

RESILIENCE VS. DISABILITY: EFFECTIVE COPING APPROACHES IN THE CONTEXT OF A FAMILY CRISIS

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Abstract: Disability represents a complex condition involving physical, intellectual, or sensory limitations, resulting in significant restrictions in daily activities and social participation. Adapting to the needs of a child with disabilities involves additional financial resources, amplifying financial pressures and uncertainty about the family's economic stability. Besides the consequences at the family level, society as a whole experience the repercussions of this issue. Stigmatization and marginalization of children with disabilities and their families constitute an unacceptable reality, generating exclusivity and social inequities. In this article, I intended to detail the coping strategies of families facing a crisis related to their child's disability. The exploratory research (conducted within a master's thesis) was carried out on a sample of 10 parents whose children receive free services at a Day Center in Iasi. The results of this preliminary research offer a significant perspective on the coping methods of families facing their child's disability and familial crisis. These findings can serve as a solid foundation for the development of larger-scale studies that contribute to identifying effective intervention strategies and tailored support for the specific needs of these vulnerable families.

Keywords: coping, family crisis, disabilities, adaptation skills, resilience, strengths, weaknesses.

Résumé : Le handicap représente un état complexe impliquant des limitations physiques, intellectuelles ou sensorielles, entraînant des restrictions significatives dans les activités quotidiennes et la participation sociale. L'adaptation aux besoins d'un enfant en situation de handicap nécessite des ressources financières supplémentaires, ce qui amplifie les pressions financières et l'incertitude concernant la stabilité économique de la famille. Outre les conséquences au niveau familial, la société dans son ensemble ressent les répercussions de cette problématique. La stigmatisation et la marginalisation des enfants en situation de handicap et de leurs familles constituent une réalité inacceptable, générant l'exclusivité et les inégalités sociales. Dans cet article, j'ai l'intention de détailler les stratégies d'adaptation des familles confrontées à une crise liée au handicap de leur enfant. La recherche exploratoire (réalisée dans le cadre d'une thèse de master) a été menée sur un échantillon de 10 parents dont les enfants bénéficient de services gratuits dans un Centre de Jour à Iași. Les résultats de cette recherche préliminaire offrent une perspective significative sur les méthodes d'adaptation des familles confrontées au handicap de leur enfant et à la crise

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familiale. Ces constatations peuvent servir de solide base pour le développement d'études de plus grande envergure contribuant à l'identification de stratégies d'intervention efficaces et de soutien adapté aux besoins spécifiques de ces familles vulnérables.

Mots-clés: adaptation, crise familiale, handicap, compétences d'adaptation, résilience, forces, faiblesses.

Rezumat: Dizabilitatea reprezintă o stare complexă ce implică limitări fizice, intelectuale sau senzoriale, având ca rezultat restricții semnificative în îndeplinirea activităților cotidiene și a participării sociale. Adaptarea la nevoile copilului cu dizabilități implică resurse financiare suplimentare, ceea ce amplifică presiunile financiare și incertitudinea privind stabilitatea economică a familiei. Pe lângă consecințele la nivel familial, societatea în întregul său resimte repercusiunile acestei problematice. Stigmatizarea și marginalizarea copiilor cu dizabilități și a familiilor lor constituie o realitate inacceptabilă, generând exclusivitate și inechități sociale. În acest articol am intenționat să detaliez care sunt modalitățile de coping ale familiilor, care traversează o situație de criză legată de dizabilitatea copilului. Cercetarea de explorare (întreprinsă în cadrul unei teze masterale) s-a realizat pe un eșantion format dintr-un grup de 10 părinți, ai căror copii beneficiază de servicii gratuite în cadrul unui Centru de Zi din Iași. Rezultatele acestei cercetări preliminare oferă o perspectivă semnificativă asupra modalităților de coping ale familiilor care se confruntă cu dizabilitatea copilului și criza familială. Aceste constatări pot reprezenta o bază solidă pentru dezvoltarea unor studii ulterioare, de proporții mai mari, care să contribuie la identificarea unor strategii eficiente de intervenție și sprijin adaptat nevoilor specifice ale acestor familii vulnerabile.

