Meurens, 2013). The ministerial authority revealed, from a monitoring report on the rights of children with intellectual disabilities performed during a project of Inclusion Europe in 2011 (questionnaires submitted to families), that almost half of children with disabilities have not attended a nursery school. From those who attended, most of them attended a nursery school for children with special needs. The access to the regular nursery schools is regularly being refused because of the disability (<http://www.disability-europe.net/>). Therefore, parents of children with special needs tend to be faced with a continuous barrage of challenges from societal isolation, financial strain, difficulty finding resources to outright exhaustion or feelings of confusion or burn out.

Studies show that some countries are developing early intervention plans for social services for families with children with disabilities in order to increase the chances that these children are educationally and socially integrated. The role of the family in promoting early social and emotional attitudes and appropriate behavior is crucial for stimulating the potential of children with disabilities (Baily & Bruder, 2005). In this sense, some researches (Guimond, Wilcox & Lamorey, 2008) took into account parental beliefs on the effectiveness of their protective and educational interventions in relation with the role of the environment on child's development.

## ***II.2. National statistics***

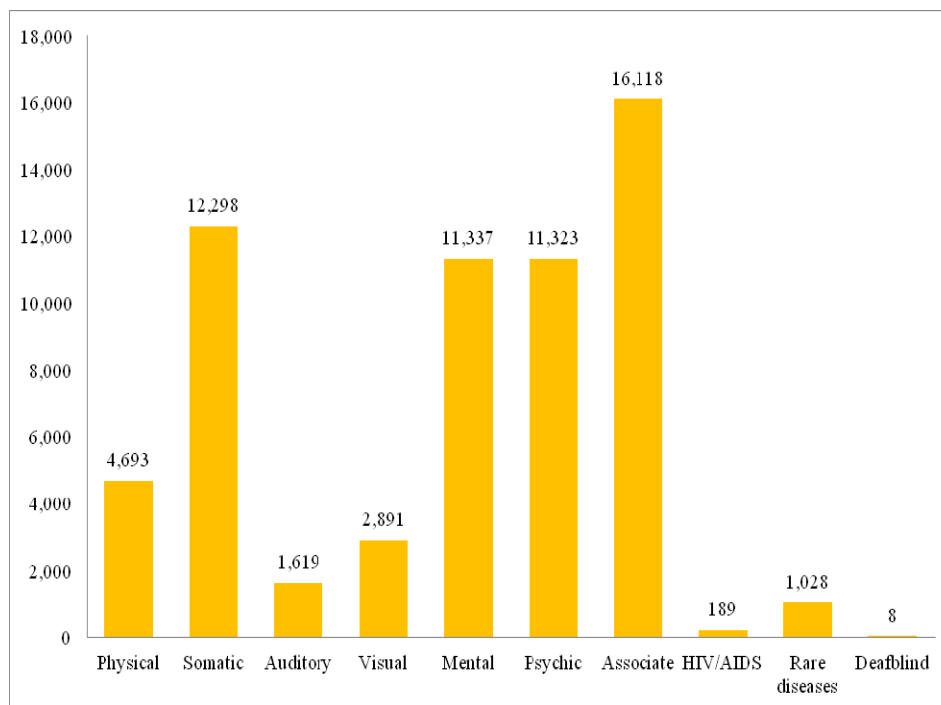
On March 31, 2017, the total number of persons with disabilities communicated to the National Authority for Disabled Persons within the Ministry of Labor and Social Justice, through the general directorates for social assistance and child protection of the county, respectively local ones of the Bucharest municipalities, was 784 527 persons. Of these, were 61 504 children with disabilities registered in Romania. Most of them are not living in institutions (NADP, 2017). So they are cared by family members. Having a family member with a disability can have an effect on the entire family; the parents, siblings, and extended family members. It is a *unique shared experience* for families and can affect all aspects of family functioning. The importance of valuing the families of these youth, building on their strengths, and having available an array of social supports

has been widely endorsed in the children's mental health field (Cheney & Osher, 1997; Karp, 1993; Koroloff, Friesen, Reilly & Rinkin, 1996).



**Figure 1. Institutionalised and uninstitutionalized disabled persons (adults and children), on March 31, 2017 (NADP, 2017)**

On the other hand, according to law no. 448/2006 on the protection and promotion of the rights of persons with disabilities, republished, the types of disabilities are: physical, visual, auditory, deafness, somatic, mental, psychic, HIV / AIDS, associate, rare diseases.



**Figure 2. Number of children with disabilities by type of disability, on March 31, 2017 (NADP, 2017)**

Also, according to law no. 448/2006 on the protection and promotion of the rights of persons with disabilities, republished, the degrees of disability are: severe, accentuated, medium and easy. The number of persons with severe disabilities represents 36.91% of the total, the disabled with accentuated disabilities represents 51.66% and with medium and easy disabilities represents 11.43% (NADP, 2017).

However, reports indicate that this figure does not take into account all of the children with disabilities in Romania since it only includes children with disabilities registered in the official database. Such registrations are only being made on a voluntary basis by a child's parents or guardians. In addition, such data does not reflect the real number of children with intellectual disabilities because the legislation and public policies do not define clearly what falls under the scope of intellectual and psychosocial disabilities and mental illness, which generates confusion in providing specialised services and registration.

### ***II.3. Inclusion Policies in Romania***

In the past 27 years in Romania there have been major changes at a political, social, economic and educational level. The economic and social transition in Romania, after communist regime, had mixed implications for the education of children seen as having special needs. Policy, research and practice in special education and inclusion of children with disabilities in the mainstream school system and social life are one of the most important priorities in Romanian educational policies. The basic premise of the integration/inclusion movement is that principles of anti-discrimination, equity, social justice, and basic human rights make it imperative that students with disabilities and special needs should enjoy the same access as all other students to a regular school environment and to a broad, balanced and relevant curriculum (Gherguț, 2011).

Romania takes account about international bodies recommendations and created the legislation on the education of persons with special educational needs, in according whit international documents which was joined: *United Nations Convention on the Rights of the Child (1990)*, *The Jomtien Statement on Education for All (1990)*, *The Standard Rules on Equalisation of Opportunities for People with Disabilities (1993)* and *The Salamanca Statement (1994)* (Vrașmas & Daunt, 1997; Gherguț, 2011).

Gherguț (2011) made a brief presentation of principal moments and events which have marked reform process of inclusion on Romanian educational system after communist regime:

- Since 1993 the Ministry of Education in Romania, with support from UNICEF, has carried out a series of initiatives in order to explore ways of encouraging the development of more inclusive practices. The Romanian initiative has included a programme of awareness-raising involving teachers, inspectors and teacher trainers from around them country;

- The Salamanca Conference on Special Needs Education from 1994 came in a ripped time for Romania - one year after the two pilot projects have started – focusing on integration. The concept of inclusive education was launched inside the two pilot projects and in the RENINCO (National Network of Information and Cooperation for Integration into the Community of Children with Special Needs) activities, starting with the autumn of 1994;

- Other teacher education initiatives, such as the Tempus Programs, since 1995, which fund collaborative partnerships between Western universities and East European teachers and their trainers, have taken steps towards developing the understanding of leaders in this field about how to manage and support the process of change;

- The Education Law from 1995 has included an implicit inclusive approach: all Romanian citizens have an equal right to education, at all levels and in all forms, regardless of gender, race, nationality, religious, or political affiliation and social or economical status; also, the state is ensuring the principles of democratically education, and guarantees the right to differentiated education, on the basis of educational pluralism;

- After 1997 has extended the development of partnerships between schools and national and relevant international organizations in the field (RENINCO, UNICEF, UNESCO, etc), developing training programs about integration for teachers in regular schools and special schools, developing local projects for inclusion, developing partnerships between professionals, parents and volunteers;

- The isolation in special schools has been slightly stopped in 2001, when 18.000 children with disabilities from special schools were transferred to ordinary schools. Unfortunately this decision has generated many convulsions and resistances to change from schools and parents because the conditions needed here were not enough

developed (for example, adapted curriculum, training of teachers and the development of a supportive attitude in schools);

- Between June 2002 - December 2003 was developed National Program *A School for All* launched by the MEC in partnership with UNICEF Romania, National Authority for Child Protection and Adoption (NACP) and the RENINCO, which has sought information, awareness and preparation of school and community to integrate children and youth with special educational needs;

- Between 2004-2007 was applied *Develop National Action Plan on Education for Children with Special Educational Needs* with 3 directions: develop and implement ongoing training programs for teaching staff in schools; schools, families and communities awareness on the importance and positive effects of socialization process and social integration of children with disabilities; acceptance of human diversity as a natural fact necessary in society.

- A Government Decree, 1251 from 2005 has introduced a new concept – *integrated special education* – not clearly defined. The terms *inclusion*, *inclusive education* and *inclusive school* have been also introduced in this recent piece of legislation, but under the umbrella of *integrated special education*. The definition of *inclusion* in the Decree from 2005 is the following: “*Inclusive education means an ongoing process of upgrading the school institution, with the aim of exploiting (valuing) the existing resources, particularly human resources, in order to support the participation in learning of all pupils from inside a community.*” It has taken 10 years since the inclusive concept already launched in the scientific and practical work in Romania to be included in a piece of legislation;

- Legislation has been supplemented by rules, methodologies and regulations developed and approved by order of minister by Ministry of Education (MEC): Order by Minister no. 4378/7.09.1999 regarding the approval of the program: “*Measures for the organization of special education*”; Order by Minister no. 3634/12.04.2000 to maintain the approving the national program: *The integration and rehabilitation of children with disabilities in/by community*; Order Minister of Education and Research, no. 5379/25.11.2004 on methodology of organization and operation of educational services by teachers support/peripatetic teacher for children with special educational needs in mainstreaming education; Order MEC no. 3662/27.03.2003 approving the Methodology for establishing and functioning of the Commission of Internal Continuous Assessment

of children with special needs; Government Decision 1251/2005, which has structure, organization, forms and types of institutions and personnel in special schools and especially integrated Government Decision no. 1251/2005 on the organization of special education; Order Ministry of Education, Research and Youth, no. 1529/18.07.2007 diversity on development issues in the national curriculum; Order of Ministry of Education, Research and Innovation, no. 3414 of 16.03.2009 on approval of the Framework Plan for special education school.

At present, there are frequent debates around the role of environmental and attitude factors, in order to emphasize that disability is not an attribute of the person but rather a relationship between a person with a particular disability and/environment. The unadjusted environment is the one that "disables" the person, especially due to architectural obstacles but not only, and in this relationship the assumption of responsibility to remove barriers and to facilitate active participation in the social life of people with disabilities becomes an obligation of each of us (UNICEF, 2013).

Currently, the most powerful international disability instrument is the United Nations Convention on the Rights of Persons with Disabilities, adopted by the United Nations General Assembly on 13 December 2006, together with the Optional and Open Protocol for the United Nations Headquarters in New York, starting with March 30, 2007. The Convention is the highest legal document that ensures the full enjoyment of all human rights and freedoms by all persons with disabilities. Romania signed the Convention on September 26, 2007 and ratified it by Law no. 221/2010, published in the Official Gazette no. 792 of 26 November 2010 but has not yet ratified the Optional Protocol. In order to ensure the effective implementation of the Convention, the European Commission adopted, on 15 November 2010, *The European Disability Strategy 2010-2020: a renewed commitment to a barrier-free Europe*, setting out the priorities and the work plan for the coming years. The overall objective of this strategy is to give people with disabilities the capacity to enjoy full rights and to fully benefit from participation in European social and economic life. The strategy focuses on removing barriers in eight main areas of action: Accessibility, Participation, Equality, Employment, Education and Training, Social Protection, Health and External Action (UNICEF, 2013).

#### ***II.4. Support programs for parents in Romania***

The support and caretaking of people with disabilities is the focus of the educators, pediatric doctors, kineto-therapists, logopedy but also of the parents/legal guardians of the children with disabilities. The Salamanca Declaration (UNESCO, 1994) underlines the role that parents need to play in education: *“...the purpose of a successful education of the children with SEN is not only the duty of the Ministry of Education and of the schools. A successful education necessitates the cooperation of families, community, volunteer organizations as well as the public at large”, and later “Parents [...] as much as possible, need to be given the choice of the type of education they want for their children.”* Thus, the currently accepted model for inclusive education is that of a partnership between the educational psychologist and the parent. This partnership involves a distribution of responsibilities (O'Connor, 2003; Gliga & Popa, 2010) where the parent overcomes his/her role of “client” and takes an active role in their children education. Whether this partnership is successful depends on the interplay between traditional and modern values in society. In many societies teachers are traditionally considered as being the sole actors in taking educational decisions, and parents of children without disabilities are reluctant to any changes in their children educational environment (Mitchell, 2005). Gliga and Popa (2010) focus on parents' views about inclusive education because of the crucial role those have as “teachers”, “partners” and “lawyers”, especially at the moment where children finish kindergarten and start school. Their role of teachers is required to reinforce and generalize the skills required for formal schooling. As partners, they work along with the educational psychologists to help the child familiarize with the new environment and demands and solve any difficulties encountered. Also they often have to navigate through legislative procedures in order to obtain the financial and educational benefits their child requires. The belief that inclusive education can and will work for their child is therefore the crucial drive, without which many will not have the strength to embark on this path (Gliga & Popa, 2010).

To increase the access of children with disabilities to community life, day care and recovery centers are of vital importance. The number, diversity and availability of such services are limited and on the other hand, transport insurance is a key element. In June 2013, the Bucharest Branch of ASCHF-R organized 4 focus groups to investigate the obstacles faced by parents and their needs. The report shows how hard it is for parents

to find solutions for the complex, educational, rehabilitation and socialization services their children need (UNICEF, 2013; [www.czaurora.ro](http://www.czaurora.ro) ). In order to prevent and/or overcome the situations that could lead to separation of the child with disabilities from his/her family but also the aggravation of the child's deficiencies, day services should be present in all communities in different forms such as day centers, counseling and support for parents, recovery centers, occupational therapy centers, assistance and support, and others. Local councils and county councils should intervene by providing assistance and support to parents and by developing diversified, affordable and quality services tailored to the needs of the child in order to grow and develop (UNICEF, 2013).

Social Assistance Law no. 292/2011 mentions the possibility of organizing social services in an integrated system, along with those in the field of employment, health, education or other social services in the community. This way of providing services implies a very good coordination of activities in different areas of intervention, as well as a close and effective collaboration between professionals in these areas. The purpose of providing integrated services is to better meet the complex needs of users, as well as to make better use of existing resources at the local level (Social Assistance Law no. 292/2011).

And yet, even if there is an encouraging legislative framework, the diverse needs of children make parents persistently look for the type of center where the child has access to more services and be cared for, encouraged and supported in everything he does. Sometimes parents have the initiative to set up such a center, as it did in 1995, when parents of children with severe and associated neuromotor disabilities decided to set up the Aurora Day Center or in February 2000 ([www.czaurora.ro](http://www.czaurora.ro)), when the parents of the St. Ana Association have established a day care center with direct care, recovery, socialization and support for school education for their children with mental and associated disabilities ([www.sf-ana.ro](http://www.sf-ana.ro)) and examples can continue. Caritas Romania ([www.caritasromania.ro](http://www.caritasromania.ro)) founded in 1992 a center for children with Langdon-Down Syndrome, which since 2008 has become a center for supporting preschool and school children with disabilities and their families, and which, besides the specific services of recovery, therapy occupational, speech therapy, psychomotricity, provides parents with information and guidance, emotional support, psychological counseling, counseling, and parental school programs (UNICEF, 2013).

Many services have been set up and/or developed by non-governmental organizations in the early intervention area, precisely because of the importance to be given to it but, at the same time, have a limited sphere of action. The Inocenti Foundation in Bistrita has initiated an early intervention program for children with developmental and neuro-psycho-motor deficiencies in the county and offers therapeutic and psychological rehabilitation and kineto services at home and at home, counseling and information , support groups for parents but also support in taking steps related to the medical recovery of the child ([www.inocenti.ro](http://www.inocenti.ro)). Another type of early intervention takes place at Târgu Mureş Center for Early Prevention and Intervention of Neuro - Psycho - Motors Disabilities, organized by the Alpha Transilvana Foundation. The Impuls Center has in time developed an efficient way of collaboration and partnership with the local authorities, the Neonatology Clinic and the Premature Clinic of the Mureş County Clinic Hospital, with family doctors, so far over 1000 children have benefited by specialized services aimed at reducing or eliminating neuro-psycho-motor delays of young children aged 0 to 3, as well as counseling and assistance to parents ([www.alphatransilvana.ro](http://www.alphatransilvana.ro)).

Opportunities for developing specialized services have been created in recent years by the active funding lines through the Structural Funds. Through the project "And they must have a chance! - support program for the social and professional integration of people with Autistic Spectrum Disorders ", for example, 40 counseling and assistance centers were set up and endowed for children/young people with TSA and their dependents (UNICEF, 2013). In the same context, the Ministry of Labor, Family, Social Protection and Elderly People implemented the project "Increasing the Capacity of Local Public Authorities in Romania to Support Children with Disabilities within Their Own Family". Twenty multidisciplinary mobile teams, consisting of a speech therapist, physical therapist, occupational therapist, pediatrician, specialized educator, social worker, have been created to provide support to children with disabilities, their parents and specialists in the community where the children are in order to meet the objectives set in the recovery plan and the formation of its members in the counties: Arad, Arges, Bihor, Bistrita Nasaud, Braila, Brasov, Dambovita, Dolj, Galati, Giurgiu, Gorj, Mehedinti, Vaslui, sector 4 and sector 6 - Bucharest. The mobile teams set up by the project have subsequently become an integral part of the services provided by the DGASPC in the counties involved ([www.mmuncii.ro](http://www.mmuncii.ro)).

The functioning of the family cannot be separated from the societal context. No matter how strong it may be, however much cohesion is among its members, the family also needs support from other members of society. In addition, the social perception of disability is often not favorable, social inclusion is inevitably affected by societal and cultural barriers (Gherguț, 2007; Roth & Rebeleanu, 2007). As we can see here, the role of society, of the values that it promotes, intervenes, which also contribute to the integration of this population into the community.

Synthesizing the data obtained from qualitative analyzes and quantitative analysis, Chercheș (2011) reported the most important problems/needs encountered in families with a disabled child: difficulties in accessing specialized medical services, problems with the integration of children into an educational structure, insufficient resources financial difficulties, difficulties for children and families in rural areas in accessing services (specific therapies, medical recovery services, etc.), the fact that they do not have information about the services they can benefit from, they have difficulties in understanding the information provided by the specialists, on the future of children, given that there are no services such as: sheltered workshops, occupational therapy centers, residential centers, respiration centers etc. Taking into account these specific needs of children with disabilities and their families, in order to improve the quality of individual and family life, the researchers propose a series of steps: accessing non-reimbursable funds for the development of new services of those mentioned as nonexistent; public awareness campaigns on the implications of individual, family, community and social disability, and the role of the active involvement of each member of society in helping those who face such problems; initiating and developing research in the field to assess the phenomenon and proposing appropriate intervention measures; developing partnerships between public, private and civil society institutions; the compatibility of legislation in the field with the real needs of this category (Chercheș, 2011).

