

**Building Bridges:
Promoting wellbeing for family**



Erasmus+

Program 2016-1-RO01-KA204-024504KA2
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Strategic Partnerships for adult education Development and Innovation

HANDBOOK for parents



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BUILDING BRIDGES: PROMOTING WELLBEING FOR FAMILY HANDBOOK FOR PARENTS

Coordinator **Aurora Adina COLOMEISCHI**

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Part I

Promoting resilience and wellbeing within family of disabled children

1. Stress and resilience within family (Romania)

Petruța Rusu

“Stefan cel Mare” University of Suceava

“Ever tried. Ever failed. No matter. Try Again. Fail again. Fail better.” (Samuel Beckett)

Abstract

The aim of this book chapter is to provide theoretical and practical information on stress, coping and resilience in families raising children with special needs. The present chapter presents the prevalence of special needs in Europe and reviews studies focused on family stress, chronic sorrow, individual and dyadic coping strategies in family and resilience. Suggestions for stress management are provided to parents; they could find information on special education services and useful online resources in order to cope with stress.



1. Glossary

Stress

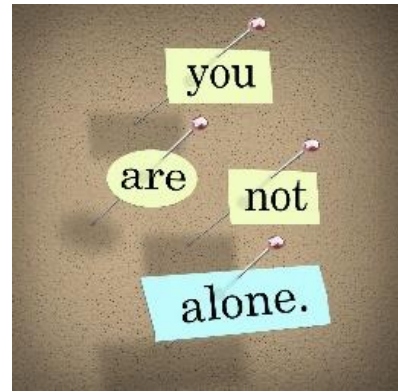
- **Family stress** – change, disturbance in the family balance emerging from external factors (e.g. unemployment) or internal issues (e.g. a child disease).
- **Stress spill-over** - intra-individual transmission of stress from one domain (e.g. work) to another domain (e.g. family life).
- **Stress cross-over** - inter-individual transmission of stress from one partner to the other in family relationships

Coping

- **Emotion-focused coping** - managing emotional distress, efforts to deal effectively with emotions in stressful situations
- **Problem-focused coping** – efforts to solve the source of stress
- **Dyadic coping** – stress management process involving both parents, joint coping efforts of the parents, support provided from one parent to the other and cooperative use of common resources in order to cope with stress
- **Religious Coping** – the use of religious behaviours and religious faith in order to find meaning to and cope with the stressful events.

Family Resilience – family competence to adapt, cope with stress and restore the family well-being in adverse situations

2. You are not alone – *Statistics related to children with special needs and their parents*



The diagnosis of special needs (SN; e.g. intellectual disability, autism, Down Syndrome, ADHD, behavioral and emotional disorders, learning disabilities) affects approx. 15 million of families in Europe and 800 million of families worldwide (European Commission, 2012). The prevalence is 1 in 160 children with Autism Spectrum Disorder (WHO, 2017), 1 in 600 – 1000 children with Down Syndrome (European Down Syndrome Association) and 5 in 100 children with ADHD (ADHD Europe), 5 - 12 in 100 with dyslexia (European Dyslexia Association). Over 15% of the world's population live with a specific form of disability (UNICEF, 2013).

Caring for a child with special needs, as a parent, has been found to negatively affect both mental well-being and physical health outcomes. Studies suggest that parents of children with special need report increased levels of stress, depression, anxiety related to the child's future and decreased levels of general well-being (Crnic, Neece, McIntyre, Blacher, & Baker, 2017; McConnell, Savage, & Breitkreuz, 2014; Smith & Grzywacz, 2014). The negative consequences of having a child with special needs on parents' well-being might be explained by their emotional depletion, time demands and financial burden.

