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## Families of children with disabilities: specific problems and models of support

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### Abstract

Studies show that families with one or more children with disabilities face a series of specific problems, in addition to those with typical children, as a result of special living situations, difficulties in coping with child care, material, medical problems, socialization and restricted communication with relatives or the community. The therapy addressed to children and adolescents with disabilities did not take into account from the beginning the need for support for their parents, who form their main support. The family can be part of the therapeutic recovery process, in addition to its primary role as parents, but for this, it is necessary that its condition and functioning and that of its members be optimal.

**Keywords:** family, children with disabilities, stress, anxiety, depression, support, counseling, parenting, coping, resilience

### Introduction

Specialized scientific studies, carried out in Romania and internationally, highlight numerous specific challenges faced by families with children with disabilities. The problems encountered are diverse and can range from emotional and social difficulties to financial challenges and problems accessing appropriate services. Thus, among the specific problems in families that have at least one disabled child, highlighted by studies, we mention:

***Emotional stress and mental health of parents.*** Stempovschi (2021) explored the emotional impact on parents of children with disabilities. The study found that these parents experience high levels of stress, depression and anxiety, mostly due to a lack of social support and the pressure to manage their children's complex behaviors. Șleahțișchi & Gavrilă, (2020) reveal in a study the particular aspects of the manifestation of stress among mothers who have children with neuromotor disorders. A meta-study published by Hayes and Watson (2013) showed that parents of children with ASD show significantly higher levels of parenting stress compared to parents of typical children. They also have an increased incidence of depression, largely due to feelings of social isolation and stigma. Martin et al (2019) identified eleven studies that highlighted the relationship between parental stress and the sleep problems of their children with ADHD and ASD. There has been much research (Manning & Gregoire, 2006) on the impact of parental mental illness on children, particularly depression. Parental mental illness has been shown to affect attachment formation and children's cognitive, emotional, social, and behavioral development. These children are also at increased risk of developing psychiatric disorders in childhood,

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adolescence and later in adult life. Other studies (Karimzadeh et al. 2017) highlight the strong relationship between children's behavioral disorders and the general health of parents, as well as the significant role of parental depression in children's behavioral disorders, resulting in the need to take measures to reduce the impact of parental disorders on children.

Considering the special situation of these families and the impact that the parents' ailments can put children with disabilities at risk, increased care and special support given to them is required. Parents' anxiety is fueled by worries about financial resources, helplessness in the face of the diagnosis, lack of time, the roads, the looks of those around them. Moreover, the responsibilities of the parents also increase, now having several roles: they are the child's educators, they must ensure the harmonious development of the child, they must integrate the family into the social area of the city, contribute to the development of the family's financial situation, be the child's supervisors with severe deficiency (Magerotte, 2012). Basically, parents' physical well-being (for example, health), material well-being, emotional well-being (affectiveness, stress, self-esteem), productive well-being, social well-being (personal relationships) are affected (Roşan, 2015). These parents' quality of life is affected. The quality of life consists in the existence of good economic conditions, housing, health, work, rest, peace; it consists in the happiness of the person, to be satisfied with his own life.

***Affecting family relationships and social relationships.*** As a result of the attitudes of society and the community, the insufficient adaptation for disabled people, the lack of support services, parents of disabled children in Romania, but not only, often face social isolation. Families often withdraw from the community due to stigma and lack of support from society, which can lead to strained relationships and even higher divorce rates. Rusu, P-P., Bogdan I., Duca, D.S., Ursu, A. (2023) showed that continuous stress affects not only the couple's relationship, but also that between siblings, who can develop contradictory feelings (jealousy, guilt, neglect). They observed that families receiving external support have more stable and harmonious relationships.

***Financial challenges and access to resources*** - A report by Grigoraş et al., in 2021, pointed out that families of children with disabilities in Romania face significant financial difficulties, because therapies and support equipment are not always covered by the public health system. Many parents must interrupt their professional activity to take care of the child, which aggravates the financial problems. A European study by the European Disability Forum (2019) showed that families of children with disabilities in the EU spend more on medical services and educational support, often being affected by low incomes. These challenges are compounded by bureaucratic systems, which make access to financial benefits and specialized services difficult.