## References

1. Bailey, D. B. & Bruder, M. B. (2005). Family outcomes of early intervention and early childhood special education: Issues and considerations. Washington, D.C.: Office of Special Education Programs, Early Childhood Outcomes Center.
2. Ceylan, R. & Aral, N. (2007). An examination of the correlation between depression and hopelessness levels in mothers of disabled children. *Soc Behav Pers* 35: 903–908.
3. Cheney, D., & Osher, T. (1997). Collaborate with families. *Journal of Emotional and Behavioral Disorders*, 5, 36–44.
4. Chercheș, C. (2011). Calitatea vieții în familiile copiilor cu dizabilități neuro-motorii. Doctoral Thesis, Babeș-Bolyai University, Cluj-Napoca.
5. Deteseanu, D.-A., Ballesteros M. & Meurens, N. (2013). Country Report on Romania for the Study on Member States' Policies for Children with Disabilities. European Parliament, Brussels.
6. Gherguț, A. (2011). Education of Children with Special Needs in Romania; Attitudes and Experiences. *Procedia Social and Behavioral Sciences*, 12, 426–435.
7. Gherguț, A., (2007). Sinteze de psihopedagogie specială. Ghid pentru concursuri și examene de obținere a gradelor didactice, Editura Polirom, Iași;
8. Gliga, F. & Popa, M. (2010). In Romania, parents of children with and without disabilities are in favor of inclusive education. *Procedia - Social and Behavioral Sciences*, 2, 2, 4468-4474.
9. Guimond, A. B., Wilcox, M.J. & Lamorey, S.G. (2008). The early Intervention Parenting Self-Efficacy Scale ( EIPSES). *Journal of Early Intervention*, 30, 4, 295-320.
10. Harris, S.L. (1994). *Topics in Autism: Siblings of Children with Autism: A Guide for Families*. Bethesda, MD: Woodbine House.
11. Hayes, S. A. & Watson, S. L. (2013). The Impact of Parenting Stress: A Meta-analysis of Studies Comparing the Experience of Parenting Stress in Parents of Children With and Without Autism Spectrum Disorder *Journal of Autism and Developmental Disorders*, 43:629 - 642.
12. Karp, N. (1993). Collaboration with families: From myth to reality. *Journal of Emotional and Behavioral Disorders*, 2, 21–23.

13. Koroloff, N. M., Friesen, B. J., Reilly, L., & Rinkin, J. (1996). The role of family members in systems of care. In B. A. Stroul (Ed.), *Children's mental health: Creating systems of care in a changing society* (pp. 409–426). Baltimore, MD: Paul H. Brooks Publishing Company.
14. Law no. 292/2011 of the social assistance, published in the Official Gazette of Romania, Part I, no. 905 of December 20, 2011, art. 28.
15. McCubbin, M.A. & McCubbin, H.I. (1987). *Family stress theory and assessment: the T-double ABCX model of family adjustment and adaptation*. Madison, WI, USA: University of Wisconsin-Madison.
16. Mitchell, D. (2005). *Contextualizing Inclusive Education. Evaluating old and new international perspectives*, Routledge David & Francis Group, USA, 1-37.
17. Murphy, N. A., Christian, B., Caplin, D.A. & Young, P.C. (2007) The health of caregivers for children with disabilities: caregiver perspectives. *Child Care Health Dev* 33: 180–187.
18. National Authority for Disabled Person (NADP). (2017). *Statistic Data*, Ministry of Labor and Social Justice  
<http://anpd.gov.ro/web/transparenta/statistici/trimestriale/>
19. ND20, 3<sup>rd</sup> Edition. (2003). *Parenting a Child with Special Needs*. National Information Center for Children and Youth with Disabilities.
20. O'Connor, U. (2003). *Parental Views on Inclusive Education for Children with Special Educational Needs*, National Disability Authority, Ireland.
21. Pinkerton, D. (1991). *Preparing Children with Disabilities for School*, ERIC Clearinghouse on Handicapped and Gifted Children, Reston, VA
22. Roth, M. & Rebeleanu, A. (2007). *Asistența socială. Cadru conceptual și aplicații practice*, Presa Universitară Clujeană, Cluj-Napoca.
23. Silver, E.J., Westbrook, L.E. & Stein, R.E. (1998). Relationship of parental psychological distress to consequences of chronic health conditions in children. *J Pediatr Psychol* 23: 5–15.
24. UNICEF. (2013). *Children with disabilities. Raport*, București
25. United Nations Educational, Scientific and Cultural Organization (UNESCO). (1994). *The Salamanca Statement and Framework for Action on Special Need Education*, Spain.

26. Vrasmas, T. and P. Daunt (1997). The Education and Social Integration of Children and Young People with Special Needs in Romania: A National Programme. European Journal of Special Needs Education, Vol. 12, No. 2, pages 137-147.
27. Watson, S. L., Hayes, S. A., & Radford-Paz, E. (2011). 'Diagnose me please!': A review of research about the journey and initial impact of parents seeking a diagnosis of developmental disability for their child. International Review of Research in Developmental Disabilities, 41, 31
28. <http://www.disability-europe.net/>
29. [www.sf-ana.ro](http://www.sf-ana.ro)
30. [www.czaurora.ro](http://www.czaurora.ro)
31. <http://caritasromania.ro/>
32. [www.inocenti.ro](http://www.inocenti.ro)
33. [www.alphatransilvana.ro](http://www.alphatransilvana.ro)
34. [www.mmuncii.ro](http://www.mmuncii.ro)
35. <http://www.childrenontheedge.org/romania-early-intervention-for-children-with-special-needs.html>

### **III. GENERAL BACKGROUND INFORMATION FOR SPAIN**

Spain is a state located on the Iberian Peninsula in southwestern Europe, and it counts with two large archipelagoes, the Balearic Islands in the Mediterranean Sea, and the Canary Islands, in the North African Atlantic coast. It also has two cities, Ceuta and Melilla, in the North African mainland and several small islands in the Alboran Sea near the Moroccan coast. It has a total area of 505,990 km<sup>2</sup> and it is considered the largest country in Southern Europe.

Spain is a parliamentary democracy and constitutional monarchy. The current Spanish king is Felipe VI. It is a middle power and a major developed country. Spain's capitalist mixed economy is the 14th largest worldwide and the 5th largest in the European Union, as well as the Eurozone's 4th largest.

In 2008 the population of Spain officially reached 46 million people. 88% of the population is native Spaniards. Another 12% is constituted by immigrants, mainly from Latin America and North Africa. The capital is Madrid, with 3,165,235 citizens. Spain is also considered a plurinational country, with distinct traditional identities with different languages. These populations include the Basques, Catalans, Galicians, Andalusians and Valencians.

State education in Spain is free and compulsory from the age of six to sixteen. The current education system is regulated by the 2006 educational law, LOE (Ley Orgánica de Educación), or Fundamental Law for the Education.

#### ***III.1. Description for parents of children with special needs***

According to the current regulations, both the student and the family are part of the community and they participate proactively, since they are the main protagonists. Families and school share a common objective: the educational success of the students. Family and school are two worlds that need to be recognized to make good accompaniment to the students.

Although parents feel there may be not the ideal support system at times, according to the Department of Education, families constitute a central part of the educational community and the schools must be conceived as an essential entity to develop the projects. Parents of children with special needs are taken into account at

any moment of the process. In fact, the relationships between family and school are based on mutual respect, trust and acceptance of singularities of each one. There are not two equal teachers, neither two equal families. Contact and relationship with the families must allow the models of intervention and relationship with children to be enriched. It is needed that families felt understood, that they have spaces for participation within the educational project and are counted on them for to the development of the educational assistance of their children.

Educative policies enhance a tendency towards an inclusive school, which means leaving behind the simple participation of the family in targeted programs for teachers in favor of the creation of new avenues for parental involvement in decision-making and in the educational process of their children. This involves an implication with a collaborative model between professionals and families, in which one and the other recognize mutually necessary knowledge and expertise, which focus on enrichment and the opportunities that are generated beyond the needs.

This fact is even more relevant when it comes to students with special educational needs, given the conditions of vulnerability that often go with their development and learning process. The collaboration of families thus, is a central key for the detection of the needs of the students, and to be able perform the psychopedagogical evaluation when necessary.

### ***III.2. National statistics***

According to the *Estadística de las Enseñanzas no Universitarias*, carried out by the *Subdirección General de Estadística y Estudios del Ministerio de Educación, Cultura y Deporte*, Spain has a total of 2.9% of the students (173.797 out of a total of 8.101.473) with special needs (see Table 1).

		<b>Percentage</b>
<b>Sex</b>	<i>Boys</i>	66.84
	<i>Girls</i>	33.16
<b>Type of disability</b>	<i>Hearing impairment</i>	4.33
	<i>Motor impairment</i>	7.71
	<i>Psychological impairment</i>	37.39
	<i>Visual impairment</i>	1.84
	<i>Developmental disorders</i>	17.45
	<i>Behavioural disorders</i>	22.35
	<i>Pluridisability</i>	6.01
	<i>Others</i>	2.91

According to latest reports, two out of these three children are boys and Spain is, together with countries like Luxemburg, Italy and the U.K. one of the countries with lower percentatge of students with special needs.

### ***III.3. Inclusion policies in Spain***

The Educational System in Spain arranges the necessary resources for pupils with temporary or permanent special educational needs to achieve the objectives established within the general programme for all pupils.

The public administrations give all the students the necessary support from the beginning of their schooling or as soon as they are diagnosed as having special educational needs. It is thus, important to take into account that school teaching is in all cases adapted to these pupils' needs. Didactic plans lead to programmes, which have to take into account the pupils' needs and characteristics. Additionally there is an educational project, where the objectives and the educational priorities are established, along with the implementation procedures.

The Act on the Improvement of the Quality of Education (LOMCE, 2013) considers four types of specific educational support needs:

1. Students with special educational needs
2. High-ability students
3. Late entries into the Spanish education system
4. Specific learning difficulties.

Among the ordinary measures that the Spanish Educational System offers for attending to diversity, there are: successive levels of curricular formulation, involving the progressive adaptation of the official curriculum and optional areas and subjects, the organization of reinforcement and support activities in educational establishments, and specific grouping. Once ordinary measures of attention to diversity have been applied and have proved to be insufficient to respond to the educational needs of an individual pupil, the education system considers a series of extraordinary measures. These include repeating a cycle or school year, significant curricular adaptations, support measures for pupils with special educational needs, curricular diversification and, as a last resort, social guarantee programmes.

### ***III.4. Inclusion policies in Catalunya***

Booth (2002) emphasizes that inclusive education is constituted by a body of values that impregnate both culture, such as educational policies, and teaching-learning practices, which make it possible to ensure that all people, regardless of their socio-economic and cultural origin and their innate or acquired capacities, have the same learning opportunities in any educational context. This, at the same time, helps to create more equal and fair societies.

In order to create inclusive cultures, Education Department understands that it is highly necessary a permanent and renewed dialogue with the families and the environment. The development of inclusive policies in the centers is based on the development of a school for all of the students. Schools must organize the resources properly to ensure diversity attention within their educational programs, which at the same time consider the participation of students and their families as a central part of the program development. In these plans, there are the measures and the supports minimizing the access barriers which any Student with special needs may find. Inclusive practices are the reflection of culture and inclusive policies. The development of these practices focuses on two aspects:

- Providing resources for the learning process and mobilizing resources to promote flexible educational projects that have the co-responsibility of all the teaching teams.
- Organizing classroom activities that promote autonomy and collaborative learning among students.

### ***References***

1. Booth, T. & M. Ainscow (2002). Index for inclusion. Developing learning and participation in schools. Centre for Studies on Inclusive Education (CSIE). <http://www.eenet.org.uk/resources/docs/Index%20English.pdf>
2. LOMCE, L. G. E. LLEI GENERAL DE L'EDUCACIÓ (1970).
3. Fernández-González, N. (2015). PISA como instrumento de legitimación de la reforma de la LOMCE. *Bordón. Revista de Pedagogía*.
4. González Fernández, Y. (2016). Discapacidad y educación en la enseñanza obligatoria: percepciones docentes sobre el alumnado. ODISMET.

#### IV. GENERAL BACKGROUND INFORMATION FOR PORTUGAL

From an ethical and legal point of view, the Constitution of the Portuguese Republic (articles 67, 69 and 70) assigns to the society and to the State the duty to protect family, children and young people, with a view to its integral development, and grants a special right for the protection of orphan children, abandoned or deprived of a normal family environment. Thus, there are 3 levels of intervention for different types of institutions, which will be indicated below, each with different and/or common responsibilities.

Within the essential aspects for the implementation of Intervention Programs, we are working on the basis that "... family is the first child's development and learning context, thus being of central interest in the field of Early Intervention in Childhood (IPI)...» (Sanguinho, 2011), which is why there are more and more national early intervention programs (IP) being implemented. Any national or regional entity that promotes or participates in Intervention Programmes that include children or young people have to obey to the nine (9) principles underlying any initiative, as follows:

1. The best interests of the child and young person, as first reference of the action, without prejudice to the due consideration to other legitimate interests;
2. Privacy, related to the respect for intimacy and image rights of the child or young person;
3. The intervention, as early as possible, that should be implemented as soon as the risk situation becomes known;
4. The minimum intervention, safeguarding that only the agents necessary for the promotion of rights and protection of the child or young person at risk are involved;
5. Proportional and current intervention, ensuring that its implementation takes place in accordance with the principles of reasonableness and at the immediate moment to the decision-making, producing a minimum impact in the life of the child, the young and its family;
6. The exercise of parental responsibility, being the intervention triggered so that the parents assume their respective duties towards the child or the young people;
7. Mandatory information, bearing in mind that the child, the young person, the parents, the legal representative or the person who has the respective custody must be

informed of their rights, the reasons that determine the intervention and the way it takes place;

8. Participation in the actions and in the definition of measures and the compulsory hearing are ensured for the child or young person from 12 years of age, the parents, legal representatives or those with the custody;

9. Subsidiarity in the intervention, which should lie, in the first instance, with the competent entities in matters of childhood and youth, in second instance to the National Committees for the Promotion of the Rights and Protection of Children and Young People (CPCJ) and, in the third instance, to the Courts.

This is the set of essential and global care that the detection and support measures respect, being considered to be of crucial importance by all the institutions in this field.

Portugal, is officially the Portuguese Republic, and is an unitary sovereign country located in southwestern Europe, whose territory lies in the western part of the Iberian Peninsula and in archipelagos in the North Atlantic. The Portuguese territory is delimited to the north and east by Spain and to the south and west by the Atlantic Ocean, comprising a continental part and two autonomous regions: the Azores and Madeira archipelagos. Portugal is the westernmost nation on the European continent. The name of the country comes from its second largest city, Porto, whose Latin-Celtic name was Portus Cale. Portugal is a developed country, with a Human Development Index (HDI) considered as very high. The country ranked 19th in quality of life (in 2005), has one of the best health systems in the world and is also one of the most globalized and peaceful nations in the world. It is a member of the United Nations (UN), the European Union (including the Eurozone and the Schengen Area), the North Atlantic Treaty Organization (NATO), the Organization for Economic Co-operation and Development (OECD) of Portuguese Speaking Countries (CPLP). Portugal also participates in several United Nations peacekeeping missions. The official language of the Portuguese Republic is the Portuguese, adopted in 1290 by decree of King D. Dinis. With more than 210 million native speakers, it is the fifth most spoken language in the world and the third most spoken in the Western world. It is the official language of Angola, Brazil, Cape Verde, Guinea-Bissau, Mozambique and Sao Tome and Principe, and official language along with other official languages in Timor-Leste, Macao and Equatorial Guinea. It also has official status in the European Union, the Union of South American Nations (UNASUR), the Common Market of the South (Mercosur) and the Common Market of the South

(Mercosur) and the African Union. At the level of religion, the Portuguese Constitution guarantees religious freedom and equality between religions, despite the Concordat that privileges the Catholic Church in various dimensions of social life.

Talking about cities, Lisbon (about 500,000 inhabitants - 3 million inhabitants in the region of Lisbon) is the capital since the thirteenth century (taking the place Coimbra), the country's largest city, main economic hub, holding the main seaport and Portuguese airport. Other important cities are those of Oporto (about 240,000 inhabitants - 1.5 million in Greater Porto), the second largest city and economic center, Aveiro (sometimes called the "Portuguese Venice"), Braga ("City of Archbishops" ), Chaves (historical and millenarian city), Coimbra (with the oldest university in the country), Guimarães ("City-crib"), Évora ("City-Museum"), Setúbal (third largest port), Portimão (a port of cruises and headquarters of the AIA), Faro and Viseu.

#### ***IV.1. Description for situation of parents of children with special needs***

Family is not an essential focus of attention, diagnosis and intervention. In fact, in Portugal, actions at the level of families, especially of children with NE, start from – in all institutions that in isolation or in multidisciplinary teams – actions that signalize, follow, protect and intervene in the children of these families. This process is developed as presented in the following chapters.

#### ***IV.2. National statistics***

Because of the methodology adopted and for ease of understanding, the statistics presented here are recent and based on Portuguese institutions that have responsibility to protect children and young people at risk, i.e. the CPCJ.

If we took a brief look at the household of the young people monitored we can notice two things:

- The high proportion of young people belonging to single-parent (36.5%) or reconstituted (13.4%) families was well above the existing percentage on the national resident population;
- Although this number has been decreasing, the percentage of caregivers (parents/family) whose incomes depend on the income support allowance (14%) or unemployment benefit or pensions (12.8%) was very high when compared with the general population.

The number of monitored children has grown systematically since 2007 and only was registered a slight decrease between 2010 and 2011. In the year under review were monitored less 2339 children than in 2015, corresponding to a decrease of 3.2%.

Communications/signalling made to the CPCJ – what are the special needs that arise?

In 2016 were communicated to the CPCJ 39 194 situations of children and young people at risk. The signalling was made by public and private entities and citizens. It should be noted that there was a decrease of 148 cases of physical abuse and 101 of sexual abuse compared to 2015.

Comparing the evolution of the main situations of risk signalled over the last six years (2011-2016), we highlight the following:

- The most identified situation of risk as of 2012 was the ECPCBEDC (Exposure to Behaviors that May Compromise the Welfare and Development of the Child), which has had an exponential growth, rising 12 percentage points in the last six years; Negligence, which until 2012 was the most identified situation of risk, has been decreasing in proportion, but in absolute numbers have increased slightly since 2014; The SPDE (Situations of Risk on the Right to Education) has decreased significantly in percentage values since 2014; The situation of risk CJACABED has increased in percentage and absolute values. However, there are two aspects that worth's mentioning:

2) In the fourth most identified category, CJACABED (Child/Young person that had Behaviors that Affect their Well-being and Development), the subcategory "serious anti-social and/or indiscipline behaviors" corresponded to 1492 files (25.1% of the total) and there were identified 440 situations of bullying (7.4% of the total).

Protection of children: Diagnostics and measures implemented - In 2016, after the evaluation of the CPCJ, were diagnosed 35 950 situations of risk which substantiate the implementation of a promotion and protection measure.