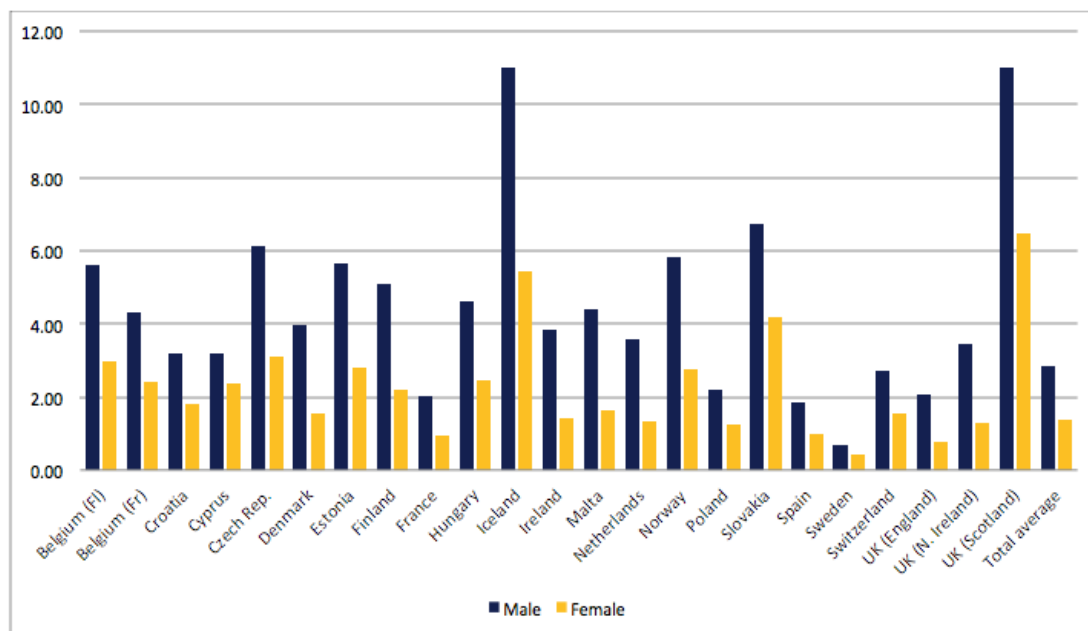


Figure 1. Children with SEN enrolled in schools in Europe

The study conducted in 23 countries identified that there are 1.37% (450,697) girls and 2.86% (942,706) boys that have an official decision of SEN. The ratio for gender distribution is 2:1 (32.35% girls and 67.65% boys).

3. Literature review: Stress in families of children with special needs



Parents learning that their child has special need experience some common reactions, such as denial, anger, fear, guilt, confusion, powerlessness, disappointment and rejection toward the child or towards other family members (McGill Smith, 2003). The Model of Stress in Families of Children with developmental disabilities (Perry, 2004, Figure 2) describes four factors for understanding family stress: Stressors (major and minor stressors related to the child, but also additional life stressors), Resources (individual and family resources for parents), Supports (formal and informal support received by parents) and Outcomes (positive and negative consequences). The **stressors related to the child** include his developmental level, cognitive and emotional characteristics. This model disentangle between objective child's characteristics (e.g. IQ) and subjective perception of parents, as sometimes parents of children with mild disabilities may experience considerable higher levels of stress than parents of children with more complex problems. Parents of children with disabilities may experience **additional stressors**, such as financial stress, work stress or health issues of other family members. These extra- stressors will negatively affect parents' ability to cope with the child disability and parents need support in coping with these stressors as well. **Individual resources of parents** refer to personal beliefs, coping strategies, personality characteristics, but also education and employment status of parents. The individual resources of parents play an important role in parents' adaptation to their situation of having a disabled child. For example, an educated, optimistic and religious parent might cope better than a parent with a low level of education, pessimistic and non-religious. **Family resources** affecting coping in parents of children with special needs include marital status (single and divorced parents will experience more difficulties than married parents) and the quality of relationship between parents. **Social support** refers to informal support (support from extended family, friends and religious community) and formal support (professional support received by parents from educators, counsellors or psychotherapists). Parental outcomes of having a child with special needs refer to both negative effects (such as depression and pessimism), but also positive effects (such as personal growth and resilience). The model of Perry (2004) can help parents to understand different factors contributing to their level of perceived stress. In addition, this model has important implications in counselling families raising children with special needs, emphasizing the protective role of individual, family and social factors.