Cuvinte cheie: coping, criză familială, dizabilitate, abilități de adaptare, reziliență, puncte tari, puncte slabe.

1. Introduction

Over the past decades, the surrounding environment has become increasingly threatening to human existence, with depression, disabilities, and incurable diseases becoming frequent themes of this century as we strive to survive. From a social perspective, disability is seen as an anomaly of society, not of the individual. Society plays a crucial role in defining the context in which individuals with health problems face difficulties in performing daily activities. Health issues become a real barrier and can limit an individual's ability to fully participate in social, professional, and personal life. From this point of view, concerning the disadvantage that people with disabilities have in society, the term „handicap” is frequently used. This term is used to describe the difference or discrepancy between a person's abilities and the social requirements and expectations, so handicap is not an intrinsic characteristic of the individual but rather of the individual-society relationship. The number of children with „different abilities” has alarmingly increased in recent years, and the families of these children face exceptional situations. Families going through a crisis are destabilized, dynamics and roles change, and resources are often minimized. Moreover, these families may also face other social phenomena such as stigmatization, discrimination, or the breakdown of the family structure.

2. Theoretical Aspects

The recognition of the rights of people with disabilities and the fight for their inclusion in society have gradually been achieved over time, as the consciousness and perceptions of society have evolved. Individuals with different physical or mental conditions did not receive the same treatment as other members of society. According to Neagoe (2014, p. 7), „in the Stone Age, people with disabilities were driven out of tribes, in Antiquity, they were thrown off cliffs, and in the Middle Ages and the Renaissance, they were treated very poorly, behavior mainly stimulated by the attitude of the Catholic Church, which led to their rejection, considering them as the satanic side and the consequence of their parents' mistakes.” According to Verza (2002, p. 14), the term disability is „the generic term for impairments, limitations of activity, and restrictions on participation,” and these „functional limitations are due to physical, intellectual, or sensory deficiencies, medical conditions, or mental illnesses, which can be permanent or temporary” (Neagoe, 2014, p. 9). Neagoe (2014) mentions that disability is closely related to respecting human rights because people with disabilities are discriminated against in education, the labour market, and social participation. Additionally, the vulnerability of these individuals makes them susceptible to violence and abuse. To avoid these phenomena, families of children with disabilities have the mission of developing their children so that they can integrate into society and acquire independent living skills. This mission is much more challenging in such cases than in general. Hence, the crisis begins.

Family crises are represented by acute situations that cause stress within the family and threaten its stability, as noted by Ciofu (1998). „Crisis is a turning point, where unforeseen events lead to increased stress, which disrupts the balance where coping mechanisms were functioning to solve problems” (Payne, 2011, p. 118). The relationship between disability and family crisis is close and complex because the appearance of a child's disability can cause significant disruptions in the family's dynamics and functioning. To support families in stressful situations, specialists have developed specific intervention methods. „A crisis intervention model is one that naturally incorporates the intervention's purpose, principles, and a set of techniques that lead to reducing distress, resuming coping efforts, and regaining the subject's normal functioning” (Vrasti, 2012, p. 9). Coping strategies are the main means to overcome the crisis. According to Lazarus & Folkman (1984, p. 118), coping is defined as „actions that control irreversible environmental conditions in order to limit psychological/physiological disorders.” Therefore, coping represents any type of action, laden with cognitive, emotional, and behavioral efforts, aimed at overcoming tense situations.

3. The Purpose and Objectives of the Research

The purpose of this research is to analyse the ways in which these families overcome inevitable family crises. The choice of this topic is related to the increased incidence of the number of children with disabilities, as well as families

that struggle to restore their balance following such a crisis. Within this research, four objectives have been proposed, which include: identifying the types of reactions families have in the face of this crisis, exploring the adaptation strategies used by families, evaluating the involvement of family members in resolving the situation, and identifying the resources utilized by these families to overcome the crisis.