### **Situation of disability or impairment**

On the profiling of children there are two specific groups which are particularly vulnerable, the children with disability or impairment and children with mental health problems. This special attention is in line with the recommendations of the Committee on the rights of the child of the Council of Europe, on the third and fourth periodic reports of Portugal, concerning the importance of the support of non-discrimination and social inclusion of children with disabilities and of children with mental health

problems, finally, 980 (1.4%) out of every 71 016 monitored children, were identified as having a disability or impairment.

**Table 1\* - Children and young people studied by type of disability**

<b>Type of disability</b>	<b>Total</b>	<b>%</b>
Mental/Intellectual	345	35,2
Other	128	13,1
Speech Problems	110	11,2
Other Psychological Disorders	65	6,6
Cerebral Palsy	56	5,7
Multiple Disabilities	55	5,6
Hearing-impaired	48	4,9
Physical Disability	41	4,2
Visual Impairment	40	4,1
General, Sensory and Other Functions Impairment	29	3,0
Musculoskeletal Disorders	27	2,8
Without Information	19	1,9
Other Organs Impairment	14	1,4
Aesthetic Impairment	3	0,3
	980	100,0

In CPCJ. (2017). Relatório de Avaliação da Atividade das CPCJ – 2016. Maio 2017

### ***IV.3. Inclusion policies in Portugal***

In Portugal, 2 new laws on childhood and youth, which do not exclude parents and family, have been passed in 1999 by the Assembly of the Republic:

- **Law on Protection of Children and Young People at Risk (LPCJP) (Law Nº 147/99, of 1st September**, Ministry of Labor and Social Solidarity, as amended by Law Nº 31/2003, of 22nd August), and

- **Law on Educational Guardianship (Law Nº 166/99, of 14th September**, Ministry of Justice.

These two legal instruments entered into force on 1st January 2001. In these two laws, the concepts of "child and young person" arise representing a new approach in the field of law, since this law provides for that a child or young person is "a person under the age of 18 years or the person under 21 years who requests the continuation of the intervention initiated before reaching age 18" (article 5 of the LPCJP). Based on these laws - and particularly on the LPCJP - the promotion and protection measures in Portugal are:

- a) close support of parents;
- b) close support of other family member;

- c) trust to a reliable person;
- d) support for life autonomy;
- e) foster home;
- f) host institution;

g) trust to a person selected for adoption or the institution with a view to future adoption (the latter as defined in law No. 31/2003 of 22nd August).

In terms of practical implementation, and having regard to the Law on Protection of Children and Young People at Risk (LPCJP), it is crucial that the protection of children and young people and the promotion of their rights are the legal responsibility of 3 entities:

- 1. Entities with Competence in the Field of Childhood and Youth (ECMIJ);**
- 2. Committees for the Protection of Children and Young People (CPCJ);**
- 3. Courts.**

1. The entities with competence in the field of childhood and youth (ECMIJ) must, within the framework of its mission, to promote primary and secondary prevention actions, in particular by defining local plans of action for children and young people, aimed at the promotion, defence and implementation of the rights of children and young people (article 6 of the LPCJ). How do they intervene? They assess, diagnose and intervene in situations of risk and danger; Implement necessary and appropriate intervention strategies to decrease or eliminate risk factors; Accompany the child, young person and their family within the execution of the intervention plan defined (article 7 of the LPCJ). In addition, they also perform the material acts inherent to the promotion and protection measures applied by the Protection Committee or by the Court, and shall draw up and keep updated a register that should bear the summary description of the proceedings performed and the respective results.

The National Plan for Early Intervention is set up within this context of Entities with Competence in the Field of Childhood and Youth (ECMIJ): in other words, the Law No. 281/2009 introduces in Portugal the National System of Early Intervention in Childhood (SNIPI), regarding a "organized set of institutional entities of family nature, with a view to ensuring conditions for the development of children with body functions or structures that limit their personal and social growth and their participation in typical activities of their age, as well as of children with serious risk of developmental delay". This is an integrated support measure that focuses on the child and the family through

the implementation of preventive actions within the framework of education, health and social action.

What is exactly this national plan?

- Is a set of actions, consisting of Multi-professional teams and Intervention Sites (ELI) and aimed at families with children from zero to six years, that aims to ensure the conditions for proper development. The **Early Childhood Intervention Program (IPI)** aims to create conditions that facilitate the overall development of the child; to create conditions for the interaction between child/family, strengthening their skills and abilities; to support children and families in a systematic way, optimizing the existing resources in the community and creating formal and informal support networks. It should be noted that parental involvement is the key for the child's development, given that family must participate in all phases of the intervention process, focusing on the skills of their children and creating perspectives for the future.

2. The **CPCJ are non-judicial official institutions** with functional autonomy to promote the rights of the child and young person or put an end to situations likely to affect their safety, health, training, education or full development. The functioning of the CPCJ is governed by Law No. 147/99 of 1st September. Therefore, and according to the law, the CPCJ had the responsibility – whenever it is not possible to the ECMIJ – to intervene in order to avoid danger, to prevent or put an end to situations likely to affect the security, health, training, education and integral development of the children (Law No 147/99, of 1st September, articles 8 and 12). In Portugal, 309 Committees for the Protection of Children and Young People are already in operation, and more six committees will become operational soon, in order to achieve full coverage of the national territory.

The national care system of children and young people at risk is organised in a structure that includes, in accordance with the law, three distinct levels: 1) emergency care; 2) temporary care, and 3) extended care.

The **National Plan of Action for Social Inclusion (PNAI)** was defined within the framework of the European Social Inclusion Process, reference document for guiding the intervention required in the national process of social inclusion. In this context, the elimination of situations of social exclusion which affect children was initially established as a goal, becoming the promotion and protection of their rights one of the priorities to be achieved. In order to make childhood a national priority, the XVII

Portuguese Government established the Initiative for Childhood and Adolescence (INIA), through which it sought to define a plan of action for the protection of the universality of children's rights.

Among the measures specifically targeted at the institutional care system in the last decade, it should be noted:

- Manual of Best Practices - A guide to the residential care of children and young people to leaders, professionals, children, young people and their family, CID (2005).
- Plan DOM – Challenges Opportunities and Changes (2007)
- Plan SERE + (to Sensitize, to Engage, to Renew, to have Hope, MORE) (2012)

#### ***IV.4. Support programs for parents in Portugal***

The Calouste Gulbenkian Foundation has taken the children and young people at risk at the top of its priorities. During a period of four years (2008/2011) priority has given to the support for families with children and young people at risk or in danger, through the execution of projects of parental education, understood as a preventive measure to institutionalization.

Portugal is currently “performing actions of awareness and prevention”, as for example the actions under the PTP (Project Tecer a Prevenção) or MPMTI (Month for the prevention of child maltreatment).

In order to create at the national level moments and practical sites that serve to inform, sensitize and reflect – comprehensively and with great impact – all those involved in education, since the institutions to parents and educators, the development of several activities with the participation of 1263 entities/institutions at the national level took place during this year, with emphasis on the high participation of Municipalities, Schools, IPSS and health services.

#### **Promotion of rights and risk prevention**

The activities in the field of promotion of rights and risk prevention, developed by all the CPCJ of the country in the exercise of the powers conferred to it in Article 18 of the LPCJP, are to a large extent the implementation of the Project Tecer a Prevenção (PTP) and the Month for the Prevention of Child Maltreatment (MPMTI), since 2008 and 2010, respectively, with a growing acceptance on the part of the CPCJ. In 2016, the CPCJ monitored 34 497 children and young people under promotion and protection

measures, which corresponds to 47.8% of the total number of children and young people monitored.

The measure "close support of parents" was the most applied, with 27 060 cases (78.4% of total measures). Measures "close support of other family member" followed with 3427 (9.9%) and the measures "residential home" were applied on 3242 cases (9.4%).

The analysis of the measures implemented at national level, as presented in Table 2, shows that the measure close support of parents (78.4%) was the most applied. The following are, in descending order, the support to other family members (9.9%), the residential care (9.4%), trust to a reliable person (1.4%), support for life autonomy (0.6%) and the foster home (0.3%).

**Table 2\* - Measures implemented and/or running by age group**

Supports	N/R	0 a 5 y	6 a 10 y	11 a 14 y	15 a 21 y	Total	%
Close Support of Parents	274	4942	5588	6308	9948	27060	78,4
Close Support Other Family member	22	760	696	769	1180	3427	9,9
Trust to a Reliable Person	3	71	78	122	193	467	1,4
Support for Life Autonomy	4			1	202	207	0,6
Foster Home	1	12	17	26	38	94	0,3
Residential Home	19	483	377	682	1681	3242	9,4
	323	6268	6756	7908	13242	34497	100

*In CPCJ. (2017). Relatório de Avaliação da Atividade das CPCJ – 2016. Maio 2017*

The analysis of the 27 060 measures of close support of parents, by age group, shows that the number of measures applied increases in direct proportion with the age increasing of children and of the young people. The age group of 15 to 21 years - 36.8% of the total of this measure - stands out in contrast to the age group of 0 to 5 years, which corresponds to 18.3%. In the distribution by gender, the children and young of the male gender predominate (56.3%; 15 225).

Overall, this is the image of the Diagnostic and Intervention Projects, in terms of Parents and Children with Special Needs.

## References

1. Ager, A. (2013). Annual Research Review: Resilience and child well-being – public policy implications. *Journal of Child Psychology and Psychiatry*, 54(4), 488-500. doi:10.1111/jcpp.12030.
2. Blacher J, McIntyre LL. (2006). Syndrome specificity and behavioral disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research*. 50(Pt 3):184–198
3. Choi, E. K., & Yoo, I. Y. (2015). Resilience in families of children with Down syndrome in Korea. *International Journal of Nursing Practice*, 21(5), 532-541. doi:10.1111/ijn.12321
4. Comissão Nacional de Promoção dos Direitos e Proteção das Crianças e Jovens. (2017). Relatório de Avaliação da Atividade das CPCJ – 2016. Comissões de Proteção de Crianças e Jovens (CPCJ). Maio 2017.
5. Coutinho, J., Ribeiro, E., Ferreirinha, R., Dias, P. (2010). Versão portuguesa da Escala de Dificuldades de Regulação Emocional e sua relação com sintomas psicopatológicos. *Rev Psiquiatria Clínica*. 2010;37(4):145-51.
6. Cunha, Sandra, (2012), “A tomada de decisão na Proteção à Infância. Como decidimos o que é o Supremo Interesse da Criança?”, Atas do VII Congresso Português de Sociologia: Sociedade, Crise e Reconfigurações, Porto, Associação Portuguesa de Sociologia.
7. Decreto-Lei nº 332-B/2000 de 30 de Dezembro. Regulamentação da Lei de Proteção às Crianças e Jovens em Risco. DIÁRIO DA REPÚBLICA — I SÉRIE-A Nº 300 — 30 de Dezembro de 2000.
8. DeLambo D., Chung W, Huang W. (2011). Stress and age: a comparison of Asian American and Non-Asian American parents of children with developmental disabilities. *J Dev Phys Disabil*. 23:129–141. doi: 10.1007/s10882-010-9211-3.
9. Diener, E. & Suh, E. (2003). National differences in subjective well-being. In Kahneman, Diener & Schwarz (Eds.), *Well-being: The foundations of hedonic psychology* (pp. 434-450). New York: Russell Sage Foundation.
10. Diener, E., Oishi, S., & Lucas, E. (2003). Personality, culture and subjective wellbeing: Emotional and cognitive evaluations of life. *Annual Review Psychology*, 54, 403-425. doi: 10.1146/annurev.psych.54.101601.145056.

11. Diener, E., Scollon, C. & Lucas, R. (2003). The evolving concept of subjective well-being: The multifaceted nature of happiness. *Advances in Cell Aging and Gerontology*, 15, 187-219, doi: 10.1007/978-90-481-2354-4\_4.
12. Diener, E., Suh, E. & Oishi, S. (1997). Recent findings on subjective well-being. *Indian Journal of Clinical Psychology*, 24 (1), 25-41.
13. Galinha, I. (2008). Bem-estar subjectivo: factores cognitivos, afectivos e contextuais. Quarteto: Coimbra.
14. Huang, C.-Y., Yen, H.-C., Tseng, M.-H., Tung, L.-C., Chen, Y.-D. and Chen, K.-L. 2014. Impacts of autistic behaviors, emotional and behavioral problems on parenting stress in caregivers of children with autism. *Journal of Autism and Developmental Disorders*, 44, 1383–1390
15. Jesus, N. (2006). Bem-estar em Psicologia da Saúde. In Leal, I. (cord.), *Perspectivas em Psicologia da Saúde* (pp. 81-87). Coimbra: Quarteto.
16. Lecavalier L, Leone S, Wiltz J. (2006). The impact of behavior problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*. 2006;50(Pt 3):172–183. Lei n.º 23/2017 de 23 de maio. Terceira alteração à Lei de Proteção de Crianças e Jovens em Perigo, aprovada pela Lei n.º 147/99, de 1 de setembro, alargando o período de proteção até aos 25 anos. *Diário da República*, 1.ª série — N.º 99 — 23 de maio de 2017.
17. Lee, J. K. & Chiang, H. (2017): Parenting stress in South Korean mothers of adolescent children with autism spectrum disorder, *International Journal of Developmental Disabilities*, DOI: 10.1080/20473869.2017.1279843
18. Lei n.º 4/2015. Procede à primeira alteração à Lei Tutelar Educativa, *Diário da República* n.º 10/2015, Série I de 2015-01-15, Ministério da Justiça.
19. Lei n.º 142/2015 de 8 de setembro. Segunda alteração à Lei de Proteção de Crianças e Jovens em Perigo, aprovada pela Lei n.º 147/99, de 1 de setembro. *Diário da República*, 1.ª série — N.º 175 — 8 de setembro de 2015.
20. Lei n.º 31/2003, de 22 de agosto. Medidas de promoção e proteção. Ministério do Trabalho e da Solidariedade.
21. Lei n.º 147/99, de 1 de setembro. Lei de Proteção de Crianças e Jovens em Perigo.

22. Lei n.º 166/99, de 14 de setembro. A Lei Tutelar Educativa entrada em vigor no dia 1 de janeiro de 2001, Ministério da Justiça.
23. Lei nº 98/98 de 18 de Abril. Criação da Comissão Nacional de Proteção das Crianças e Jovens em Risco, Diário da República — I Série - A, nº 91, 18-4-1998. Ministério do Trabalho e da Solidariedade.
24. Lucas, R., Diener, E. & Suh, E. (1996). Discriminant validity of well-being measures. *Journal of Personality and Social Psychology*, 71, 616-628. doi: 10.1037/0022-3514.71.3.616.
25. Mixão, M., Leal, I., e Maroco, J. (2007). Escala de Stress Parental. In I. Leal (Ed.). *Avaliação em Sexualidade e Parentalidade*, 199-210. Porto: Livps
26. Ng Deep, C. A. & Leal, I. (2012). Adaptation of “The Resilience Scale” for the adult population of Portugal. *Psicologia*, 23 (2), 417-433. doi:10.1590/S0103-65642012005000008.
27. Simões, A. (1992). Ulterior validação de uma escala de satisfação com a vida (SWLS). *Revista Portuguesa de Pedagogia*, 26(3), 503-515.
28. Simões, A., Ferreira, J., Lima, M., Pinheiro, M., Vieira, C., Matos, A. & Oliveira, A. (2003). O bem-estar subjectivo dos adultos: um estudo transversal. *Revista Portuguesa de Pedagogia*, 37 (1), 5-30.
29. Smith, A. M., & Grzywacz, J. G. (2014). Health and Well-being in Midlife Parents of Children with Special Health Needs. *Families, Systems & Health : The Journal of Collaborative Family Healthcare*, 32(3), 303-312. <http://doi.org/10.1037/fsh0000049>
30. Su R., Tay L, Diener E. (2014). *Appl Psychol Health Well Being*. 2014 Nov;6(3):251-79. doi: 10.1111/aphw.12027. Epub 2014 Jun 12.
31. UNICEF (1989). A Convenção sobre os Direitos da Criança 20 de Novembro de 1989 e ratificada por Portugal em 21 de Setembro de 1990.
32. Veiga-Branco, A. (2007). Competência Emocional em Professores. In. A.A. Candeias, & L.S. Almeida (Coord), *Inteligência Humana: Investigação e aplicações* (p. 361-379). Coimbra: Quarteto.
33. Walsh, F. (2012). *Strengthening family resilience* (3rd Ed). New York: Guilford.
34. Wiener, J., Biondic, D., Grimbo, T. and Herbert, M. 2016. Parenting stress of parents of adolescents with attention - deficit hyperactivity disorder. *Journal of Abnormal Child Psychology*, 44, 561-574. doi:10.1007/s10802-015-0050-7

## V. GENERAL BACKGROUND INFORMATION FOR CROATIA

Croatia is unitary parliamentary constitutional republic and a beautiful country (country of thousand islands), situated in the southeastern part of Europe on the area of 56.594 km<sup>2</sup> (21,851 square miles). It has a beautiful scenery, rich culture and tradition. Croatia has 4.224 millions of people that are members of different ethnics groups: 90.4% Croats, 4.4% Serbs, and 5.2% others (Bosnians, Hungarians, Italians, Slovenes, Germans, Czechs, Romani and others). Children and adolescents constitute 21.1% of the total estimated population - a relatively low proportion of children in the total population. Natality and natural incremental rate indicate that Croatian society is growing older, and that the population is steadily decreasing.

There are large differences in population density and development between Croatian regions as most of the population is concentrated in four county centers: Zagreb, Split, Rijeka and Osijek.

Capital city of Croatia is Zagreb and official language is Croatian. Croatian GDP total is \$59.911 billion (2015.) and GDP Per capita: \$13,994. Currency in Croatia is Kuna (HRK).

### ***V.1. Description for situation of parents of children with special needs***

Prevalence of children with disabilities in general population of children is 4.4%. (Benjak, 2017). That also means that there might be about 4% of parents of children with disabilities in general population of parents in Croatia. The fact is that those parents are vulnerable group with some specific needs. There are differences in parents' situation regarding the age of children.

„Young“ families with young children with disabilities are often full of expectations, active and focused on providing the best possible services of support for their children. Law from 2012 regulates early intervention, even though services and education for early intervention started about six years earlier. Still, there is a huge difference in number, variety, quality and availability of support services between Zagreb and big cities in compare with small cities and rural or/and distant parts of Croatia. That is why parents report feeling of frustration and dissatisfaction with the lack of information as well as incompatibility and poor coordination between services (Pećnik et al, 2013).

Furthermore, several studies showed that parents reported lack of support not only for their children but also for them in terms of psychological and emotional support especially in period during and after setting up a diagnosis to their children. ( Leutar & Štambuk 2007; Milić Babić & Leutar 2014; Pećnik at al, 2013).

Parents also showed dissatisfaction with unprofessional attitudes of experts towards them. (Milić Babić & Leutar 2014).

Results of one study show that parents of children with disabilities receive support primarily from family members, then co-workers, Church, NGO-s and finally from social workers from Social welfare Centre (Leutar & Štambuk 2007).