***Difficulties in accessing support and education services*** - The same report carried out by the International Bank for Reconstruction and Development/World Bank and coordinated by Grigoraş and collaborators in 2021 shows that Romanian parents face problems in accessing therapy, adapted education and support services psychological. In Romania, the offer of support services for children with disabilities is limited, especially in rural areas, and families have to make expensive trips to access specialized therapies. Guralnick's 2020 study highlights the lack of uniformity in access to adapted education and support services for children with disabilities. Many European and American countries have integrated programs, but access to them often depends on the region and local policies.

***Stigmatization and difficulties in social integration*** - Study by Derscariu (2023). provides insight into the coping methods of families dealing with their child's disability and family crises, highlighted that stigma continues to be a major problem. Parents feel social pressure and fear

negative community reactions, which causes them to avoid social events and limit their children's interactions. According to a study by Green (2003), social stigma is a global problem. Parents of children with disabilities report difficulties interacting with other people and a sense of social alienation. The study emphasizes the importance of community awareness and the integration of children in common activities to reduce the effects of stigma.

***Physical health problems in parents*** - Research by Gugala et al., in 2019, shows that caring for a child with cerebral palsy (CP) can be associated with adverse effects on the parents' physical and mental health. The causes of anxiety and depression symptoms associated with childcare are not yet fully understood. Sekułowicz and colleagues in 2022 identified a strong correlation between caring for a disabled child and physical and mental health problems in parents, such as exhaustion and burnout.

The symptoms of the disorder can have a great influence, because children with disabilities need special attention from parents and special care. Being the sole carers of the child, this can increase their stress level, financial difficulties or conflicts between spouses may arise, all of which affect the mental state of the parents. Since the parent must constantly consider the needs of the child, there is neglect of one's own intimate and personal needs, mental fatigue, drying up of inner resources, and the joy of living easily disappears. Physically, weight loss, insomnia, migraines, vertigo, panic attacks, etc. may occur. Mothers may have fits of crying, while fathers may acquire irritable or indifferent attitudes. Over time, both parents may become distant from family and relatives. (Predescu, 2011)

International and national studies consistently show that families of children with disabilities face a complex set of challenges. To support these families, it is essential to have well-structured, accessible and integrated interventions that meet not only the needs of children, but also parents and siblings. Investments in psychological support, financial resources and community outreach are vital to improving the quality of life for these families.

## **Findings and discussion**

In order to cope with the various difficulties and problematic situations they face, families with children with disabilities have approached various strategies. These strategies differ from case to case, being influenced by:

- the degree of the child's impairment;
- parents' daily routine;
- accumulated experiences;
- support received from other people, etc.

Examples of coping strategies used by parents of children with disabilities:

- does not accept the diagnosis;
- consultation of several specialists in the field;
- personal information regarding what the diagnosis entails;
- seeking help in the circle of friends.
- planning activities;
- participation in support groups.

In the case of families with children with special needs, the mechanism used is active coping. It is represented by the thoughts and behaviors adopted with the aim of solving the problem or to deal with it, through different methods, such as: informing about the child's deficiency,

assuming the responsibility to act appropriately in problem situations, but also through direct action, which is represented by the therapy process.

Many international and Romanian studies have focused on the strategies through which these families develop their ability to face challenges. This research explores interventions, support factors, coping mechanisms, and community resources critical to building resilience. Lupușor & Bodrug-Lungu (2023) explore coping strategies and factors that influence the resilience of parents of children with disabilities. Research suggests that social support, access to information and involvement in support networks help increase resilience.

Preda (2022) analyzes the effect of parenting education programs in increasing the resilience of families. The findings show that parents involved in such programs show a higher level of adaptability and positive attitudes towards daily challenges. This research highlights the importance of support resources, family and community help for rural parents. Parents who have access to extended support demonstrate greater resilience in the face of obstacles related to lack of services and therapeutic support.

Tarană (2021) highlights the beneficial impact of support groups and social and psychological counseling on the mental health of parents, who are thus better able to manage stress and develop constructive coping mechanisms.