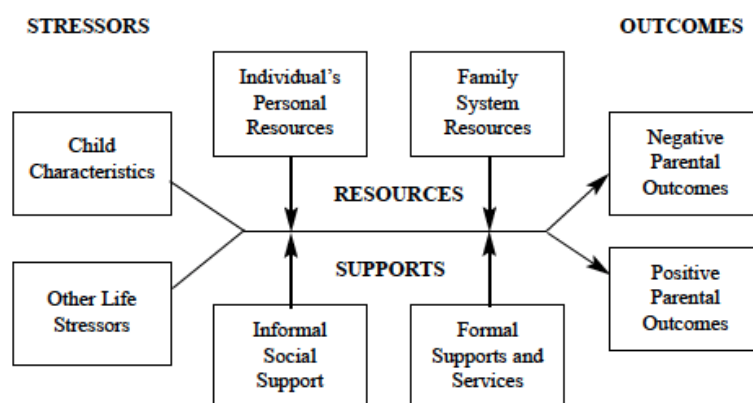


Figure 2. The model of stress in families of children with developmental disabilities (Perry, 2004)

The process of coping with family stress may require different stages. Bodenmann (2005) described the temporal progression of coping in family as the stress-coping cascade (Figure 3). In the case of experiencing a chronic and major stress (such as parenting a child with special needs), we suggest that parents need the entire coping strategies described in the model in order to better adapt to the situation. Therefore, they will use individual coping strategies (such as focusing on finding solutions to the problem, reappraising the situation), but they need support from their partners (dyadic coping) and also social support from extended family and friends and professional help from counsellors and clinicians. Parents may benefit from understanding that they cannot cope with this stress by themselves, they need support from the other parent and they also need to ask for help outside the family. The complexity of stress requires complex coping strategies.

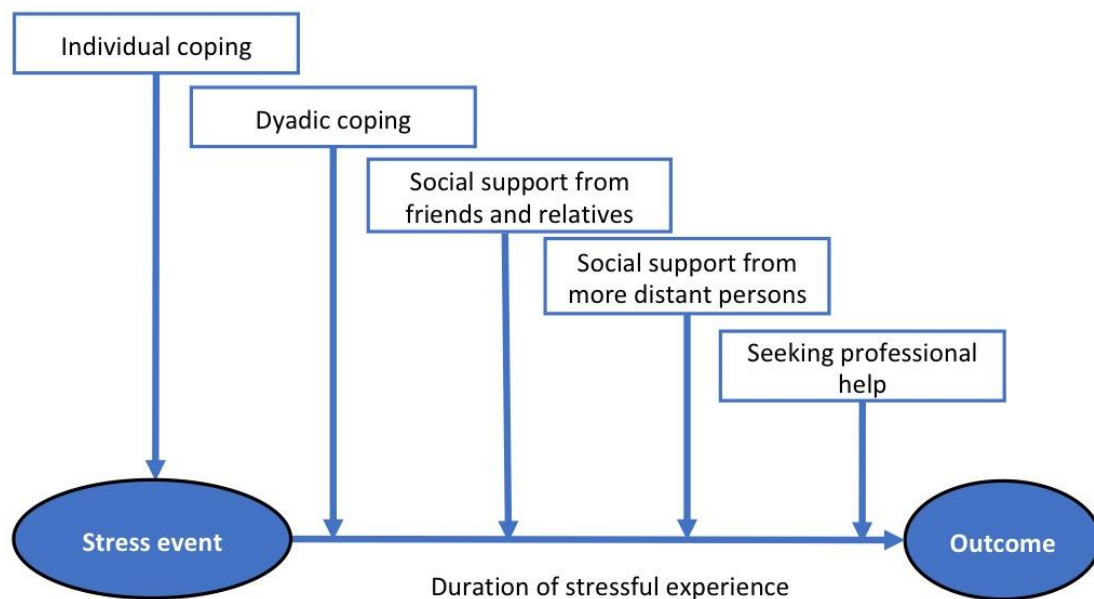


Figure 3. Stress-coping cascade (Bodenmann, 2005)