During school period parents report lack of support from school especially misunderstanding and poor communication with teachers. Mothers cited as a reason of broken marital relations lack of father role and figure and transfer of responsibilities from father to mother. Mothers state that fathers are insufficiently engaged with their children with disabilities. Despite the fact that most of mothers stated that they have support from their spouse still mothers carry most of the burden. Not only that mothers support their children in learning and rehabilitation process but also they advocate for their rights (Veldić 2012. according to Igrić et al. 2014)

On the other hand parents in „old“ families with elder children with disabilities are often isolated, exhausted, tired, old and sometimes ill. There is a serious lack of services for senior people with disabilities and their families. They rely on their own strength. They receive support from close family members or neighbors. While aging they have less and less energy to take their children to Day care centers or Ngo-s if they even have that opportunity. The biggest worry to them is how to secure care to their children if they would not be able to do that by themselves or they passed away (Wagner Jakab at al., 2016).

Awareness of importance of supporting parents of children with disabilities is increasing in Croatia. There is more and more support services for that but still not enough. Still there is lack of services addressing siblings and grandparents of children with disabilities. It is very important to develop continuous and systematic emotional support to families of children with disabilities.

## V.2. National statistics

Data from 2017 (Benjak, 2017) shows that Croatia has 4.224 million citizens. There are 511 850 children with disabilities and disabled adults, 307 934 male (60%) and 203 916 female. There are 24 278 boys with disabilities and 14 777 girls. In relation to all population of children in Croatia prevalence of children with disabilities is 4.4%.

Largest number of children with disabilities, 29%, lives in Zagreb and in Splitsko Dalmatinska County. When compare proportion of children with disabilities in relation to all citizens in county we can conclude that biggest proportion of children with disabilities is in Koprivničko Križevačka County.

Most children in Croatia have multiple disabilities (43.1%), as shown in table 1. Most children with multiple disabilities have intellectual disabilities. Intellectual disability is found in 16.3% of children where 49 % of children with ID have mild intellectual disabilities.

**Table 1. Type of disabilities in children with disabilities**

Type of disability	Number	Prevalence (%) in number of children with disabilities
Visual impairment	969	3.0
Hearing impairment	1069	3.3
Specific language impairment	12078	37.6
Locomotor system impairment	1746	5.4
CNS impairment	6035	18.8
Peripheral Nervous System impairment	363	1.1
Other organ impairment	2847	8.9
Intellectual disability ID	5246	16.3
Mental and conduct disorder	3221	10
Pervasive development disorder	1257	3.9
Congenital anomalies chromosomopathy	2662	14.6
Multiple disabilities	8673	43.1

Most common diagnosis of CNS impairment are dystonia in 2161 children; juvenile cerebral palsy in 1627 children and epilepsy in 1510 children. The most common chromosomopathy is syndrome Down in 675 children.

According to those statistical data, five children with disability attempt suicide, 36 of them were abused. Children with disability in Croatia are included in educational process, 21555 of them, as the record shows. The most common education program is in

inclusive condition with individualized plan, mostly for children with specific language impairment i learning disabilities, multiple disabilities and ID.

Children with disabilities lives mostly within family (97.5%), some of them are in foster care (0.6%), and 275 children with disabilities lives within the institutions.

### ***V.3. Inclusion policies in Croatia***

The inclusion requires responding to the diversity of needs among all learners, through increasing participation in learning, cultures, and communities, and reducing exclusion from and within education. It involves changes in content, approaches, structures, and strategies, driven by a common vision that covers all children and the conviction that it is the responsibility of the regular system to educate all of them (UNGEI, 2010). Inclusion implies adaptation and openness of the educational system to all pupils, regardless of the type and degree of difficulty, the culture to which they belong, the language or any other possible difference.

Inclusive education in Croatia is in the process of developing the capacity of the school to adapt to all its students. The education system in the Republic of Croatia affords all children, students and young people – including children with developmental disabilities, children who are members of national minorities, gifted students and children and young people in a disadvantaged position – inclusion in the education system on all levels (EASNIE, 2017).

Croatia is a participant of all major international human rights conventions, such as UNESCO Convention on the Rights of the Child (1989). Croatia ratified the Convention on Rights of People with Disabilities (2007) and adopted the Facultative Protocol for the Implementation of Convention. The establishment of Ombudsman for People with Disabilities was the one step forward in repressing discrimination on this basis but also on every other basis in general.

The development of inclusive school practice in Croatia's primary and secondary education had been advanced through Act on Education in Primary and Secondary Schools (Official Gazette 87/08, 86/09, 92/10 and 105/10) and the Pedagogic standard (2008).

The legislative framework is an important prerequisite for educational inclusion, but in addition it is important to inform, increase awareness and sensitization of

stakeholders in the educational process about children's rights as well as empowerment of teachers, informing and empowering parents and children (Žic Ralić, 2012).

Children with mild disabilities are enrolled in mainstream education, while children with extensive disabilities are enrolled in special education institutions. The enrolment process consists of a legally established procedure of assessing the child's psychophysical state in order to determine the most suitable education program and the necessary support, methods and teaching tools during the period of compulsory education (Official Gazette, 102/06). The goal is to provide every child with the opportunity of learning in the natural environment and therefore there is a tendency of placing the children in mainstream education.

Educational inclusion is implemented according to two models of education, full and partial inclusion. Full inclusion implies the inclusion of students with disabilities in mainstream class in which they master the regular curriculum customized to individualized ways of learning or curricula adjusted to their capabilities. Partial inclusion means that pupils with disabilities (mostly mild intellectual disability) part of education (math, language, science) acquire in a separate class with special education teacher, and the other part (arts and PE) in the mainstream class with regular teacher. The program of partial integration is not implemented in each school.

Inclusion requires professional support and spatial, pedagogical and didactic adjustment in order to ensure suitable education and socialization for children with developmental disabilities. Professionals in the education area, who work with children with developmental disabilities, provide support to their teachers and parents; include educational rehabilitators, speech and language therapists and social pedagogues who are members of school expert team. Mostly there are one among mentioned experts who provide support for children with disabilities in one school, but, still there are schools without any expert responsible for children with disabilities. The inclusive education in Croatia, still, has not been developed to provide the same quality to all Croatian pupils.

Croatia followed international trends and made provisions in its national educational plans, strategies and legislation for the teacher assistant. The teacher assistant and mobile expert team support for children with disabilities, implemented in Croatia from 2007, is one of the models of support aimed at improving access to mainstream education.

Children with special needs who finish primary school can continue with their secondary education. Students with special needs who want to take the state graduation exam can do so with the use of adjusted exam technology. This is done in co-operation with the National Centre for External Evaluation in Education.

The statutes and regulations of higher education institutions in the Republic of Croatia include constitutional principles on the prohibition of every form of discrimination and the equal right of all students to good quality study programs. Four out of seven universities in the Republic of Croatia (the Universities of Zagreb, Zadar, Rijeka and Osijek) have set a goal to facilitate access to higher education and to provide support for students with disabilities.

#### ***V.4. Support programs for parents in Croatia***

There is a lack of literature about support programs for parents in Croatia. Although there is a common understanding that support for families is a vital part of every system of support for children with disabilities, that principle is often not evident in practice.

Specific education and support for parents of children with disabilities is provided within programs of educational and social institutions. Usually, parents receive individual support or small group support. Support usually includes topics like improving parental skills and teaching a parent how to support a child in acquiring a new skill or how to deal with the problem behavior. The support is usually more informal and the quality of support usually depends on motivation and effort of individual special teacher or other staff and is not systematically delivered within the institution. It is also not planned or evaluated in most of the institutions.

There are some education packages that are developed for families of children with disabilities. Workshops "Let's grow together plus" were developed with the support of the UNICEF office for Croatia for parents of children with disabilities. The intention of the program is giving the parents information, knowledge and skills that will support them in their parental responsibilities and promotion of their personal growth and competences of the parent as well as competences of the child. Those workshops are conducted by educated professionals in various institutions for children with disabilities and in NGOs, and the program is being evaluated (Starc, 2014).

Program that is focused on families of children autism spectrum disorders (ASD) "Positive approaches to autism" is being developed within ESIPP ERASMUS + project on the base of survey of parents (Preece et al, 2017). The goal of the program is to give the parents knowledge about ASD and autism specific parenting skills and strategies (Preece et al, 2017a).

Support groups for brothers and sisters are organized in different institutions and NGOs by different professionals. Model of Wagner Jakab, Cvitković and Hojanić (2006) is used in some NGO's and institutions.

To conclude, there are some initiatives and activities for parent support but there are a lot of challenges:

- Support that is offered is often project based, it is not sustainable
- Education programs are various but not systematic and consistent
- There is no systematic education for parents across the country, education is not reachable for all parents
- Existing education programs are often not evaluated
- When parents are taught to use a specific program there is no follow up, supervision nor any other support for them when they start using those programs with their children

## References

1. Benjak, T. Report about people with disabilities in Republic of Croatia, Croatian Institute for Public Health, 2017. Available at: [https://www.hzjz.hr/wp-content/uploads/2016/04/Invalidi\\_2017.pdf](https://www.hzjz.hr/wp-content/uploads/2016/04/Invalidi_2017.pdf)
2. European Agency for Special Needs and Inclusive Education, Croatia - Special needs education within the education system, visited on July 10th 2017 <https://www.european-agency.org/country-information/croatia/national-overview/special-needs-education-within-the-education-system>
3. Igrić, Lj., Fulgosi-Masnjak, R. & Wagner Jakab, A. Roditelji i djeca s teškoćama, Centar inkluzivne potpore IDEM. 2014 <https://bib.irb.hr/prikazi-rad?&rad=763032>

4. Leutar, Z. & Štambuk, A. Invaliditet u obitelji i izvori podrške, Hrvatska revija za rehabilitacijska istraživanja, 43(1):2007 pp 47 – 61  
<http://hrcak.srce.hr/22099>
5. Milić Babić, M. & Leutar Z. Iskustva s ranom intervencijom roditelja djece s teškoćama u razvoju, Ljetopis socijalnog rada, 20(3):2014 pp 453-480  
<http://hrcak.srce.hr/118484>
6. Pećnik et al. Kako roditelji i zajednice brinu o djeci najmlade dobi, Printera Grupa d.o.o. 2013, available at: [http://www.unicef.hr/wp-content/uploads/2015/09/Kako\\_roditelji\\_i\\_zajednice\\_brinu\\_o\\_djeci\\_najmlade\\_dobi.pdf](http://www.unicef.hr/wp-content/uploads/2015/09/Kako_roditelji_i_zajednice_brinu_o_djeci_najmlade_dobi.pdf)
7. Preece, D., Symeou, L., Stošić, J., Troshanska, J., Mavrou, K., Theodorou, E. & Frey Škrinjar, J. Accessing parental perspectives to inform the development of parent training in autism in south-eastern Europe. European Journal of Special Needs Education, 32 (2):2017, pp 252-269.
8. Preece, D., Stošić, J., Frey Škrinjar, J., Troshanska, J., Symeou, L., Mavrou, K., Theodorou, E. & Trajkowski, V. (a) Education for Families of Children with ASD. 9th International Conference of the Faculty of Education and Rehabilitation Sciences University of Zagreb. 17-19 May 2017, Zagreb

## **VI. GENERAL BACKGROUND INFORMATION FOR LITHUANIA**

### ***VI.1. Description for situation of parents of children with special needs***

Support for parents of children with special needs is provided by both governmental and non-governmental institutions. The goal of both governmental and non-governmental institutions is to help families to fulfil their functions by adapting to changing conditions, without losing their identity.

The support is closely linked to the health, education and social security services.

The Law on the Social Integration of the Disabled of the Republic of Lithuania (2000) establishes the right of persons with a disability to a complex of medical, professional and social rehabilitation measures.

Medical rehabilitation is carried out in multi-profile hospitals, outpatient clinics, at home, in sanatorium departments. Social and occupational rehabilitation is carried out by municipal care and welfare institutions, social care and welfare institutions, educational training institutions, social organizations for the disabled, special professional and social institutions for the rehabilitation of the disabled.

Especially important is the early rehabilitation services, which determine the success of further work with the family. They provide early complex assistance to children from birth to 3 years old. And in special cases and up to 7 years old. They help to ensure the early detection of child's impairment and to provide complex assistance in a timely manner to both children with disabilities and their parents. Early rehabilitation services are provided as close as possible to the child's place of residence, primary health care facilities and children's departments of in-patient health care facilities.

The Early Rehabilitation Department provides assistance to parents of children with disabilities or children with a risk factor for developmental disruption. The purpose of the department is the medical, psychological and social rehabilitation of children and families, improving their social adaptation and functioning. Upon assessment of the child's development, after the diagnosis of a developmental disorder, all information is provided to parents. A child rehabilitation program is organized, information on the child's most appropriate methods of rehabilitation and education, and parents are taught how to apply them at home. Parent self-help groups, support team works. The information is shared with parents' and specialist organizations.

Each city municipality has established social support centers whose purpose is to provide social services and benefits to residents who cannot afford to take care of their personal (family) life independently and who need assistance in meeting their essential needs and addressing social problems.

Family Support Service is set up at the Social Support Center. Its purpose is to provide assistance in solving the crisis situation in a family. The main function of Family Support Service is to individually inform and advise family members on social issues and psychological issues, mediate between the client and other social assistance agencies. Those services are for families raising children under the age of 18 who are in a crisis situation due to one or several social problems (various dependencies, disability, poverty, lack of social skills, etc.) and who, due to the circumstances, are not able to cope with the crisis individually. It also provides individual information and advice on a wide range of social and psychological issues through telephone, customer home and office, mediated through cooperation between specialists from different institutions in solving common issues of social support for clients.

Many non-governmental organizations operate in Lithuania, they are considered as equivalent partners in the development of social services, especially in the context of parents of children with disabilities. In this area, NGOs are the initiators of new and effective forms of organization of services, and their representatives are invited as consultants in shaping social policy.

Social services are provided by NGOs in two forms: establishing new NGOs providing services or assistance and support provided directly through NGO programs.

## ***VI.2. National statistics***

**1 table. Number of children recognised as disabled for the first time**

<b>Year</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>	<b>2014</b>	<b>2015</b>
Profound	157	147	143	138	156
Moderate	718	850	818	1 015	949
Minor	1 165	1 110	762	767	655

**Note.** Figures taken from the Department of Statistics <https://osp.stat.gov.lt/statistiniu-rodikliu-analize?hash=06a08946-fb13-41ed-a85e-edf57950ea82#/>

**2 table. General school pupils with special educational needs**

		<b>2014-2015</b>	<b>2015-2016</b>	<b>2016-2017</b>
Special classes and developmental classes (Partial integration)	<b>Total</b>	959	986	1 023
	Pupils with disabilities	915	929	909
	Pupils learning difficulties	43	53	112
	Pupils with learning disadvantages	1	4	2
General classes (full integration)	<b>Total</b>	34 596	34 032	34 143
	Pupils with disabilities	4 407	4 284	4 145
	Pupils learning difficulties	29 785	29 388	29 567
	Pupils with learning disadvantages	404	360	431
Special schools and special educational centers	<b>Total</b>	3 663	3 638	3 680
	Pupils with disabilities	3 390	3 433	3 446
	Pupils learning difficulties	271	205	231
	Pupils with learning disadvantages	2	-	3

**Note.** Figures taken from the Department of Statistics <https://osp.stat.gov.lt/statistiniu-rodikliu-analize?hash=06a08946-fb13-41ed-a85e-edf57950ea82#/>

In 2015-2016 about 2,600 disabled children received social services in day care centres.<sup>3</sup>

There was 29 special schools and special education centres with 1 062 children; 4 Social care homes for children and young people with disabilities with 460 children in Lithuania in 2016.<sup>4</sup>

There were 67 pre-school establishments with special groups in Lithuania in 2016. According to the table 3 1 555 children have attended those establishments in urban and rural areas.

**3 table. Number of children in pre-school establishments with special groups**

<b>Total</b>	<b>2014</b>	<b>2015</b>	<b>2016</b>
	1 801	1 737	1 555
Intellectual disability	69	56	60
Speech and language disorders	836	832	694
Visual impairment	18	18	8
Hearing impairment	74	57	66
Physical disabilities and neurological disorders	35	52	18
Complex disorders	589	561	504
Other cases	180	161	205

**Note.** Figures taken from the Department of Statistics <https://osp.stat.gov.lt/statistiniu-rodikliu-analize?hash=08e0868a-7428-4bdc-8a04-3554398f7747#/>

<sup>3</sup> <https://osp.stat.gov.lt/informaciniai-pranesimai?articleId=5178560>

<sup>4</sup> <https://osp.stat.gov.lt/informaciniai-pranesimai?articleId=5178560>

In 2016-2017 about 16 976 Children with special educational needs were integrated into general-purpose groups of preschool education institutions.<sup>5</sup> In 2016-2017 about 37760 children with special needs were integrated in general schools (table 4).

**4 table. General school pupils with special educational needs**

		<b>2014-2015</b>	<b>2015-2016</b>	<b>2016-2017</b>
Special classes and developmental classes (Partial integration)	<b>Total</b>	959	986	1 023
	Learning disadvantages	1	4	2
	Intellectual disability	495	504	479
	Learning difficulties	-	-	-
	Speech and language disorders	11	18	40
	Visual impairment	1	3	1
	Hearing impairment	17	8	-
	Physical disabilities and neurological disorders	7	6	14
	Behavioral and/or emotional disorders	-	-	1
	Many- sided developmental disorders	13	13	40
	Complex and other disabilities	382	395	375
	Complex disorders	31	33	69
	Other cases	1	2	2
General classes (full integration)	<b>Total</b>	34 546	33978	34 090
	Learning disadvantages	404	360	431
	Intellectual disability	2 553	2 413	2 326
	Learning difficulties	6 482	6 110	5 952
	Speech and language disorders	17 228	16 837	16 723
	Visual impairment	85	86	90
	Hearing impairment	177	185	199
	Physical disabilities and neurological disorders	551	550	536
	Behavioral and/or emotional disorders	451	460	446
	Many- sided developmental disorders	232	312	332
	Complex and other disabilities	759	684	609
	Complex disorders	5 624	5 981	6 446
	Other cases	-	-	-

<sup>5</sup> <https://osp.stat.gov.lt/statistiniu-rodikliu-analize?hash=69881f7a-ef0d-4e81-b5b3-637f4cb9ce4f#/>

Special schools and special educational centers	<b>Total</b>	3 639	3 606	3 647
	Learning disadvantages	2	-	3
	Intellectual disability	1 650	1 660	1 643
	Learning difficulties	-	-	-
	Speech and language disorders	1	-	-
	Visual impairment	68	67	59
	Hearing impairment	202	178	172
	Physical disabilities and neurological disorders	92	112	105
	Behavioral and/or emotional disorders	71	15	14
	Many- sided developmental disorders	31	43	41
	Complex and other disabilities	1 319	1 339	1 393
	Complex disorders	2	5	16
	Other cases	197	185	201

*Note. Figures taken from the Department of Statistics*

<https://osp.stat.gov.lt/web/guest/statistiniu-rodikliu-analize?portletFormName=visualization&hash=2de1e301-befe-441b-af67-ed7d04779452#/>

### ***VI.3. Inclusion Policies in Lithuania***

In 1991 having approved the first Law of Education of the restored independence of the Republic of Lithuania (1991), the right of every person with special educational needs to develop and choose the educational institution closest to the home was established. This provision has become the beginning of formal education and integrated education for people with special educational needs.