Popa (2012) explores the link between parental resilience and successful school integration of children with disabilities. The study points out that resilient parents are better able to support the social and educational integration of their children. Bayat (2007) shows that parents who develop a positive perspective on the child's situation and have strong family relationships show increased resilience. The role of positive thinking and family support as major resilience factors is emphasized.

Bekhet et al (2012) conduct a synthetic review of existing research and identify coping strategies, educational interventions, and support groups as critical resources for resilience in parents of children with ASD. The authors highlight the need for formal and informal support for the development of sustainable resilience. Other studies (McConnell et al. 2014) explore ways in which parents develop resilience in the face of behavioral difficulties of children with disabilities. The importance of social support and flexible coping mechanisms to help parents cope with changes and stress is emphasized.

Paster et al., (2009) carry out a comparative study in which they analyze the differences in the coping strategies used by the parents of children with disabilities and those of typical children. The results show that parents of children with disabilities use emotional support and active coping strategies more often, and these techniques are linked to greater long-term resilience.

Widyawati et al (2012) aimed to examine the associations between different dimensions of parental resilience and children's quality of life in Indonesia. The findings suggest that parents who have a positive attitude, an extensive social network, and who involve community resources show greater adaptive capacity.

The literature emphasizes the importance of holistic support for families. This is crucial not only for the child's progress, but also for the mental and emotional health of the whole family, which can be greatly affected by the stress and challenges associated with raising a child with a disability. Here are some key aspects and methods of providing support for families who have children with disabilities:

### **1. Family education and counseling**

- Information about the condition and therapeutic options: Providing clear information about the child's condition, prognosis and therapeutic strategies can reduce anxiety and improve family involvement in the recovery process. The literature shows that education supports families in adjusting their expectations and developing a positive attitude towards the child's progress.

- Psychological counseling: It is essential to have psychological counseling to help parents cope with stress, guilt and anxiety. Studies indicate that these interventions contribute to improving the mental health of parents, facilitating a more stable and supportive family environment for the child.

### **2. Social support and support groups**

- Support groups for parents: Support groups allow parents to share their experiences and learn from the strategies of other families. Research shows that belonging to a support group can reduce social isolation and provide a sense of community and mutual understanding.

- Involvement in community networks: Integrating the family into community networks or working with support organizations for people with disabilities can facilitate access to resources and information about the rights and benefits to which they have access.

### **3. Parental training and development of care skills**

- Behavior management techniques: Specialists offer parenting training to help parents manage their child's behaviors, which can sometimes be challenging. Such trainings have shown effectiveness in increasing parents' confidence in handling difficult situations and in promoting positive discipline.

- Stimulating the development of the child's autonomy skills: The family plays an essential role in increasing the child's independence. Parent training can help parents use techniques to support autonomous development, facilitating a smoother transition to a more independent life for the child.

### **4. Emotional support and the development of coping strategies**

- Interventions to strengthen resilience: Families of children with disabilities often face emotional and relational challenges. Studies show that the formation of positive coping strategies and techniques to strengthen resilience (mindfulness, relaxation techniques) can have a significant impact in maintaining emotional well-being.

- Support for siblings: Siblings of children with disabilities may need counseling and support as they too may feel the stress and develop complex feelings (jealousy, guilt). The literature emphasizes the importance of paying attention to the whole family to avoid emotional imbalances.

### **5. Practical support and material resources**

- Access to financial resources and social assistance: Families often face financial difficulties due to the high costs of therapies and treatments. Counseling in accessing available resources (subsidies, special benefits) and community support services can reduce financial stress and facilitate better involvement in the recovery process.

- Educational resources and support in school integration: For the integration of children with disabilities in the education system, the support offered in the choice of institutions and the adaptation of school programs is essential. Collaboration between families, teachers and therapists helps ensure an educational experience adapted to the child's needs.



### Services for families

In Romania and in Europe there are several organizations that offer support both to children with disabilities and their families. These organizations carry out various activities, from therapy and education to counseling and social support, facilitating integration and providing resources to support the development of the child and the emotional balance of the whole family. Here are some relevant organizations and types of activities:

**Association for Dravet and other Rare Epilepsies** organizes therapy programs for children with rare epilepsy and supports families through information sessions, psychological counseling and financial support for access to treatments and medical equipment. It also provides legal support for families who need help accessing social benefits.