Additionally, through the initiation of the research, the following questions were aimed to be addressed:

- What are the experiences that families have gone through when a child with disabilities is born into their family?
- What are the common characteristics of families in which a child with disabilities is born?
- How do families overcome the crisis caused by the birth of a child with disabilities?
- What is the opinion of families with children with disabilities regarding their current situation?

The collected responses to the research questions aim to create an enriched perspective on the ways in which families adapt to the situation when a child with disabilities is born.

4. Methods, Participants, Instruments

The interview was used as a research technique, which is „a psychological and sociological measuring instrument” (Chelcea 2001, p. 267) for phenomena in society, through which information about the experiences, feelings, and opinions of the interviewed individuals can be collected. The research was conducted in April 2023. In accordance with the Interview Guide, 55 questions were addressed to a sample of 10 individuals. The questions were structured starting from the general framework, leading to the specific crisis situation, and covered aspects related to: identification information, financial situation, family structure and roles, relationships between family members, the health status of the child/children, reactions to the crisis situation, and opinions about it, perspectives on the current situation.

Through collaboration with specialists from the *Bethany Iasi Foundation for Social Services*, ten individuals were interviewed (all being women), whose children suffer from either autism spectrum disorders or other cognitive disorders. According to Table 1 (from Appendix 1): Socio-demographic data of research participants, the interview participants reside in the Iasi County area and benefit from the organization's free services. Mostly, the interview participants are the personal caregivers of the children and their ages range from 32 to 58 years. Regarding their origin, five of the interviewed individuals are from rural areas, while the other half is from urban areas. To protect the identity of the interview participants, they were denoted with the letter X, followed by numbers from one to ten, based on the order of their interviews (from X1 to X10).

5. Results

We grouped all the significant responses on some relevant issues as we can identify in the following subtitles:

A. Income. Financial status

Most participants in the study described their financial situation as modest. Mainly, their primary source of income comes from salaries, with three respondents mentioning that their main source of income is the child-rearing allowance. As for the main expenses, these include household maintenance, instalments, and groceries, but for four of the participants, the payment of therapies and treatments for their children is a major concern. Many respondents indicated that they experienced financial difficulties during the crisis period.

B. Family Structure and Roles

Regarding family structure, participants described the family as characterized by „unity” and „resilience.” The number of members in the analyzed families ranges from two to six individuals, of which seven out of ten individuals live only with their nuclear family, while three participants live together with their extended family, benefiting from the support of other family members.

C. Relationships Between Family Members

After analysing the relationships between family members, it was found that six participants described these relationships as good or very good. As for activities and time spent together as a family, participants engage in relaxing activities and involve family members in actions that contribute to the development of the child with different abilities. Furthermore, in terms of the relationship with their partners, the interviewed individuals who are married characterized this relationship as very good and good, based on respect and mutual love. Moreover, at the time of the child's diagnosis, the presence of the partner eased their transition through the crisis period: „When we found out that we have a child with special needs, I was devastated. He encouraged me, supported me, and told me that everything will be fine, that together we will succeed” (said X2). Also, participant X6 mentions that: „After we received the child's diagnosis, I had problems at work and at home. He was there for me, offering the balance I needed. Without him, I wouldn't have succeeded.”

D. Health Status of the Child

According to the responses obtained in this set of questions, approximately 90 percent of the children were diagnosed with autism spectrum disorder. Most parents became aware of the diagnosis before the child reached preschool age. However, seven out of the ten interviewed individuals were not aware of this disorder before the diagnosis. Additionally, the majority of the interview participants mentioned that they administer medication to their children.

Analysing the responses of the interviewees, the moment when parents found out about the child's diagnosis represented a family crisis for all participants, significantly impacting the dynamics and functioning of the family.