At that time, there was a huge variety of education systems and their financing models in Europe: one-track countries, two-track countries, multitrack countries. It was decided to choose the "multitrack countries" model, hoping to offer the opportunity to choose the range of services that would ensure both the coherent functioning of both the general and the special education system (Aidukienė, Labinienė, 2003). The education of children with special educational needs is provided by compulsory and universal

education schools, in special cases, schools (classes) for pupils with special educational needs<sup>6</sup>.

According to the Law on Special Education (1998), people with special educational needs are “children and adults who, because of congenital or acquired impairments, have limited opportunities for participating in the educational process and social life”. According to the Law, special educational needs may be mild, moderate, profound or severe. Groups of learners with special educational needs shall be determined and their special educational needs shall be divided into minor, moderate, profound and severe, according to the procedure laid down by the Minister of Education and Science, the Minister of Health and the Minister of Social Security and Labour.

Article 14 of the new law amending the Law on Education (2011) defines special educational needs as a need for assistance and services in the education process that occurs due to being exceptionally gifted, having congenital or acquired disorders, or disadvantages in a person’s surroundings. The Minister of Education and Science, Minister of Health Care and Minister of Social Security and Labour of the Republic of Lithuania enacted the legislative act on statements/identification of people with special educational needs and levels of special educational needs on 13 July 2011. This legislative act set out a statement to identify pupils with disabilities, learning difficulties, disadvantages and levels of special educational needs according to A, B and C (based on the Organisation for Economic Co-operation and Development’s tripartite cross-national categorisation system: pupils with disabilities, learning difficulties and disadvantages).

Article 14 of the new law amending the Law on Education (2011) states: The purpose of education for learners with special educational needs shall be to help learners learn and to be trained according to their abilities, attain an education level and acquire a qualification by recognising and developing their abilities and capacities. The education of learners with special educational needs shall be organised in accordance with the procedure laid down by the Minister of Education and Science.

In the current system of education in Lithuania, general education schools are divided into mainstream schools and schools for pupils with special educational needs (special schools).

Regardless of which school will be chosen, a pupil with SEN should have the opportunity to learn according their abilities and to acquire education and

---

<sup>6</sup> LR švietimo įstatymas (2011)

qualifications, recognizing and developing capacities and powers. Accessibility of education must be ensured by adapting the school environment, providing psychological, special pedagogical, special and social pedagogical assistance, providing technical support measures for education at school and specific teaching materials. In the general education school for pupils with special educational needs "... persons who have profound and severe special educational needs are accepted".<sup>7</sup>

The education of pupils with special educational needs is being implemented by all schools providing compulsory and universal education, other education providers, and, in other cases, - schools (classes) designed for pupils with special educational needs.

Education in school for pupils with special educational needs can be offered only for pupils with inherent or acquired disabilities with profound or severe special educational needs.<sup>8</sup> Pupils with profound or severe educational needs can be educated in general schools for pupils with special educational needs till 21 years of age.<sup>9</sup>

Types of general education schools for pupils with special educational need: special schools, special educational centres, special educational multifunctional centres and etc.

Special schools are designed for pupils aged 7 (6) to 20 years old to study in accordance with adapted primary, basic education programs and social skills development programs. Special educational centres are designed for pupils aged 7 (6) to 20 years old to study in accordance with adapted primary, basic and secondary education programs and social skills development programs, by obtaining the necessary education assistance and providing methodological assistance to other schools' teachers, educational assistance specialists in adaptation of general education programs, educational environment, selection of special training materials, counselling of parents (or caretakers), which enables to improve the qualification of teachers and educational assistance specialists. Special school – special educational multifunctional centres are designed for pupils aged 7 (6) to 16 years old that have profound or severe educational needs to study according adapted primary and basic education programs and social skills development programs; other non-formal education programs for children and (or) adult non-formal education are also being implemented in this centres, providing opportunities for the cultural, social and other services necessary for the local community.

---

<sup>7</sup> LR švietimo įstatymas (2011)

<sup>8</sup> Mokyklų, vykdančių formaliojo švietimo programas, tinklo kūrimo taisyklės, 2011

<sup>9</sup> LR švietimo įstatymas (2011)

Organization of education in special schools. Schools, in meeting the special educational needs of pupils, must ensure education in an adapted educational environment, provision of educational support, special teaching and learning material and technical support.<sup>10</sup>

Special classes and developmental classes are designed in special schools. Special class - the class for pupils with inherent or acquired disabilities with profound or severe special educational needs. Developmental class – the class for pupils with „mild, moderate or severe intellectual disability, multiple disorders or other developmental disorders“.<sup>11</sup>

Educational curriculums are adapted and individualized taking into account pupils' special educational needs, needs of parents (caretakers), and recommendations of pedagogical psychological service or educational support specialist. Pupils with special educational needs due to intellectual disability are educated according to an individualized primary, basic education programs, which may result in continuing vocational training or education in accordance with the program of social skills development.<sup>12</sup>

Pupil's individualized education plan – is a learning plan tailored to his or her abilities and learning needs; it is designed to help the pupil to reach the higher educational achievements in accordance with his or her powers, to develop personal responsibility, skills, and fulfil the set goals. An individual education plan is developed for a pupil whose specific educational needs cannot be met by a general school curriculum. Individual education plan is designed according pupils' intellectual disabilities (mild, moderate or severe), the form of learning, the way in which the teaching is organized, and the purpose of the school implementing the education.

Social skills development programs can be implemented in schools/ classes for pupils with special educational needs, according recommendations from Pedagogical Psychological service.

School implementing social skills development program can choose the form of organization, educational content is delivered through subject and other activities,

---

<sup>10</sup> Mokinių, turinčių specialiųjų ugdymosi poreikių, ugdymo organizavimo tvarkos aprašas (2011). Valstybės žinios, 2011-10-11, Nr. 122-5771

<sup>11</sup> Mokyklų, vykdančių formaliojo švietimo programas, tinklo kūrimo taisyklės, 2011

<sup>12</sup> Mokinių, turinčių specialiųjų ugdymosi poreikių, ugdymo organizavimo tvarkos aprašas (2011). Valstybės žinios, 2011-10-11, Nr. 122-5771.

taking into account the powers of the pupil, the school's specialists, and the teachers of subjects. In order to ensure the effectiveness of education of pupils with SEN, all schools should provide the necessary educational support.

Educational support – is a support provided by educational specialists for pupils, their parents (caretakers), teachers and education providers. It includes vocational guidance, educational information, psychological, social pedagogical, special pedagogical (speech therapist, special teacher, tiflopedagogue, surdo pedagogue) support and special assistance (sign language interpreter, teacher assistant), school health care, counselling, teacher qualification improvement and other support.<sup>13</sup>

According the Law on Education (2011) completion of formal education programs may, for the purposes of special education, take longer than the established period. A learner who studies at intervals may complete the programs by way of discrete modules. Individuals with special needs who study according to programs that meet national standards for attainment of an education level may attain such a level and/or a qualification. In certain cases a qualification is acquired without having attained an education level. Pupils with special educational needs can complete formal education programs at shorter or longer than a fixed time, can study intermittently, can complete these programs with separate modules. Pupils with moderate, profound or severe special educational needs can be educated till 21 years of age in general schools designed for pupils with special educational needs.

At present, the three-level pedagogical psychological assistance for children with special educational needs model (Inkliuzinis ugdymas ir komandinė pagalba mokiniui, 2011) is being implemented in the Lithuania by these institutions:<sup>14</sup>

- School Child Welfare Commission,
- local pedagogical-psychological services,
- The National Centre for Special Needs Education and Psychology.

Each institution carries out its functions. First level – School Child Welfare Commission. Functions of this commission are:

---

<sup>13</sup> LR švietimo įstatymas (2011)

<sup>14</sup> Inkliuzinis ugdymas ir komandinė pagalba mokiniui. Metodinės rekomendacijos mokytojams, švietimo pagalbos teikėjams, 2011

1. to provide primary special pedagogical, psychological, social pedagogical, social assistance for pupils in their immediate environment;
2. to provide methodical assistance for teachers, parents;
3. to carry out a preliminary assessment of children with special educational needs;
4. to analyse the effectiveness of the educational assistance provided to the pupil.

Second level – pedagogical-psychological service. Their main area of activity is to provide assistance to the pupil, teacher and school:

1. psychological, social pedagogical, educational information assistance for pupils;
2. special pedagogical assistance for persons with special educational needs;
3. information, expert and counselling assistance to parents and schools;
4. psychological, social pedagogical, special pedagogical assistance for schools without educational assistance specialists.

According to the Law on Education (2011) the Child Welfare Commission appoints educational assistance, while the pedagogical-psychological service designates special education provision. A Child Welfare Commission shall carry out the initial evaluation of learners' special educational needs. A pedagogical-psychological service shall evaluate a learner's special educational needs (except those occurring because of exceptional talents) in terms of pedagogical, psychological, medicinal and socio-pedagogical aspects. Special education shall be assigned by the head of a pedagogical-psychological service and – in certain cases – by the school principal with the consent of the parents or guardians, in accordance with the procedure laid down by the Minister of Education and Science.

Third level – National Centre for Special Needs Education and Psychology is the responsible institution under the Lithuanian Ministry of Education and Science for developing the system of special pedagogical and psychological support in Lithuania. Main functions of the Centre are:

1. to coordinate the first and the second level of the special pedagogical and psychological support system;
2. to organise training programs for specialists of the municipal pedagogical psychological services;

3.to provide advice on assessment or supervision on difficult or problematic cases to psychologists, speech therapists and special teachers working in the municipal services;

4.to construct or adapt psychological and achievement tests and make recommendations for their use in the municipal pedagogical psychological services;

5.to develop and adapt the legislation acts that follow the implementation of the Law on Special Education;

6.to cooperate with municipal pedagogical psychological services;

7.to provide methodical support for the municipal pedagogical psychological services.

## ***References***

1. Aidukienė, T., Lapinienė, R. (2003). Vaikų, turinčių specialiųjų poreikių, ugdymo tendencijų apžvalga tarptautiniame bei Lietuvos švietimo reformos kontekste (1990–2002 m.). Specialiojo ugdymo pagrindai (Sud. J. Ambrukaitis, A. Ališauskas, R. Labinienė, J. Ruškus). Šiauliai: Šiaulių universiteto leidykla.

2. Inkluzinis ugdymas ir komandinė pagalba mokiniui. Metodinės rekomendacijos mokytojams, švietimo pagalbos teikėjams, 2011

3. LR švietimo įstatymas (2011).

4. LR Specialiojo ugdymo įstatymas (1998).

5. LR sveikatos apsaugos ministro 2000 m. gruodžio 14 d. įsakymas Nr. 728 „Dėl Vaikų raidos sutrikimų ankstyvosios reabilitacijos antrinio ir tretinio lygio paslaugų organizavimo principų, aprašymo ir teikimo reikalavimų“.

6. Mokinių, turinčių specialiųjų ugdymosi poreikių, ugdymo organizavimo tvarkos aprašas (2011). Valstybės žinios, 2011-10-11, Nr. 122-5771.

7. 2015–2016 ir 2016–2017 mokslo metų pagrindinio ir vidurinio ugdymo programų bendrieji ugdymo planai. TAR, 2015-05-08, Nr. 6951.

8. Mokyklų, vykdančių formaliojo švietimo programas, tinklo kūrimo taisyklės, 2011, 2016-04-20.

## **VII. GENERAL BACKGROUND INFORMATION FOR TURKEY**

Turkey is a democratic, secular, unitary, parliamentary republic. It is situated at the crossroads of the Balkans, Anatolia, Middle East, and eastern Mediterranean. Turkey is also surrounded by the Black Sea in the north, the Aegean Sea on the west, and the Mediterranean Sea on the south. The country has also an inland Sea of Marmara which connects the Black Sea to Aegean Sea.

Capital city of Turkey is Ankara and official language is Turkish which is written with Latin characters. The population of Turkey is 80,477,188 million according to the census of 2017. The major cities are Istanbul, Ankara (capital), Izmir, Bursa and Adana.

### ***VII.1. Description for situation of parents of children with special needs***

Parents with disabled children are the most vulnerable group of people in Turkey because their needs are not acknowledged and identified by the policy makers, professionals in education and medical field, and other family members.

Parental involvement in the entire process of special education is very crucial for the benefits of the children. The quality of the interaction between parents and schools system depends on by the families' socio-cultural characteristics and parents' understanding of the disability, which may have effects on the child's educational and social development (Diken, 2006). The importance of this involvement has recently been valued, understood, and recognized by the government. Therefore, professionals who are competent, culturally sensitive and well-trained as to how to reach to and communicate with parents may play critical roles on meeting parents' needs and their children's educational achievement. A study conducted by Diken (2006) reported that parents did not accept that their children has a disability and it is not a temporary situation. Most sought religious support in order to cope with difficulties they face. Unfortunately, most of the professionals in this field do not seem to be adequate and prepared when working with children and their families. Diken (2006) also indicates that parental involvement should be encouraged and they also should be part of the decision making process regarding special education services and future educational plans for their children.

Supporting parents of children with disabilities is being more valued and its importance is more and more recognized in Turkey. Even though there are many

different support services for families with disabled children, it is far from being enough. As long as the needs in the close environment of the families and their children are not thoroughly acknowledged, recognized, and addressed, there will be neglected and missing links (e.g., siblings, other close relatives), which will negatively affect the relationships in the family. Therefore, continuous and systematic emotional support to families of children with disabilities plays a key role in healing the scars of the family members.

Diken (2006) reports that many mothers are left alone by the members of the family and get no support from them. Mothers reported that they were very concerned about the future of their children if something bad happens to them. Along with depression, panic and anxiety, many mothers also deal with marital conflicts, sometimes divorces. Economical distrains, lack of father's support and resources, being responsible for too many tasks may completely negatively affect the mother if she does not receive any emotional and social support. Therefore, it is very important to develop sufficient emotional and social support programs to empower mothers and families.

## ***VII.2. National statistics***

National Research on the Disabled in Turkey (DIE, 2005) reported 9 million disabled people in Turkey, which consists of 12.3% of the general population (Tufan, Yaman, Arun, 2007). Of this population, close to 2 million children have disabilities in Turkey (Eres, 2010) (see Table 1 and 2).

Basic education is guaranteed by constitutional law in Turkey. It is mandatory, free, and under the control of Ministry of National Education (MoNE). Despite for the opportunity to the open and free access to education, unfortunately, individuals with disabilities cannot benefit from education in the way that healthy individuals have access and opportunities to achieve literacy (Arun, 2014). Individuals with disabilities are often neglected in the educational system and schools are not well equipped enough to serve these individuals, in terms of educational settings, teachers, other special education professionals, resources, and educational materials.

**Table 1. The profile of the disabled in Turkey (data from Turkey Disability Survey, 2002).**

Types of Impairment								
Gender		Orthopedic Impairment	Visual Impairment	Hearing Impairment	Speech and Language Impairment	Mental Retardation	Multiple Disability	Total
Male	Count	416.338	194.816	73.083	57.683	139.845	158.172	1.039.937
	%	40,0	18,7	7,0	5,5	13,4	15,2	100,00
Female	Count	301.490	139.996	62.493	26.279	92.821	109.288	732.367
	%	41,2	19,1	8,5	3,6	12,7	14,9	100,00
Total	Count	717.828	334.812	135.576	83.962	232.666	267.460	1.772.304
	%	40,5	18,9	7,6	4,7	13,1	15,1	100,00
Data is taken from Arun (2014).								

**Table 2. Number of students between age zero and 18 in special education , 2004-05**

Type of disability	%	Number of students
Visual impairments	0.2	49.920
Hearing impairments	0.6	149.760
Physical disabilities	1.4	349.440
Mental disabilities	2.3	574 080
Speech and language impairments	1	873.600
Health impairments	1	249.600
Emotional and behavioral disabilities	2	249.600
Gifted and talented	2	499.200
Total	14	3.494.400
Compiled data available at <a href="http://orgm.meb.gov.tr/Istatistikler/2007%20yılı%20genel%20sonuç.doc">http://orgm.meb.gov.tr/Istatistikler/2007%20yılı%20genel%20sonuç.doc</a>		

### ***VII.3. Inclusion policies in Turkey***

Individuals with disabilities are protected by the special education Law 573 (Cavkaytar, 2006). However, the idea of inclusion is relatively new in Turkish educational system, which has been around for more than 25 years (Rakap & Kaczmarek, 2010). MoNE is responsible for the organization of both general and special education. MoNE describes the concept of inclusive education as follows: “ Inclusive education is a special education practice based on the principle that the education of

individuals with special education needs (SEN) continue their education with their peers without disability in the official and private schools at pre-school, primary education, secondary education, and adult education level by providing them with education support services” (MoNE, 2006).

Even though there are many positive steps that was made in terms of inclusive education in Turkey, it is now known that some of the families with disabled children are not aware of their rights and the services provided for them. Another important point is the negative attitude and perception towards inclusive education and children with disabilities. Children with disabilities and their families are seriously discriminated and isolated in the school system by classroom teachers and school administrators. Another problem that students with disabilities face in the classroom is the competency of teachers (knowledge and skills) and lack of implementation of effective and sufficient educational services. Lastly, physical conditions of schools and classrooms are not suitable for educating students with disability in inclusive classrooms.

Even though the number of students who are benefiting from inclusive education in primary years appears to be increasing, it is hard to see these students in secondary education years due to increasing and unmet needs in educational settings (see Table 3).

**Table 3. Number of students in inclusive classrooms, 2010-13**

<b>Inclusive education</b>	<b>Number of student</b>	
	<b>2010-2011</b>	<b>2012-2013</b>
Primary school	84.580	147.048
Secondary school	7.775	14.247
Total	92.355	161.295

#### ***VII.4. Support programs for parents in Turkey***

Children with disabilities and their families are provided with some support within the school system and national rehabilitation centers. Usually parents get some support individually or in small groups, but these attempts are not enough to help the families. Teaching some parental skills when dealing with the child or teaching him/her new skills could be provided within the school system with the help of special education professionals, however this is very limited and not sufficient to support families. Some associations and non-profit organizations (NGOs) give seminars, run workshops, and teach some survival to parents; again, these programs may not reach to wider

population, because being able to contact with families may not be very easy for them. Another problem is that families may not be followed up to determine if there is a sustainability in terms of how they implement what they have learned during the education. There is also no support program developed by MoNE or other organizations.

### **References**

1. Arun, O. (2014). Disability in Turkey: The risks in being disabled for accessing educational opportunities. *Mediterranean Journal of Humanities*, IV/1, 53-62.
2. Cavkaytar, A (2006). Teacher training on special education in Turkey. *The Turkish Online Journal of Educational Technology (TOJET)*, 5 (3), 1-5.
3. DIE (Turkish Republic Government Statistical Institute) (2005). *Research on the Disabled in Turkey*, Report for 2005. Ankara: DIE Publishing House
4. Diken, I. (2006). Turkish mothers' interpretations of the disability of their children with mental retardation. *International Journal of Special Education*, 21 (2), 8-17.
5. Eres, F. (2010). Special education in Turkey. *US-China Education Review*, 7(4), 94-100.
6. Rakap, S., & Kaczmarek, L. (2010). Teachers' attitudes towards inclusion in Turkey. *European Journal of Special Needs Education*, 25 (1), 59-75.
7. Tufan, I, Yaman, H., & Arun, O. (2007). Disability in Turkey: Suggestions for overcoming current problems. *International Social Work*, 50(6), 839-846.