**Save the Children - Romania** organization offers psychological, social and educational support for vulnerable children and adolescents, including those with disabilities. Organize parent and sibling support groups, summer camps, and parenting programs to help families develop a healthy relationship and cope with challenges.

**"Ana și Copiii"** Association offers educational programs, counseling and recreational activities for children, as well as support for families. Parental education courses and support in the school and social integration of children with disabilities are organized.

**Romanian Autism Association** offers support for children with autism spectrum disorders and their families, including ABA therapy, psychological counseling, support groups and training for parents. The association also provides support for school integration of children and promotes autism awareness campaigns.

**Star of Hope Romania** Foundation is dedicated to supporting children with disabilities and their families, offering recovery services, special education, counseling and training for parents. It organizes social integration activities, camps and events for public awareness.

Another form of support for families is the establishment of *Respiro centers* for children with disabilities and their families, such as **Curcubeul Magic**, in Bucharest, sector 4, which offer supervision, care, consiliere, socialization, leisure, medical assistance, support activities and consiliere for parents, offering parents a short break from daily tasks, to be able to recover physically and mentally.

However, as a UNICEF Romania report shows, services for people with disabilities are not sufficient, both in rural and urban areas. The insurance budget for these services is low and not all service providers have contracts with Health Insurance Companies, so people are forced to pay their full cost. (Copăceanu & Costache 2022, p 21)

In Europe, some of the best-known organizations and associations that offer services to people with disabilities and their families are:

**European Association of Service Providers for Persons with Disabilities (EASPD)** provides support to organizations in various European countries to develop and implement services for people with disabilities, including support for families. It organizes conferences, webinars and workshops focused on the exchange of the best practices and strategies for social and educational inclusion.

**Autism Europe** is an umbrella organization that brings together organizations across Europe dedicated to people with autism and their families. It provides informational support and promotes the rights of people with autism through awareness campaigns and educational activities. It also lobbies at the European level to improve access to services and social inclusion.

**Inclusion Europe** promotes the inclusion of people with intellectual disabilities and supports their families. The organization works with governments and other organizations to develop social and educational inclusion policies. Provides resources and organizes outreach and networking events for parents and professionals.

**European Disability Forum (EDF)** represents the rights of people with disabilities and supports integration initiatives and support for families at a European level. The organization collaborates with European institutions for the development of inclusive policies, facilitates access to information and supports education and awareness-raising projects.

**Fundación ONCE (Spain)** is a Spanish organization that provides services for people with disabilities, including support for families. It organizes educational, counseling and support programs for integration into the labor market. It also supports parent training programs and recreational activities for families.

### **Types of activities carried out with and for families who have children with disabilities**

The organizations mentioned, and many others, offer various activities aimed at children with disabilities and their families, including:

- Counseling and family therapy sessions: Emotional support and stress management therapies for parents and siblings.
- Workshops and trainings for parents: Training parents in child behavior management techniques and educational support.
- School and social integration: Supporting families in the process of adapting the educational program to the child's needs, as well as access to resources for community integration.
- Camps and recreational activities: Organization of summer camps, trips and social activities for children with disabilities and their families.
- Support groups: Regular meetings for parents where they can share their experiences and learn from the experiences of others.

These organizations play an essential role in the lives of families of children with disabilities, offering a wide range of services designed to support both the child's development and the family's emotional and social balance.

### **Conclusion**

The role of the family is central to the recovery and development of children with disabilities. Providing comprehensive support – educational, emotional and practical – helps families to be better equipped to support their children, which can lead to significant improvements in the quality of life for the whole family.

There are several factors that contribute to the development of resilience in families with children with disabilities, including: **social support**: Support groups, friends and community networks are essential to create a network of support during difficult times; **parenting**: parenting training programs help parents develop effective coping skills; **financial resources and access to services**: access to financial resources and support can reduce stress and allow parents to focus on the positive aspects of their relationship with their child; **positive outlook and family cohesion**: positive attitude, cohesion and acceptance of the parenting role contribute significantly to family resilience.

All this reveals the need for well-structured interventions that support families both in Romania and in other countries, through psychological support programs, access to resources and opportunities for social integration.

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