Chronic stress experienced by parents raising a child with special needs may negatively influence not only the quality of parent-child interaction, but also parent-parent relationship. The Stress-Divorce Model (Bodenmann, 2005) posits that chronic daily stress decreases the quality of marital interactions and may lead to divorce. Parents experiencing chronic daily stress related to their child will spend less time together as a couple and marital communication will be negatively affected. Therefore, it is important for these parents to focus on strengthening their couple communication, to support the other parent in order to cope with stress and to find solutions together for adapt to daily stressors related to the child.

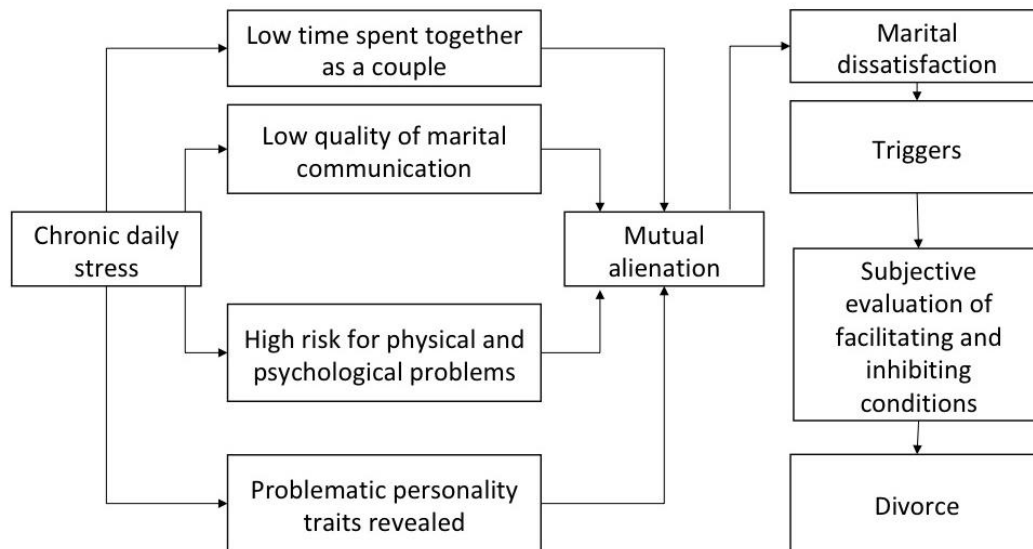


Figure 4. The stress-divorce-model (Bodenmann, 1995, 2000)

According to the Systemic Transactional Model (Bodenmann, 2005), coping is defined as a dyadic concept, involving positive and negative strategies used by both partners to cope with stress together. Positive strategies of dyadic coping include supportive dyadic coping (SDC, one's partner efforts to support the other partner), common dyadic coping (CDC, participation of both partners in the coping process through sharing of feelings, finding solutions to problems or relaxation together) and delegated dyadic coping (DDC, reducing the partner's stress by taking over his/her responsibilities). Both SDC and CDC could be problem-focused (focusing on helping partner to find solutions in the case of SDC or finding solutions together in the case of CDC) or emotion-focused (offering emotional support to the partner, being empathic and understanding in the case of SDC or sharing feelings in the case of CDC). Negative forms of dyadic coping refer to supporting the partner in a negative way, including hostile dyadic coping (disinterest, blaming and minimization of partner's stress), ambivalent dyadic coping (supporting the partner unwillingly) and superficial dyadic coping (supporting the partner without empathy and sincerity).