## **STRESS, COPING AND WELL BEING FOR PARENTS OF CHILDREN WITH SPECIAL NEEDS: A CROSS-CULTURAL RESEARCH STUDY**

Petruța Rusu<sup>1</sup>, PhD

Adina Colomeischi<sup>2</sup>, PhD

<sup>1,2</sup> *Department of Education Sciences,  
University “Ștefan cel Mare” of Suceava, Romania*

### ***Introduction***

The importance of parental stress in family life has been demonstrated in different studies. In general research shows that parenthood is associated with significant changes in parents' life and parenting in itself can be stressful. In the family context, stress negatively influences parents' wellbeing, the quality of their relationship and the quality of parent-child interaction. Studies from family psychology analyzed the influence of different types of stressors on couple and parent-child interaction (i.e. minor, major, acute, chronic, external and internal stressors, Bodenmann, 2005). In general, major and chronic stressors (such as having a child with special needs - SN) determine more instability and dysfunction in family than the other types of stressors. Stress associated with being a parent of a child SN affects parents' well-being and the quality of their parenting. This category of parents represents a vulnerable group of individuals in each society. Studies have shown that families parenting a child SN experience higher levels of stress compared to families with children with a typical development (Delambo, Chung, & Huang, 2011; Lee, 2013). Having a child SN requires more effort and involvement from parents (i.e. long term psychological therapies, medical treatments). The stress faced by families raising children with special needs may continue during adolescence and adult life of their children, influencing the quality of family relationships on a long term.

The stress faced by families raising children SN may continue during adolescence and adult life, influencing the quality of family relationships on a long term. Parents of

children with SN experience higher levels of emotional distress (Lecavalier, 2006), depression (Benson, 2006), anxiety (Pakenham, Sofronoff, & Samios, 2004) and social isolation. This category of parents may feel overwhelmed by the problems associated with their child disability. Therefore, interventions to help parents raising children with disabilities to reduce stress and enhance well being are needed.

The aim of the project Building Bridges: Promoting Social Inclusion and Wellbeing for Families of Children with Special Needs is to help parents of children with SN to improve their coping strategies and to enhance their parenting skills in order to foster their social inclusion and wellbeing. For parents of children with special needs is important to know that they are not alone and that they could rely on positive social sources such as counselors and groups of parents confronting with the same problem. Social support is an important resilient factor for families of children with special needs.

The purpose of the present research is to increase understanding of stress, coping and wellbeing within parents of children with special needs through pursuing a research to define the influence of stress on individual and family outcomes in parents of children with special needs. The main aims of this research are: 1) to analyze the associations between parental stress, coping, negative emotions, emotion regulation, social support, family communication and parents' psychological well-being, 2) to evaluate the influence of individual variables (coping strategies, negative emotions, emotion regulation) on family outcomes (family communication and parents' psychological well-being), 3) to investigate the moderating role of parents' socio-emotional competence and social support in the association between stress and parents' psychological well-being. The hypotheses are built on: the theoretical models of family stress and coping (Bodenmann, 2000), the literature on stress, coping, emotions, family communication, and psychological well being.

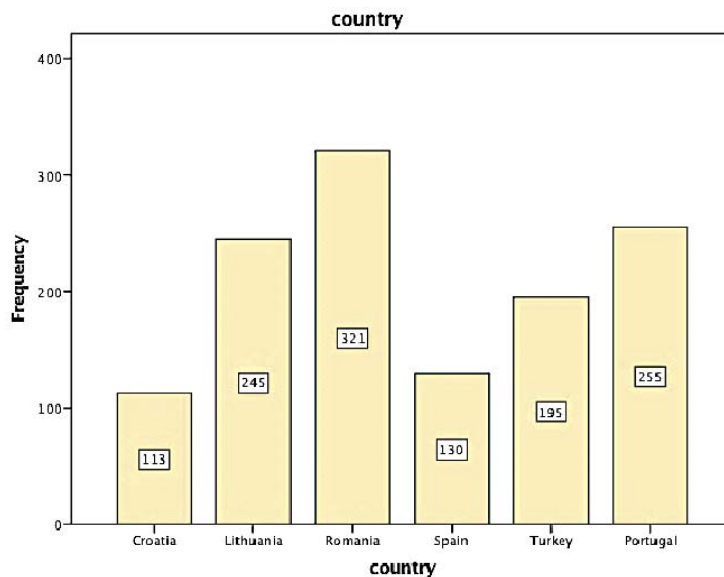
## ***Method***

### ***Sample***

#### **Total sample:**

The data for the present study were collected from a sample of 1259 parents (a total of 796 mothers and 400 fathers, 63 participants did not provide information about gender). From the total sample, 321 parents were from Romania, 255 from Portugal, 245 parents from Lithuania, 195 from Turkey, 130 from Spain and 113 from Croatia. The

distribution of parents across countries is presented in figure 1. The majority of parents (43.6%) were between 35 and 44 years old, 25.5% were between 45 and 54 years old, 20.7% of participants were between 25 and 34 years old, 6% between 18 and 24 years old and 0.6 participants were older than .65 years old. On average, families had 2 children ( $SD = .86$ , range = 1-8 children). According to the socio-economic status of the sample, measured by family income, 37.7% of parents reported family incomes lower than 500 EUR, 19.9%, reported incomes between 500 and 1000 EUR, 14.3% had a family income between 1000 and 1500 EUR and only 18,9 % of parents had a household income higher that 1500 EUR per month. Regarding the marital status of the parents involved in the present study, 74.4% of them were married, 12.1% divorced, 2.8% were widowed, 4.3% single parents and 5.6 being in a couple relationship.



**Figure 1.** Distribution of parents participating in the study across countries

### ***Procedure***

Parents from each participating country were recruited through local Special Education Centers for children and local organizations that offer parent support services. Special education teachers, school managers, counselors, psychologists and students were involved in the data collection process; they were instructed about the purpose of the study, the privacy of the data and were asked to distribute the questionnaires to parents of children with different special needs (autism, ADHD, Down syndrome, mental deficiency, physical disabilities). Parents agreed to participate in the

study on a voluntary basis. The Institutional Review Board of the Romanian University approved the study. All parents signed an informed consent to participate in the study.

The English versions of the questionnaires were first translated into each language (Romanian, Croatian, Spanish, Portuguese, Turkish and Lithuanian language) and then back translated into English by independent translators. The resulting versions were analyzed and the discrepancies in translation were solved by agreement.

### **Measures**

The purpose of the present study was to collect information about different factors that influence family relationships for parents having a child with special needs. This survey assessed aspects of family stress, coping strategies, communication in family, emotions experienced by parents, social support, marital satisfaction and parents' well being. Socio-demographic variables were measured by items about age, gender, marital status, income, number of children, education, and type of child' disability. The survey contained measurements of the following variables:

**General stress.** One subscale from the Multi-Dimensional Stress Questionnaire for couples (MSF-P, Bodenmann, Schär, & Gmelch, 2008) was used in order to measure the stressors originating outside the family (related to job, social contacts, free time, living situation, finances). The items of this subscale are rated on a Likert scale from 1 (not at all) to 4 (strong).

**Parental stress.** The Parental Stress Scale (Berry & Johnson, 1995) was used in the present study to measure stress in parent child relationship. The scale contains 18 items, answered using a 5-point Likert scale (1 – strongly disagree; 5 – strongly agree).

**Parent child interaction.** The Emotional warmth subscale from Parental behaviour Questionnaire (Jaursch, 2003) and Negative communication subscale from Parenting Questionnaire (Schwarz, Walper, Gödde, & Jurasic, 1997) have been used for assessing parent child interaction. The items from these two subscales were rated on a 5 point Likert scale (1 – never to 5 – very often).

**Coparenting** with the current partner was measured with the short version of Parent Problem Checklist PPC" (Dadds & Powell, 1991). The items assess parental cooperation on parental issues. The responses range from 1 – never to 5 – very often.

**Supportive Dyadic Coping.** Dyadic Coping Inventory (DCI; Bodenmann, 2008) was used to measure *supportive dyadic coping* provided to the partner (Suportive Dyadic

Coping by Oneself) and supportive coping received from the partner (Supportive Dyadic Coping by Partner). Participants were asked to rate on a 5-point Likert scale (1 = very rarely to 5 = very often) how often they provide to their partner emotion-focused SDC (e.g., *I show empathy and understanding to my partner*) and problem-focused SDC (e.g., *I try to analyze the situation together with my partner in an objective manner and help him/her to understand and change the problem*) and how often they receive support from their partners.

**Couple Relationship satisfaction.** Relationship Assessment Scale (Hendrick, 1988) was used to measure general relationship satisfaction. The scale has 7 items measured on a 5-point Likert scale ranging from 1 (low satisfaction) to 5 (high satisfaction).

**Emotional competence.** The short version of the Difficulties in Emotion Regulation Scale (Gratz & Roemer (2004) was used in this study. The scale contains 18 items and measures the following dimensions: lack of emotional awareness, lack of emotional clarity, non-acceptance of emotional responses, difficulties in emotion regulation strategies, difficulties in engaging in goals and difficulties in impulse control. The items are rated on a 5-point scale from 1 – almost never to 5 – almost always.

**Religious coping.** In the present study we used the Brief RCOPE (Pargament, Koenig, & Perez, 2000) questionnaire to assess positive religious coping (finding meaning in a stressful situation, reappraising the stressor as an opportunity for spiritual growth) and negative religious coping (evaluating the stressful event as a punishment from God). The items are rated on a 4-point Likert scale ranging from 1- not at all to 4 – a great deal.

**Psychological well-being/Positive functioning** was measured with the Relationship subscale from the Comprehensive Inventory of Thriving (CIT, Su, Tay, & Diener, 2014). The scale contains the following dimensions: support, community, trust, respect, loneliness and belonging. The items of this inventory are rated on a 5-point Likert scale, from 1 – strongly disagree to 5 – strongly agree.

## ***Results***

Means, standard deviations and the results of the Mann-Whitney test for comparing gender differences are presented in Table 1. The results showed that fathers reported significantly higher levels of general stress than mothers, while mothers

reported significantly higher levels of negative communication with their children and higher levels of support received from the community compared to fathers. Table 2 provides information about the correlations between the study variables.

*Table 1 - Descriptive statistics and gender differences for the study variables*

<b>Variable</b>	<b>Mean</b>	<b>SD</b>	<b>Mann-Whitney test</b>
<b>1. General stress</b>			<b>.00</b>
Mothers	2,19	0,83	
Fathers	2,40	0,94	
<b>2. Parental stress</b>			<b>.86</b>
Mothers	2,23	0,61	
Fathers	2,22	0,58	
<b>3. Emotional warmth</b>			<b>.76</b>
Mothers	4,43	0,63	
Fathers	4,41	0,70	
<b>4. NC</b>			<b>.01</b>
Mothers	2,51	0,81	
Fathers	2,39	0,85	
<b>5. PRC</b>			<b>.74</b>
Mothers	2,75	1,08	
Fathers	2,78	1,04	
<b>6. NRC</b>			<b>.26</b>
Mothers	1,97	1,02	
Fathers	1,92	1,01	
<b>7. SDCO</b>			<b>.15</b>
Mothers	3,94	0,91	
Fathers	3,84	0,97	
<b>8. SDCP</b>			<b>.72</b>
Mothers	3,68	1,16	
Fathers	3,65	1,15	
<b>9. RS</b>			<b>.47</b>
Mothers	3,38	0,61	
Fathers	3,42	0,84	
<b>10. DER</b>			<b>.39</b>
Mothers	2,39	0,64	
Fathers	2,42	0,66	
<b>11. Support</b>			<b>.02</b>
Mothers	4,21	0,90	
Fathers	4,06	0,92	
<b>12. Community</b>			<b>.08</b>
Mothers	3,67	1,30	
Fathers	3,61	1,35	
<b>13. Trust</b>			<b>.90</b>
Mothers	3,36	0,78	
Fathers	3,42	1,21	
<b>14. Respect</b>			<b>.27</b>
Mothers	3,96	0,70	

Fathers	4,02	0,72	
<b>15. Loneliness</b>			.20
Mothers	2,18	1,13	
Fathers	2,24	0,98	
<b>16. Belonging</b>			.15
Mothers	3,48	1,06	
Fathers	3,59	1,00	

Note:  $n = 295$  women and 295 men,  $df = 293$

\*\* $p < .01$  (two-tailed)

**Table 2 - Correlations among study variables**

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. General stress															
2. Parental stress	.402**														
3. Emotional warmth	-.023	-.242**													
4. Negative communication	.201**	.290**	-.128**												
5. Positive religious coping	.116**	.011	.041	-.018											
6. Negative religious coping	.047	.173**	-.025	.047	.573**										
7. SDCO	-.109**	-.209**	.250**	-.095**	.074*	.008									
8. SDCP	-.189**	-.247**	.184**	-.125**	.011	-.058	.740**								
9. Rel. Satisfaction	-.050	-.113**	.102**	-.102**	.017	-.010	.425**	.474**							
10. DER	.352**	.403**	-.151**	.278**	.003	.006	-.217**	-.243**	-.194**						
11. Support	-.146**	-.229**	.175**	-.071*	-.166**	-.181**	.234**	.203**	.196**	-.225**					
12. Community	-.043	-.121**	.064*	.005	.200**	.054	.145**	.067*	.066*	-.048	.158**				
13. Trust	-.177**	-.150**	.019	-.034	.018	-.089*	.121**	.159**	.069*	-.115**	.233**	.266**			
14. Respect	-.112**	-.190**	.181**	-.151**	.059	-.149**	.235**	.239**	.264**	-.272**	.381**	.198**	.405**		
15. Loneliness	.300**	.354**	-.044	.109**	.201**	.330**	-.206**	-.268**	-.224**	.352**	-.326**	-.122**	-.160**	-.272**	
16. Belonging	.026	-.048	.083**	-.069*	.314**	.089*	.073*	.092**	.176**	-.087**	.133**	.230**	.255**	.352**	-.052
** Correlation is significant at the 0.01 level (2-Tailed).															
* Correlation is significant at the 0.05 level (2-tailed).															

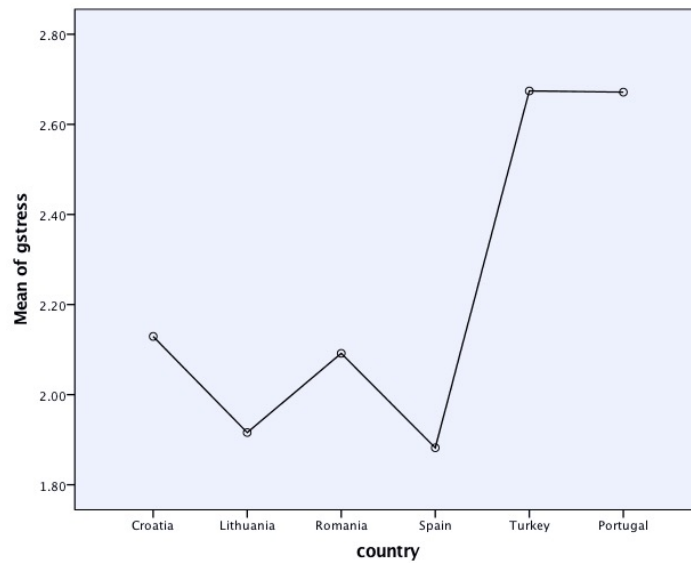
In order to compare the study variables across countries, we used one-way ANOVA. Considering that our data did not meet the homogeneity of variances assumption and the unequal sample sizes, we used the Games Howell post hoc test. The means for the study variables for each country participating in the study are presented in Table 3.

**Table 3 - Means for the study variables across countries**

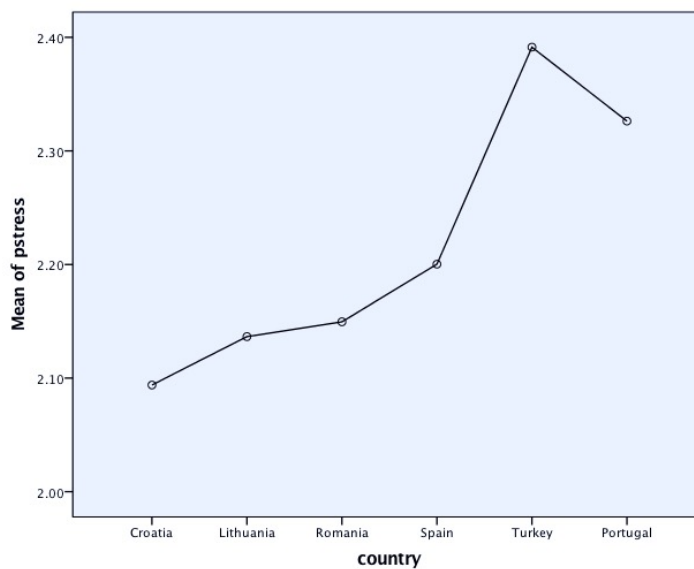
	Gstress	Pstress	EW	NC	PRC	NRC	SDCO	SDCP	DERS	WB
Croatia	2,13	2,09	4,59	2,62	2,09	1,28	3,84	3,85	2,42	3,82
Lithuania	1,92	2,14	4,35	2,58	1,86	1,44	4,04	3,86	2,39	3,79
Romania	2,09	2,15	4,42	2,40	3,42	2,69	3,97	3,68	2,16	3,71
Spain	1,88	2,20	4,19	2,30	-	-	3,81	3,66	2,31	3,77
Turkey	2,67	2,39	4,31	2,67	3,18	1,73	3,71	3,33	2,85	3,82
Portugal	2,67	2,33	4,60	2,31	-	-	3,91	3,66	2,37	3,82
Total	2,25	2,22	4,42	2,47	2,76	1,96	3,90	3,67	2,39	3,78

Gstress = General stress; Pstress = parental stress; EW = emotional warmth; PRC = positive religious coping; NRC = negative religious coping; SDCO = supportive dyadic coping by oneself; SDCP = supportive dyadic coping by partner; DERS = difficulties in emotion regulation; WB = well-being (relationships).

The results showed that parents living in Turkey and Portugal reported the highest levels of general stress and parental stress. Moreover, the level of general stress reported by parents from Turkey and Portugal were significantly higher than the stress reported by parents from the other countries (Figure 1, Figure 2), while the level of parental stress reported by parents from Turkey and Portugal were significantly higher than the stress reported by parents from Croatia, Lithuania and Romania, but not significantly higher than the stress of Spanish parents. The findings did not show significant differences between Turkey and Portugal in terms of general and parental stress, parents from both countries experience similar high levels of stress.