E. Reactions to the Crisis

The crisis was described by interview participants as „a moment of imbalance.” Participant X6 said, „The crisis is an imbalance, things were functioning normally maybe in that system, but something happened, which made the family feel stressed and anxious. We all have such moments in life, some more often, others more rarely, but all families face these situations. The important thing is to realize that they are only temporary periods and not to get lost in them.” The crisis period was characterized by a high level of stress, shock, and concern for most participants. Among the most frequent reactions were refusal or denial of the diagnosis, expressing the difficulty of accepting the situation and coping with the associated emotional impact. Throughout the crisis period, the family experienced changes in their lifestyle dynamics. Family members collaborated to change their lifestyle and adapt it to the needs of the child. Similarly, families sought information on caring for a child with such a diagnosis. The emotional component was managed through emotional ventilation and accessing psychological support services. All these actions by the family contributed to the development of new resilience skills. Regarding the reactions of the members, it was observed that nuclear family members worked together to overcome the family crisis through various means. Mainly, they provided emotional support, communicated actively, and took on new roles. As a result, the family was able to build a harmonious family environment favourable to the development of a child with different abilities.

Analysing the coping mechanisms of the interviewed individuals, two types of coping were identified. The first type is problem-focused coping, which involves actively seeking relevant information, accessing specialized support services, and adapting the living environment based on the specific needs of the child. Essentially, this type of coping focuses on action, i.e., finding practical and functional solutions to cope with daily challenges. The second type is emotion-focused coping, which consists of open and sincere communication within the family, expressing feelings and emotions associated with the difficult situation, and seeking psychological support to manage emotional burdens. Essentially, this type of coping focuses on emotional regulation.

F. Perspective on the Current Situation

Currently, after going through the crisis period, the interviewees consider themselves part of functional families. Participant X3 mentions, „The current situation is stable and progressive. We are all doing well, we have adapted, learned what to do, and are evolving.” Additionally, most of the participants (eight out of ten) claim that the family's situation has improved, as they see progress in the child's development, the atmosphere within the family is no longer tense, and the family feels more united at present. For two of the interviewees, the family

structure has changed due to divorce, and thus, these families faced another challenging moment. However, the two families that went through a divorce have developed an optimistic perspective on their current situation. Participant X7 mentions, „When we found out about the diagnosis, we used to have frequent fights with my ex-husband. We were shocked; we didn't know what to do. He eventually found a solution and stopped coming home. I think he had a relationship before deciding to leave us. It is painful that he left because he is not the father of a sick child. The pain was twice as great. Now, things have settled down; there is harmony at home, and I have learned to support my child without anyone's help, and that makes me happy.”

When asked to give a message to families facing similar situations, the interview participants provided the following responses: „The family is obliged to create a supportive environment for this child, offering security, acceptance, and patience. They should accept and fight for the child without wasting time lamenting their situation; there will come a day when everything will change. The umbrella may not remove the rain, but it will protect you from it. Faith may not remove suffering, but it will help you go through it” (Participant X6). Additionally, participant X2 added, „They must move forward, fight for their child, seek solutions for the child's recovery. Accept and think positively. After every storm, the sun will come out, and after all the efforts made for the child, they will be rewarded.”

Based on the information obtained in this study, it can be observed that families facing a crisis due to the birth of a child with disabilities go through complex and demanding experiences. However, they demonstrate remarkable resilience and adaptability to difficult situations. Financial status is an important aspect, and most of the interviewed families face limited financial resources, which can add additional pressure in managing the child's needs and associated expenses. Family structure and dynamics play an essential role in crisis management, and families are characterized by unity and mutual support. The relationships between family members are evaluated as good and have adapted to the new requirements and responsibilities generated by the presence of a child with disabilities. Life partners play a crucial role in providing emotional support and approaching the situation, contributing to problem-solving and family adaptation during the crisis.

The diagnosis of the child represents a significant crisis moment for the interviewed families, causing stress, worry, and anxiety. Nevertheless, families managed to find resources and strategies to cope with the situation. Identified coping mechanisms include problem-focused approaches, such as seeking relevant information and adapting the living environment to the child's needs, as well as emotion-focused approaches, such as open communication, freely expressing feelings, and accessing psychological support. These adaptive strategies contribute to stress and uncertainty management and facilitate the development of resilience skills in facing challenges. Currently, the interviewed families report a more stable and improved state, where progress is observed in the child's development, and the family atmosphere is more harmonious. Although families went through difficult

periods and experienced significant changes, they managed to find a balance and redefine their roles and priorities within the family.