Empirical evidence suggests that stress is associated with negative relationship outcomes (such as hostile verbal aggression) even for couples with high levels of dyadic coping (Bodenmann, Meuwly, Bradbury, Gmelch, & Ledermann, 2010). Contextual factors, such as stress, may influence dyadic coping resources, as stress negatively affects relationship well-being by 1) creating additional relationship problems (e.g. parents raising a child with special needs may also experience financial strain) and 2) hindering partners energy and resources necessary to cope effectively with stress (parents of children with special needs need more time and energy for child care) (Neff & Karney, 2017). Studies showed that different stressors affect support in couple in different ways. Regarding the explaining mechanisms involved in the negative association between stress and support in couple, previous studies found that stress depletes emotional and self-regulatory resources of partners (McNulty, 2016) and decreases positive emotions of partners (Rusu, Hilpert, Falconier, & Bodenmann, 2017), which in turn affect men and women ability to provide support to their partners. Parenting a child with special needs may affect emotional resources of parents and decrease their positive emotions experienced daily. In consequence, the couple relationship may be negatively

influenced, as these parents do not have resources to support their partners and to focus on positive couple interactions.

Stress of midlife parents raising children with special needs has been associated with long-term negative consequences on parents' health and well-being (Smith & Grzywacz, 2014). Specifically, parents of children with special needs reported more depressive symptoms and more limitations in daily activities compared with parents of children with typical development. However, the study found that these parents become resilient over time, as they develop new competences and attitudes in order to adapt to the child's problems. Therefore, parents of children with special needs need to develop resilience in order to cope with their stress.

a. Chronic sorrow

The concept of chronic sorrow has been first proposed by Olshansky (1962) in order to describe the emotional response of parents having children with intellectual disabilities. In the following years, researchers have started to study this concept in other populations. Chronic sorrow refers to a permanent experience of sadness, loss, guilt and self-blaming, feelings that are recurrent over time (Masterson, 2010). Recent studies revealed that chronic sorrow is related to social isolation and hopelessness for parents of children with special needs. In addition, there are gender differences in chronic sorrow, mothers experiencing more chronic sorrow than fathers (see for review Coughlin & Sethares, 2018). The most important triggers of chronic sorrow are health care crises and developmental milestones (Coughlin & Sethares, 2018).

In previous studies focused on parents' coping with chronic sorrow, different strategies have been identified as being useful. In order to help parents to cope with chronic sorrow it is important to provide them information and resources and to show them compassion. These parents need to receive knowledge, to be supported and encouraged by both health care professionals and by community. Educating people from community to accept, respect and help parents of children with disabilities is an important issue to be addressed. Despite the fact of receiving professional support and participating in specific trainings related to their children's disabilities, these parents need to be socially integrated in the community and not being judged and excluded by parents of children with typical development.

b. Stress management

The most important strategies that parents of children with special needs could use in order to cope with stress (Ambrozich, n.d.; Logsdon, 2018; McGill Smith, 2003) are the following:

- Collect information about the child's special needs and available services in order to help him and learn the terminology about child's disability;
- Read books and blogs written by other parents of children with special needs;
- Join a group of parents experiencing the same problem (online groups are also available for parents of children with different disabilities);
- Rely on other family members or extended network (talk with other parents of children with special needs,
- Expressing emotions and learn how to deal with negative feelings;
- Focus on the present and not worrying about the future;
- Keeping realistic standards and admitting their limits;
- Adopting a healthy life style (exercising, healthy nutrition and healthy sleep);



c. Resilience

Bodenmann (2016) classified the factors influencing resilience in family in the following categories: individual factors, family factors, social factors and ecological factors of resilience. We are going to explain these factors in the following section.

Individual factors:

- *favorable personality traits* (friendly character, amiability, independence, psychological stability and well-adjusted temperament, positive self-esteem, intelligence, extraversion, tolerance, openness to novelty);

- *elevated competences* (problem-solving skills, social competences, emotion regulation competences, coping with stress, relationship skills).