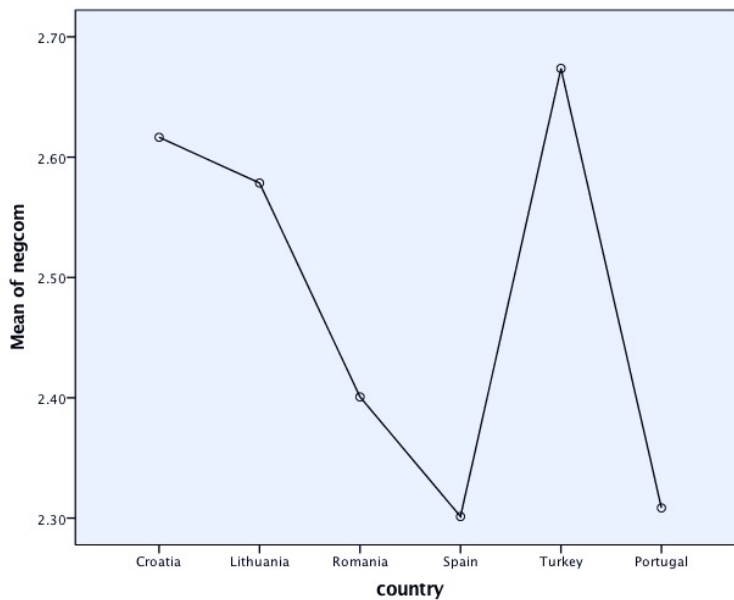


**Figure 2. General stress across countries (job stress, stress related to social contacts, free time, living situation, finances)**



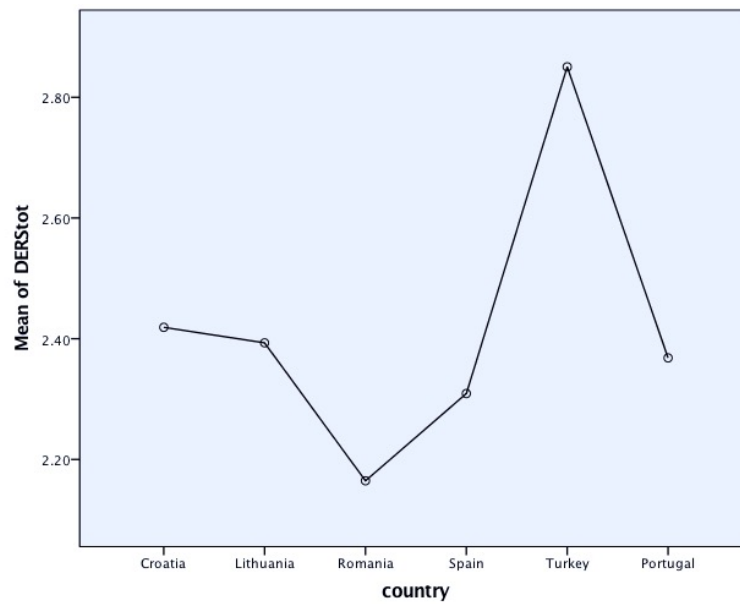
**Figure 3. Parental stress across countries**

In terms of negative communication in parent-child interaction, parents from Turkey reported the highest level of negative communication with their children, while parents from Spain reported the lowest level. The level of negative communication in Turkish families was significantly higher than in Romanian, Spanish and Portuguese families. The findings also indicated lower levels of negative communication in Spanish families than in Croatian and Lithuanian families.



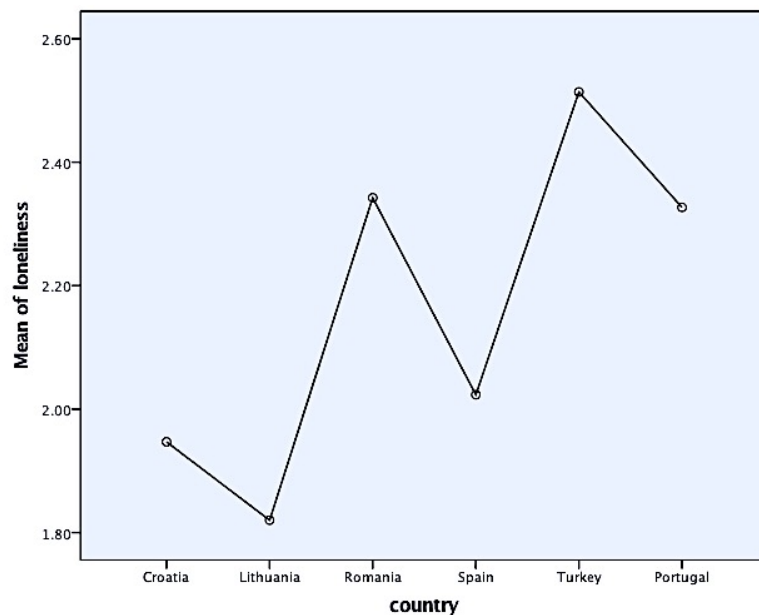
**Figure 4. Negative communication in parent-child interaction**

Regarding the variable *difficulties in emotion regulation*, Turkish parents reported the highest score (more difficulties in emotion regulations), while Romanian parents reported the lowest score (less difficulties in emotion regulation). The comparisons between countries indicated that the parents of children with special needs from Turkey have significantly more difficulties in regulating their emotions than the parents from Croatia, Lithuania, Romania, Spain and Portugal. On the other hand, the findings indicated that Romanian parents regulate their emotions significantly better than parents from Croatia, Lithuania, Turkey and Portugal. Spanish parents also reported good strategies for emotion regulation; there were no significant differences between Spanish and Romanian parents.



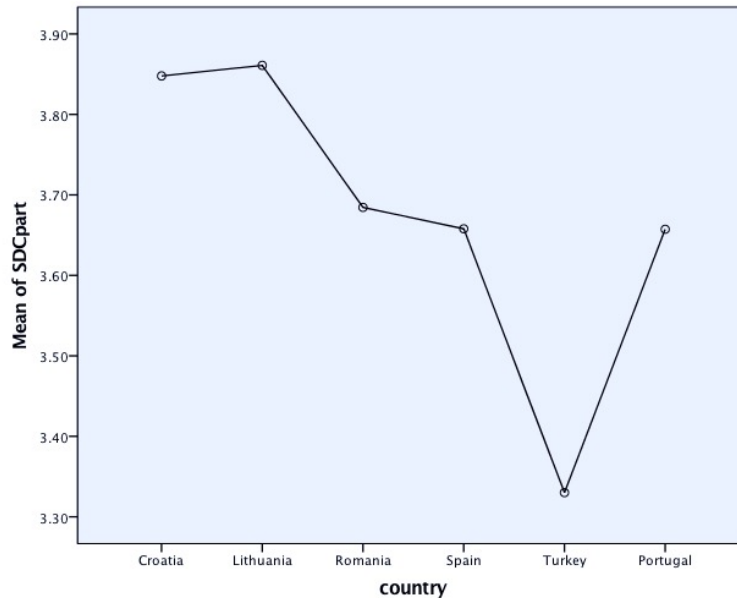
**Figure 5. Difficulties in Emotion Regulation across countries**

As shown in Figure Turkish, Portuguese and Romanian parents of children with special needs reported feelings loneliness at the highest levels compared to parents from the other three countries. The feelings of loneliness reported by Turkish, Portuguese and Romanian parents were significantly higher than the ones of Croatian, Lithuanian and Spanish parents.



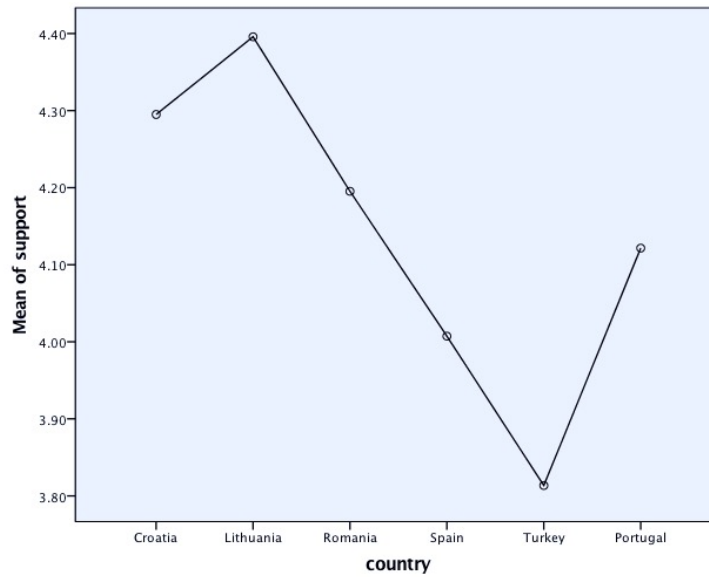
**Figure 6. Perceived Loneliness across countries**

In terms of Supportive dyadic coping by partner (emotion-focused and problem-focused support received in times of stress by one parent from the other), the highest levels of SDCP were reported from Lithuanian and Croatian parents, while Turkish parents reported the lowest level. The SDCP of Turkish parents was significantly lower than the SDCP reported by parents from Croatia, Lithuania, Romania and Portugal.



**Figure 7. Support received from the partner**

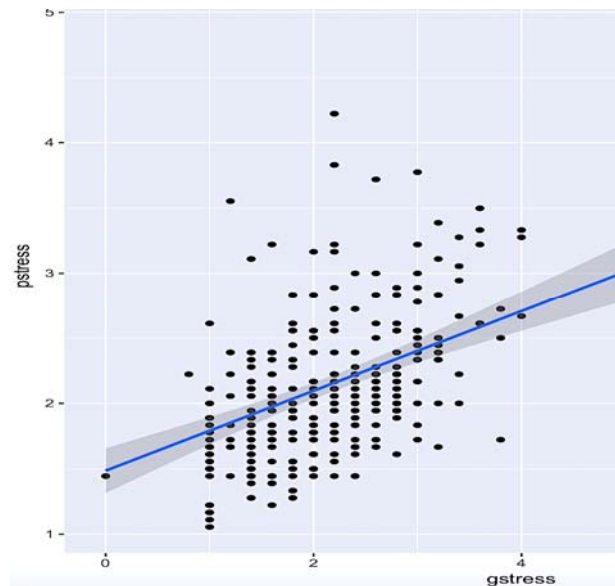
The results regarding the support received from community revealed that Lithuanian and Croatian parents reported higher levels of support, while Turkish parents the lowest level. Lithuanian parents reported significantly higher levels of support from community than Spanish, Turkish and Portuguese parents. Moreover, the support reported by Turkish parents was significantly lower than the support received by parents from Croatia and Romania.



**Figure 8. Support from community**

In the following section we will present several figures with the most important associations between the study variables. All the relationships depicted in the figures below are statistically significant in the depicted direction.

### General stress and parental stress



**Figure 9. The relationship between general stress (job stress, financial stress, social stress) and parental stress;**

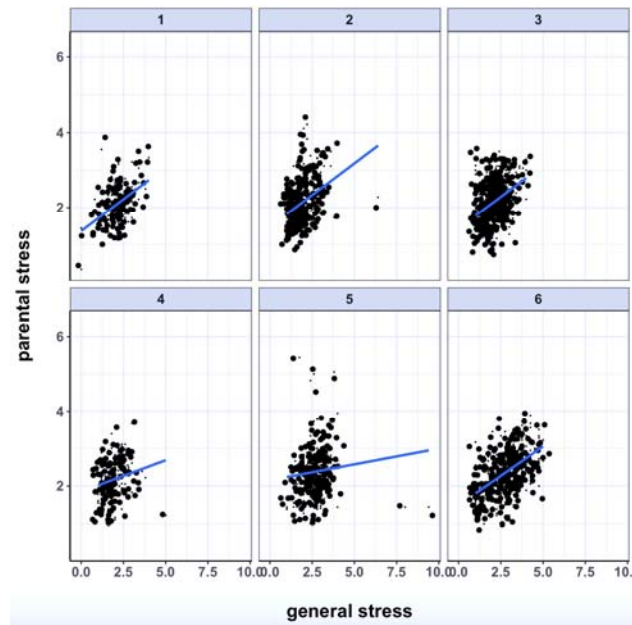


Figure 10. The relationship between general stress (job stress, financial stress, social stress) and parental stress across countries; 1- Croatia, 2- Lithuania, 3 - Romania, 4 - Spain, 5 - Turkey, 6 – Portugal

### Stress and parent-child interaction

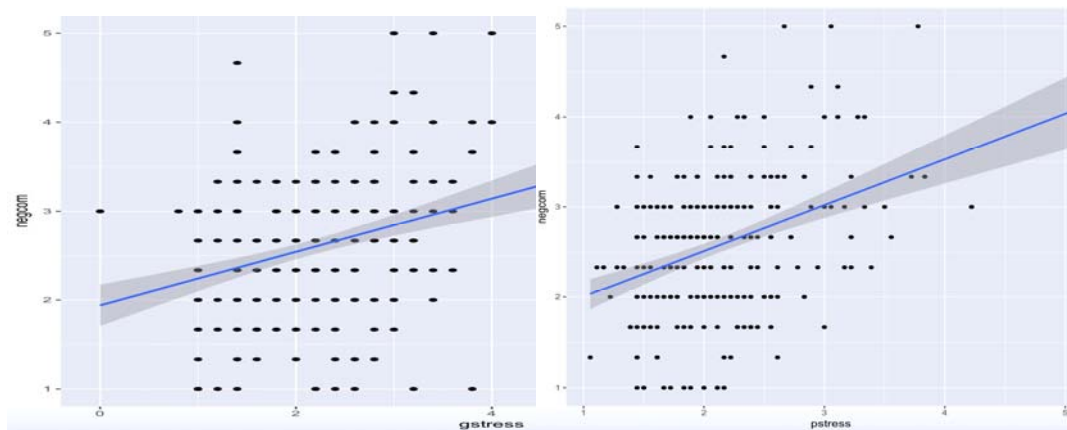
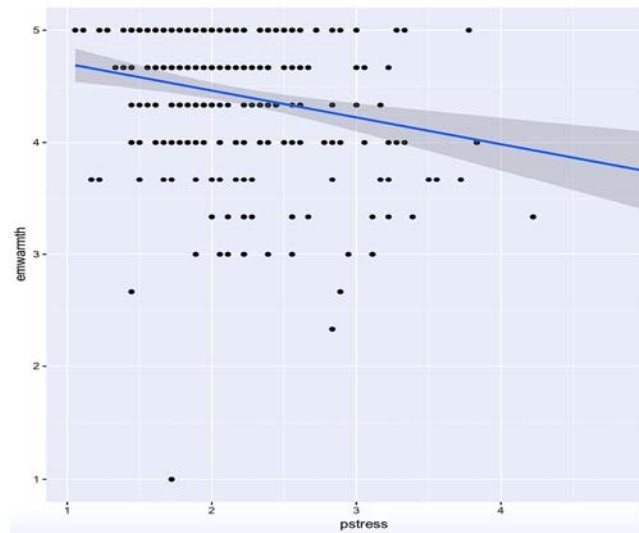
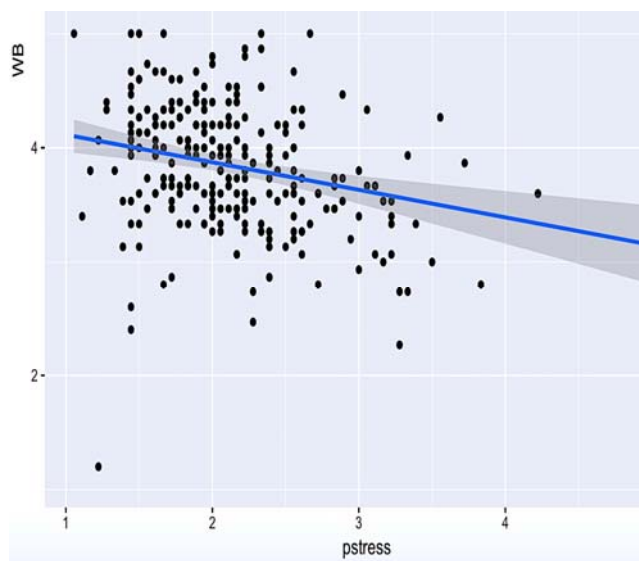


Figure 11. The relationship of general and parental stress with negative communication between parent and child



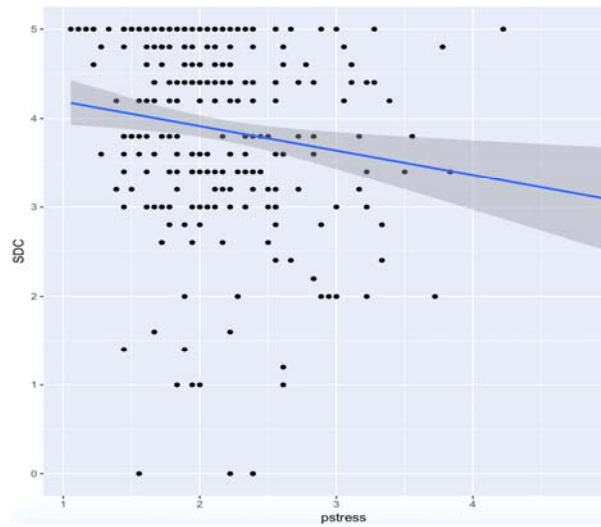
**Figure 12.** The relationship parental stress and emotional warmth

### Stress and parents' well-being

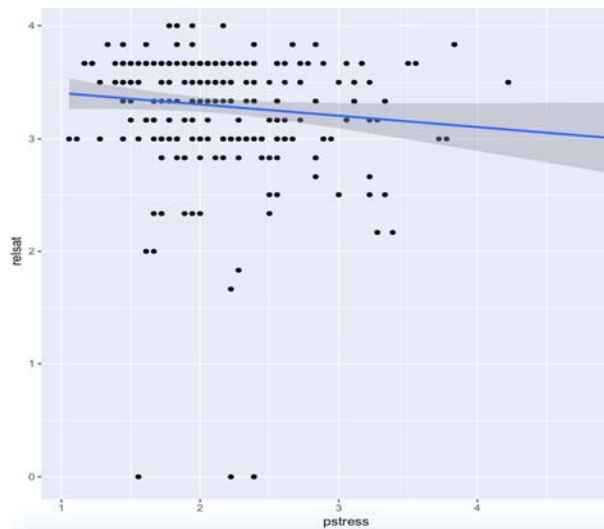


**Figure 13.** The relationship between parental stress and parents' well-being

## Stress and couple interaction

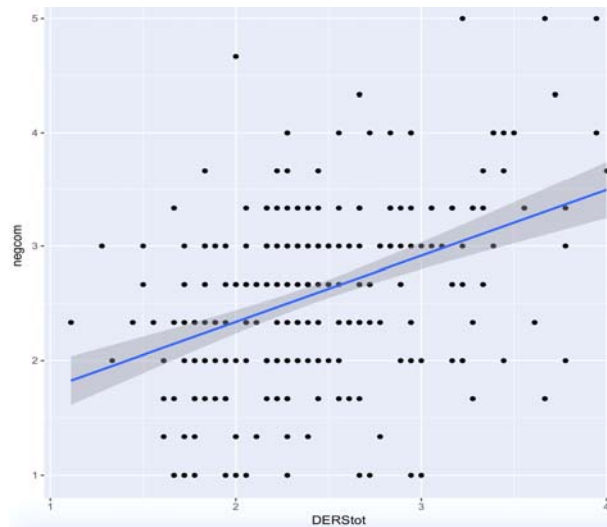


**Figure 14.** The relationship between parental stress and Supportive dyadic coping in couple (support provided to the partner in stressful situations)