6. Conclusions

In conclusion, the birth of a child with disabilities generates a crisis within the family, affecting both family dynamics and roles, as well as available resources. These families face significant challenges but seek support and treatment for the child, acquiring new skills to actively participate in the child's therapeutic process. They also learn how to engage in activities that support the emotional and mental well-being of the child. Although family stability may be threatened, families rely on resilience and commitment to manage these challenges and create an environment conducive to the child's development. Despite the difficulty of the situation, families demonstrate a high level of adaptability and determination in meeting the child's needs and maintaining family unity.

Based on the research results and the initial objectives, the following have been observed: the reactions of families facing a crisis following the birth of a child with disabilities are influenced by factors such as culture, education, level of information, and interpersonal relationships. Common reactions include shock, sadness, denial, guilt, and despair. The coping methods of families are problem-focused coping and emotion-focused coping, both of which are correlated and interdependent. Communication and support within the family, seeking information about disabilities, and resorting to specific intervention methods are among the most frequently mentioned coping strategies. Additionally, family members' involvement in resolving the crisis situation is influenced by family roles and dynamics. Partners emotionally engage and share responsibilities, while siblings are directed towards understanding and supporting the child with disabilities.

The birth of a child with disabilities impacts the family's resources, including emotional, social, and financial resources. Families rely on internal support from family members, faith, and love for the child, as well as external support, such as specialized services and moral support from other families in similar situations. Families develop new personal resources, such as resilience and optimism, to cope with the difficult situation. The research also addressed the initial questions, thus observing that family reactions include negative emotions and negative social phenomena, but there are also common characteristics such as love for the family and commitment to the child and the family. Families overcome the crisis through action, seeking support and resources, adapting family dynamics, and creating support networks with other families in similar situations. Moreover, families develop an optimistic perspective and become aware of their adaptability and the changes brought about by the child with disabilities.

The birth of a child with disabilities profoundly affects families, but they manage to overcome the crisis through the use of adaptive strategies and emotional and practical support. In reality, Romanian society does not have sufficient infrastructure to support families through the crisis period caused by the birth of a

child with disabilities. Access to services and treatment is extremely difficult, even impossible in areas with limited resources. The institutions and organizations that offer free therapy are inadequate compared to the number of children in need of help. Additionally, the level of awareness among the population regarding the signs and symptoms of developmental disorders is low, negatively affecting the child's development process, as specialized intervention needs to be initiated as early as possible. Parents of these children must realize the importance of involving all family members in the therapeutic process and interacting with the child in a way that fosters their development. It is not enough to rely solely on specialist intervention; children need a supportive environment and trust from those around them to integrate into a society that often seems limited. From society-level to family members, all these networks must collaborate to ensure that these special children do not lose their brightness and uniqueness, but rather contribute to the vibrant and inclusive modern society where each individual has their place and is valued for who they are.

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Appendix 1:

Table of Participants

Id number	Age	Occupation	Residency	Education	Marital status	Child's diagnosis
X1	38	Personal assistant	Urban	University	Married	Autism
X2	47	Personal assistant	Rural	University	Married	Autism
X3	46	Personal assistant	Rural	High school	Divorced	Down Syndrome
X4	43	Personal assistant	Rural	High school	Married	Autism
X5	32	Household	Urban	Gymnasium	Married	Autism
X6	45	Social Worker	Urban	University	Married	Autism
X7	50	Household	Urban	University	Divorced	Autism
X8	57	Household	Rural	Gymnasium	Married	Autoimmune encephalitis
X9	48	Schoolmistress	Urban	University	Married	Down Syndrome
X10	58	Household	Rural	Gymnasium	Married	Autism