Family factors influencing resilience:

- *family cohesion*

- *family adaptability*

- for the resilience of children: a) *emotional stability of parents*, constant and strong bonds between parents and children and b) *sensitivity and trustworthiness of parents* for the education of secure bonds, internal locus of control and a positive self-esteem;

- *authoritative-constructive education*, characterized by emotional warmth, love, acceptance, appreciation, support, clear structure with rules and borders, consistence within person and between parents in the child education;

- *family rituals* (having the meals together, celebrations of birthdays and other festivities and traditions);

- *time for children*, not only the quantity of time, but the quality of time spent together is important. Parents should show their children full attention, interest and care;

- *few destructive conflicts between parents and the absence of divorce*;

- *mothers having a job* is an important factor of resilience, as working mothers have a greater level of well-being due to the social integration, personal balance, independence for the partner and professional fulfillment.

- *religiosity*;

- *number of children in the family*. An important resilience factor is having less than 4 children, separated by at least 2 years, so that parents can give each child the attention and importance he or she deserves. In general families with more than four children experience higher levels of stress;

- *the timely use of support* services by parents experiencing psychological issues, couple and family problems. Asking for help in time of need (e.g. participation in courses, counseling, specialized therapy) is an important factor of family resilience.

Social factors of resilience include support from colleagues, neighbors, members of extended family and teachers, being part of social groups, but also leisure activities and hobbies of family members.

Ecological factors of resilience are related to the living conditions (quality of housing and living environment, security) and opportunities in the neighborhood for families (e.g. playgrounds).

Peer & Hillman (2014) conducted a systematic literature review on parents of children with intellectual and developmental disabilities and identified three resilience factors for these parents: ***coping style, optimism and social support***. Specifically, the authors suggested that problem-focused coping (focusing on finding solutions to the specific demands that parents experience) is a



protective factor for parents' stress and it is more related to parents' well-being than emotion-focused coping (focusing on regulating the emotions determined by the specific situation). Moreover, dispositional optimism (having a positive view of the situation and positive expectations for the future) has been found to have positive consequences on parents' well being. Finally, the availability of social support from extended family, friends and community, but also professional help (being part of support group, receiving psychological counseling) are important factors of well-being for parents of children with disabilities.

A study investigating resilience of parents raising children with disabilities and behavior problems suggested that **financial situation and social support** are the most important factors for a good family functioning and family resilience (McConnell et al., 2014). The study found that parents of children with disabilities are better adapted and have a better family functioning when their financial strain is low and their social support is high. Therefore, the contextual factors are very important for the well-being of families raising children with special needs and not only the individual factors (e.g., coping, optimism, social and emotional competences) and family factors (e.g., family adaptability and cohesion, the quality of family interactions). Previous research studies revealed that economic stress has a negative influence on family life, affecting the quality of interactions between spouses. Economic strain was linked to declines in supportive dyadic coping for both males and females (Johnson, Horne, & Galovan, 2016; Rusu et al., 2017).

4. Quiz (e.g. What is your stress level?)

Quiz 1: Parental Stress Scale (Berry & Jones, 1995)

The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.

		Strongly disagree	Disagree	Undecided	Agree	Strongly agree
1	I am happy in my role as a parent	1	2	3	4	5
2	There is little or nothing I wouldn't do for my child(ren) if it was necessary.	1	2	3	4	5
3	Caring for my child(ren) sometimes takes more time and energy than I have to give.	1	2	3	4	5
4	I sometimes worry whether I am doing enough for my child(ren).	1	2	3	4	5
5	I feel close to my child(ren).	1	2	3	4	5
6	I enjoy spending time with my child(ren).	1	2	3	4	5
7	My child(ren) is an important source of affection for me.	1	2	3	4	5
8	Having child(ren) gives me a more certain and optimistic view for the future.	1	2	3	4	5
9	The major source of stress in my life is my child(ren).	1	2	3	4	5
10	Having child(ren) leaves little time	1	2	3	4	5