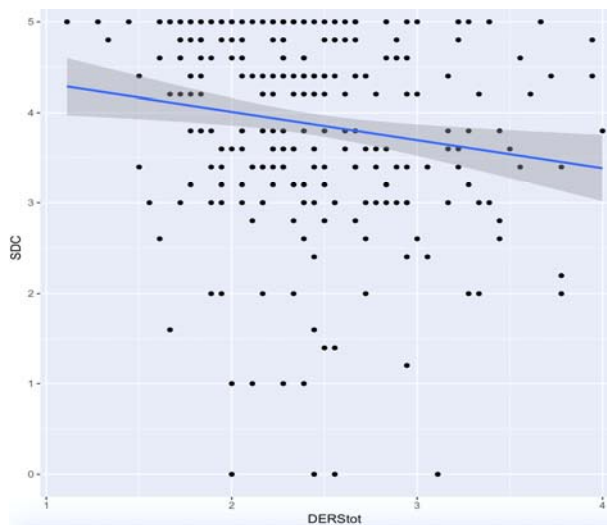


**Figure 15.** The relationship between parental stress and couple relationship satisfaction

## Parents' difficulties in emotion regulation and family interactions

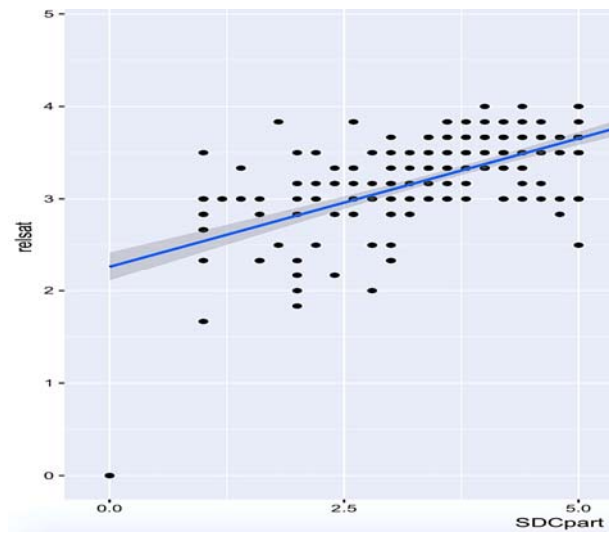


**Figure 16.** The relationship between parents' difficulties in emotion regulation and negative parent-child communication

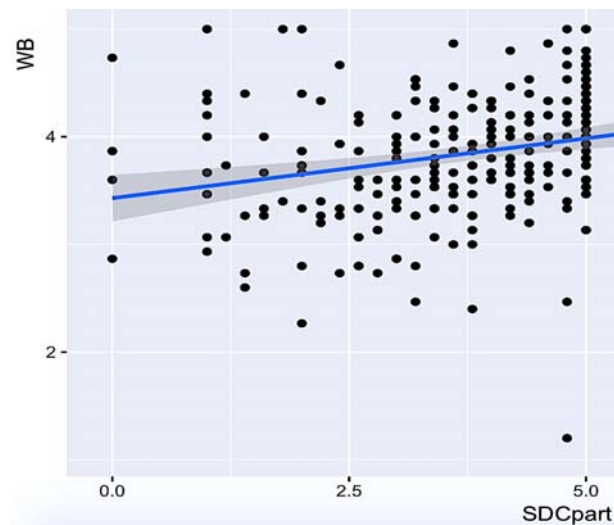


**Figure 17.** The relationship between parents' difficulties in emotion regulation and support provided to the partner

### Support received and parents relationship satisfaction and well-being



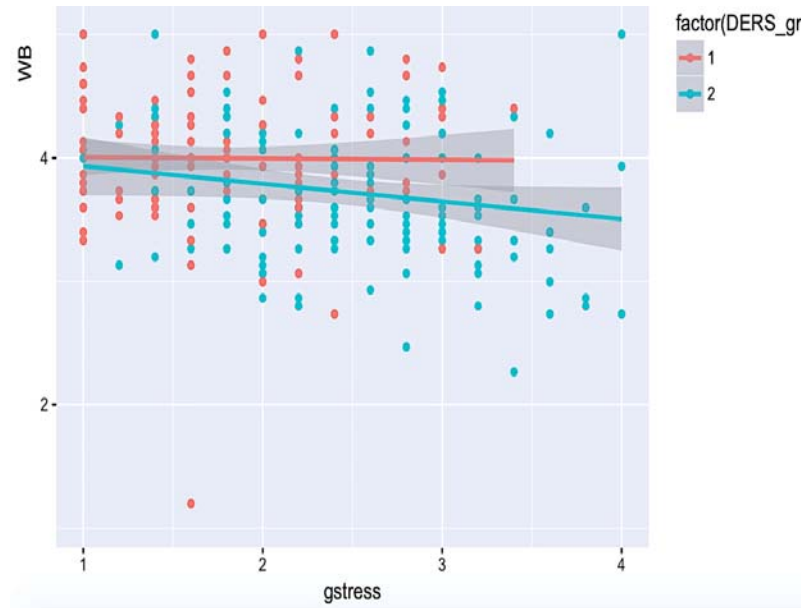
*Figure 18.* The relationship between Supportive dyadic coping by partner and couple relationship satisfaction



*Figure 19.* The relationship between Supportive dyadic coping by partner and parents' well-being

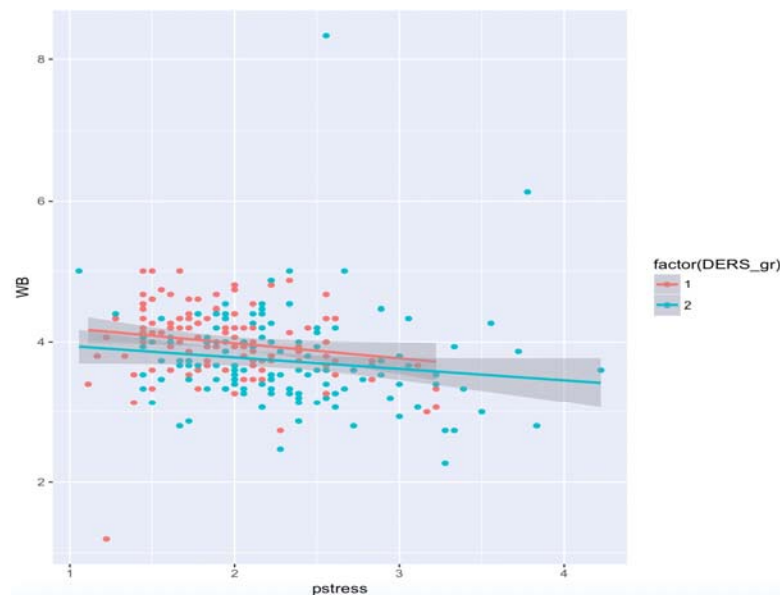
### Moderation effects

The results of the present study indicated a significant interaction effect between general stress and difficulties in emotion regulation in predicting parents' well being ( $b = -.18, p < .001$ ) CI  $[-.29, -.07]$ .



**Figure 20.** The moderation effect of DER in the association between general stress and parents' well-being

In addition, we found a significant interaction effect between parental stress and difficulties in emotion regulation in predicting parents' well being ( $b = -.15, p < .05$ ) CI  $[-.31, -.01]$ .



**Figure 21.** The moderation effect of DER in the association between parental stress and parents' well-being

## ***Discussion***

### **The spill-over of external stress into the family**

The findings of the present study revealed that the stressors originating outside the family (related to job, social contacts, free time, living situation, finances) spill over into the family relationships and affect parent-child interactions. The phenomenon of stress spill-over occurs when stress from one area of a person's life (e.g. work stress) is transmitted to other areas (e.g. family interactions between parents and between parents and children). In our study, parents experiencing higher levels of stress outside their family (related to work, financial stress, stress related to the living situation, such as apartment size and social stress) reported also higher levels of parental stress.

Research studies on family stress frequently address stress spillover, showing that family functioning is negatively affected by daily stressors (Bodenmann, 2005; Karney, Storry & Bradburry, 2005,). These findings are also consistent with results of other studies showing interactions between different types of stressors. For example, Karney et al. (2005) showed that chronic stress could moderate the influence of an acute stressor on the relationship, meaning that an acute stressor has a higher negative influence on family functioning when a chronic stressor is also present.

In addition, another spill-over effect is indicated by the significant negative association between general stress and negative parent-child communication. As stress outside the family increases, negative parent-child communication has higher levels.

This study also showed that general stress was significantly negatively associated with couple interactions between parents (support provided to and support received from the partner) and parents' well-being (feelings of loneliness).

### **The spill-over of child related stress into parents' relationship**

Parental stress was significantly negatively related to couple supportive behaviours (SDC by oneself and by partner) and with relationship satisfaction. These negative associations might be interpreted in light of recent research indicating that child-related stress impair parents' relationship quality and worsen couple communication (Zemp, Nussbeck, Cummings, & Bodenmann, 2017).

### **Parents' difficulties in emotion regulation and family interactions**

The results showed that difficulties in emotion regulation reported by parents (*non-acceptance of emotional responses, difficulty engaging in goal-directed behaviour when experiencing negative emotions, impulse control difficulties, lack of awareness of emotions, limited access to strategies for regulation and lack of emotional clarity*) have been significantly positively associated with parental stress and negative parent-child communication, while the relationship between difficulties in emotion regulation and emotional warmth was significant and negative. These findings extend the results of previous studies relating difficulties in emotion regulation to stress, depression and anxiety (Bardeen, Fergus, & Orcutt, 2012). Similarly, existing studies indicated emotion dysregulation was negatively related to supportive maternal responses. Another negative effect of difficulties in emotion regulation is related to their negative effect on parents' relationship. Difficulties in emotion regulation have been significantly negatively associated with support provided to and support received from the partner and with relationship satisfaction. In other words, difficulties in emotion regulation decrease positive coping in parents' relationship and decrease their relationship satisfaction. These findings are consistent with prior research showing that partners' difficulties in emotion regulation determine criticism, violence and low levels of relationship satisfaction (Bloch, Haase, & Levenson, 2014; Klein, Renshaw, & Curby, 2016; McNulty & Hellmuth, 2008).

The hypothesized moderating role of emotion regulation in the association between stress and well-being was confirmed by our results. Specifically, difficulties in emotion regulation moderated the association between general stress and parents' well being and between parental stress and parents' well-being. Thus, both general and parental stress will have a significantly higher negative effect on well-being for those parents with higher levels of difficulties in emotion regulation. Well-being of parents with better emotion regulation strategies will not be affected by their level of stress.

### **Support received and parents relationship satisfaction and well being**

Other important results of our study are related to the positive effect of support received by the parents on their well-being. Although, both types of support have been significantly positively associated with parents' well being, the results showed that support from the partner was more related to well-being than support from the

community. These findings are consistent with the ones of prior studies, suggesting that positive dyadic coping is positively related to partners' well being (Rusu, 2016).

### **Implications**

The results of the current study support the importance of addressing coping strategies, emotion regulation and parent-child communication in the context of counselling parents of children with special needs. Training and counselling programs for this category of parents should target parents' difficulties in emotion regulation and should focus on parents' individual and dyadic coping skills in confronting with the major stress of having a child with special needs. Adaptive emotion regulation strategies might be very beneficial for both parent-child and parent-parent interactions. According to the Systemic Transactional Theory (Bodenmann, 2005), when parents are able to cope with their stress and to regulate their emotions individually, lower levels of stress will spill-over into the family

### **References**

1. Bardeen, J. R., Fergus, T. A., & Orcutt, H. K. (2012). An examination of the latent structure of the Difficulties in Emotion Regulation Scale. *Journal of Psychopathology and Behavioral Assessment*, 34(3), 382-392.
2. Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal of autism and developmental disorders*, 36(5), 685-695.
3. Berry, J. O., & Jones, W. H. (1995). The parental stress scale: Initial psychometric evidence. *Journal of Social and Personal Relationships*, 12(3), 463-472.
4. Bloch, L., Haase, C. M., & Levenson, R. W. (2014). Emotion regulation predicts marital satisfaction: More than a wives' tale. *Emotion*, 14(1), 130-144.
5. Bodenmann, G. (2005). Dyadic coping and its significance for marital functioning. *Couples coping with stress: Emerging perspectives on dyadic coping*, 1(1), 33-50.
6. Bodenmann, G., Schär, M., & Gmelch, S. (2008). Multidimensional stress questionnaire for couples (MDS-Q). *Unpublished questionnaire*, 49-57.

7. DeLambo, D., Chung, W., & Huang, W. (2011). Stress and age: A comparison of Asian American and non-Asian American parents of children with developmental disabilities. *Journal of Developmental and Physical Disabilities*, 23(2), 129-141.
8. Gratz, K. L., & Roemer, L. (2004). Multidimensional assessment of emotion regulation and dysregulation: Development, factor structure, and initial validation of the difficulties in emotion regulation scale. *Journal of psychopathology and behavioral assessment*, 26(1), 41-54.
9. Hendrick, S. S. (1988). A generic measure of relationship satisfaction. *Journal of Marriage and the Family*, 50, 93-98.
10. Jaursch, S. (2003). *Erinnertes und aktuelles Erziehungsverhalten von Müttern und Vätern: Intergenerationale Zusammenhänge und kontextuelle Faktoren: Dissertation Friedrich-Alexander-Universität Erlangen-Nürnberg.*
11. Jones, J. D., Brett, B. E., Ehrlich, K. B., Lejuez, C. W., & Cassidy, J. (2014). Maternal attachment style and responses to adolescents' negative emotions: The mediating role of maternal emotion regulation. *Parenting*, 14(3-4), 235-257.
12. Klein, S. R., Renshaw, K. D., & Curby, T. W. (2016). Emotion Regulation and Perceptions of Hostile and Constructive Criticism in Romantic Relationships. *Behavior Therapy*, 47(2), 143-154.
13. Lee, J. (2013). Maternal stress, well-being, and impaired sleep in mothers of children with developmental disabilities: A literature review. *Research in developmental disabilities*, 34(11), 4255-4273.
14. Lecavalier, L. (2006). Behavioral and emotional problems in young people with pervasive developmental disorders: Relative prevalence, effects of subject characteristics, and empirical classification. *Journal of autism and developmental disorders*, 36(8), 1101-1114.
15. McNulty, J. K., & Hellmuth, J. C. (2008). Emotion regulation and intimate partner violence in newlyweds. *Journal of Family Psychology*, 22(5), 794-797.
16. Pakenham, K. I., Sofronoff, K., & Samios, C. (2004). Finding meaning in parenting a child with Asperger syndrome: Correlates of sense making and benefit finding. *Research in developmental disabilities*, 25(3), 245-264.
17. Pargament, K. I., Koenig, H. G., & Perez, L. M. (2000). The many methods of religious coping: Development and initial validation of the RCOPE. *Journal of clinical psychology*, 56(4), 519-543.

18. Rusu, P.P. (2016). Dyadic coping in Romanian couples. In *Couples coping with stress: A cultural perspective*, edited by M. K. Falconier, A. K. Randall, & G. Bodenmann. New York: Routledge.

19. Schwarz, B., Walper, S., Gödde, M., & Jurasic, S. (1997). Dokumentation der Erhebungsinstrumente der 1. Haupterhebung (überarb. Version). *Berichte aus der Arbeitsgruppe "Familienentwicklung nach der Trennung" # 14/1997*.

20. Su, R., Tay, L., & Diener, E. (2014). The development and validation of the Comprehensive Inventory of Thriving (CIT) and the Brief Inventory of Thriving (BIT). *Applied Psychology: Health and Well-Being*, 6(3), 251-279.

21. Zemp, M., Nussbeck, F. W., Cummings, E. M., & Bodenmann, G. (2017). The Spillover of Child-Related Stress into Parents' Relationship Mediated by Couple Communication. *Family Relations*.

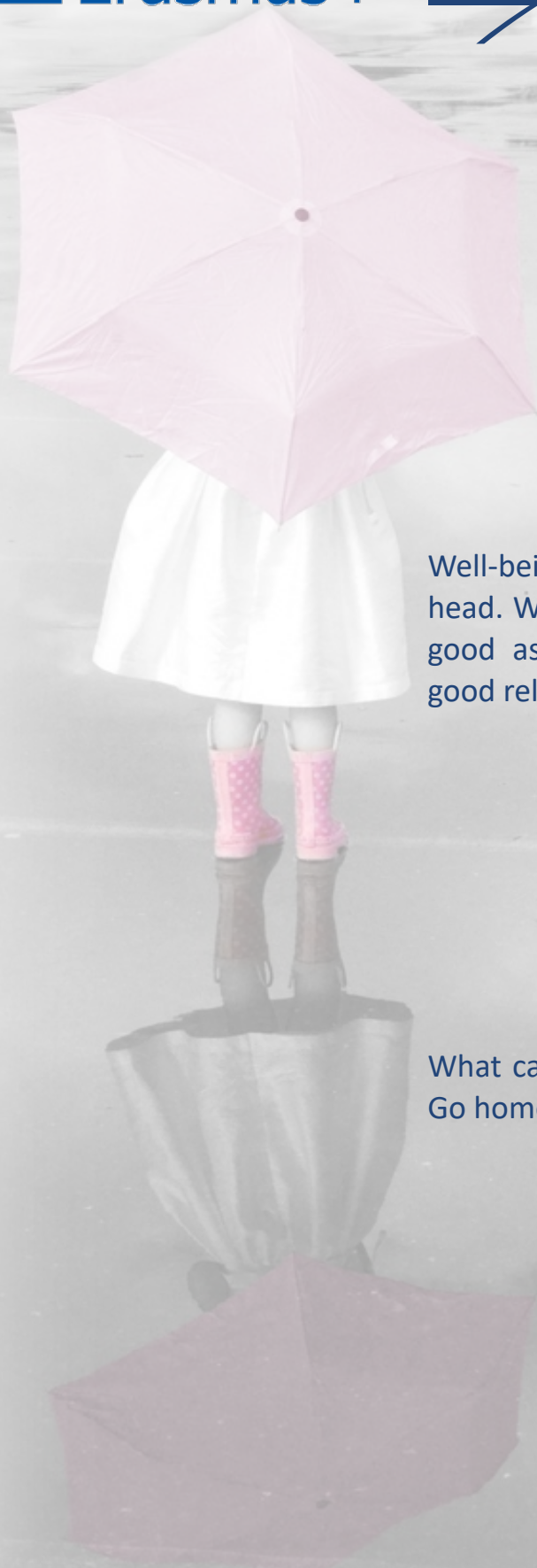


Erasmus+



Project no. 2016-1-RO01-KA204-024504

Building Bridges: Promoting  
Social Inclusion and Wellbeing for Families  
of Children with Special Needs



Well-being cannot exist just in your own head. Well-being is a combination of feeling good as well as actually having meaning, good relationships and accomplishment.

***Martin Seligman***

What can you do to promote world peace?  
Go home and love your family!

***Mother Theresa***

[www.psiwell.eu](http://www.psiwell.eu)



Funded by the  
Erasmus+ Programme  
of the European Union