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	and flexibility in my life.					
11	Having child(ren) has been a financial burden.	1	2	3	4	5
12	It is difficult to balance different responsibilities because of my child(ren).	1	2	3	4	5
13	The behaviour of my child(ren) is often embarrassing or stressful to me.	1	2	3	4	5
14	If I had it to do over again, I might decide not to have child(ren).	1	2	3	4	5
15	I feel overwhelmed by the responsibility of being a parent.	1	2	3	4	5
16	Having child(ren) has meant having too few choices and too little control over my life.	1	2	3	4	5
17	I am satisfied as a parent.	1	2	3	4	5
18	I find my child(ren) enjoyable.	1	2	3	4	5

Scoring instructions: In order to calculate your stress score for the perceived Stress Scale, firstly reverse your answers to the following items: 1, 2, 5, 6, 7, 8, 17 and 18 (1 to 5, 2 to 4, 3 remains 3, 4 to 2 and 5 to 1). For example if your answer is 2 for the first question, you have to transform it into 4. Secondly, sum up your answers to all the 18 items (both the reversed ones and the non-reversed ones). A total score higher than 54 indicates a medium to high level of stress. Discuss this result in the PsiWell training program for parents of children with special needs related to the current project.

Quiz 2: Reflect on the level of stress you have experienced in last week and then in the last 12 months related to your job, social relationships, free time, family of origin, living situation, finances and daily hassles. These factors may negatively influence your ability to cope with the stress related to your child's special needs. In order to be a better resource for your child and to reduce your general level of stress, try to cope effectively with additional stressors in your life.

Multidimensional Stress Questionnaire for Couples (MSF-P, Bodenmann, Schär, & Gmelch, 2008)

	How stressful/straining are the following situations <u>outside</u> of your relationship? This concerns stress which isn't connected to your partner.	Burden/stress during the past							
		7 days (acute)				12 months (chronic)			
		not at all	slightly	average	strong	not at all	slightly	average	strong
MSFP 15	Job/education (commotion, deadline pressure, high demands, being unchallenged, lacking acknowledgement, career opportunities, etc.)	①	②	③	④	①	②	③	④
16	Social contacts (conflicts with neighbors, colleagues, acquaintances, social commitments, gossip, etc.)	①	②	③	④	①	②	③	④



17	Free time (deadline pressure, too many activities, unsatisfactory recreational activities, too little time for yourself, pressure to perform, etc.)	①	②	③	④	①	②	③	④
18	Children (child care, upbringing, interactions, dependence, restrictions, worries about the children, etc.)	①	②	③	④	①	②	③	④
19	Family of origin (separation and dependence, conflicts, maintenance, etc.)	①	②	③	④	①	②	③	④
20	Living situation (apartment size, noise, site, etc.)	①	②	③	④	①	②	③	④
21	Finances (debts, lack of money, no raise in salary, etc.)	①	②	③	④	①	②	③	④
22	Daily hassles (losing or misplacing things, frequent disturbances, waiting lines, traffic jams, delays, etc.)	①	②	③	④	①	②	③	④



5. Where can you find assistance and ask for special help? Special Education Services

- School based support services (school counsellors, educators, school psychologists);
- Local organizations focused on children with different special needs (e.g. autism);
- Trainings and projects for parents of children with special needs developed by Universities;
- Support groups for families of children with special needs (local groups and online groups).

6. Resources for stress management in parents of children with special needs



Helpful Websites

- Center for Parent Information and Resources
<http://www.parentcenterhub.org/steps/>
- Support for parents of kids with special needs
<https://kidshealth.org/en/parents/parents-support.html>

Videos

- Managing stress as the parent of a child with special needs
<https://www.youtube.com/watch?v=NCwy5ZtmXKM>
- Mastering daily life
<https://www.youtube.com/watch?v=fh8dHWHdZ6M>



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