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Original research paper

## SUPPORT AND EDUCATION FOR FAMILIES OF CHILDREN WITH DISABILITIES: EXPLORING PARENTAL PERSPECTIVES AND RECOMMENDATION

### **Abstract:**

*Parenting a child with a disability presents unique challenges and requires additional care and attention. Parents play a crucial role in promoting their child's development, fostering their independence, and nurturing their overall well-being.*

*This research study aims to investigate the adequacy of resources and support available to families of children with disabilities, as well as the perception of parents regarding these aspects. A specially designed questionnaire consisting of 21 questions was used as the research instrument, which was distributed to families through a Google form. The research sample was convenience-based and comprised 250 parents of children with disabilities.*

*The findings of the study reveal widespread dissatisfaction among parents in relation to institutional support. The results indicate that a significant majority of parents (80%) do not receive adequate institutional support, while only 1% reported receiving it. Furthermore, not a single parent reported being satisfied with the coordination among medical, educational, and social institutions, with 56% expressing dissatisfaction and 44% indicating partial satisfaction.*

*This study highlights the need for improved coordination among various institutions, increased parent education, and the provision of comprehensive support services to ensure a better quality of life for families of children with disabilities.*

**Keywords:** *Disability, Parenting, Challenges, Support, Inclusion*

## 1. Introduction

Parenting is a complex journey that encompasses both extraordinary beauty and formidable challenges. Expectant parents envision and prepare for this role with great anticipation and dreams. They long for a child who is healthy and develops typically. However, life's lessons remind us that nearly 10% of children, to varying degrees and durations, may deviate from these expectations (UNICEF, 2021). This reality plunges parents into uncertainty, as they navigate developmental hurdles and seek answers to difficult questions gradually. Parenting, regardless of circumstances, is inherently demanding due to various factors, particularly when raising a child who faces developmental risks or disabilities. Embracing uncertainty about future outcomes becomes an essential aspect of this unique parenting experience.

Every child, regardless of their developmental path, deserves wholehearted acceptance and the opportunity to thrive as a well-developed individual. Along this dynamic journey, parents navigate the challenges that arise within these complex circumstances, facing a multitude of anticipated and unforeseen obstacles.

Parents raising children with disabilities face heightened challenges and navigate through more demanding circumstances. They shoulder additional responsibilities in their children's care, including frequent specialist visits, recurring hospitalizations, and extensive medical examinations. Daily caregiving becomes more intricate due to their child's decreased independence, requiring additional information and support. Moreover, parents must undergo a process of coming to terms with their child's uniqueness and accepting a future that may be less predictable than initially envisioned. Given these circumstances, it is crucial for them to utilize every available resource to assert their right to support in overcoming these difficulties.

## 2. Theoretical approach

UNICEF survey (2017) highlights the concerning scarcity of accessible early parenting programs, which disproportionately impacts parents of children with developmental disabilities. This study confirms what professionals working with young children facing disabilities or chronic illnesses have long recognized: parents often neglect their own well-being as they devote their attention to meeting their children's developmental needs. In the process, they inadvertently overlook the fact that their own strength is not limitless. This behaviour stems partly from the inadequately developed early support system, leading parents to seek alternative avenues for obtaining the necessary developmental assistance for their child. They are acutely aware of the significance of early intervention, and in the absence of sufficient developmental support from existing systems, their focus understandably shifts to prioritizing their child's needs. Considering these

circumstances, it is unsurprising that they struggle to find the time for self-reflection and personal care.

According to Miller (1994), parents raising children with disabilities undergo a transformative journey of adaptation to their unique circumstances. Drawing from 25 years of research and first hand insights into family dynamics, Miller observed that these parents tap into an inner resilience that aids their adjustment. Nevertheless, they express a strong desire for support in their everyday functioning. To elucidate this process, she developed a model outlining four stages of adaptation (first stage – “surviving”, second stage – “searching”, third stage – “settlement”, fourth stage “separation”). It is important to note that these stages do not always occur in a linear sequence; they may overlap or recur. The adaptation process is dynamic, and no single stage can be definitively conquered. Certain events have the potential to disrupt parental stability and undermine their sense of security, possibly leading to regression from a previously attained stage of adaptation.

Parenting a child with developmental disabilities can elicit complex emotions such as anger, frustration, guilt, anxiety, and even depression, particularly when it involves a reduced capacity to care for other children in the family. Depending on the level of intellectual capacity, a child with developmental disabilities demands significant time and energy. They rely on their siblings to support and comprehend their unique circumstances, enabling them to navigate daily life. Consequently, siblings assume a newfound, responsible role within the family, which can potentially impact their own childhood experiences and emotional growth (Ajdinski, Memedi, Keskinova, 2017).

The ability of families to effectively navigate challenging circumstances hinges upon several key factors. The quality of marital relationships, parental well-being, and the availability of appropriate service models and support systems all play crucial roles. It is essential to approach the treatment of children and families holistically, considering their health, educational, and social needs in order to foster resilience and positive outcomes (Mitchell & Sloper, 2001).

Disability exerts a significant influence on various aspects of family life, underscoring the crucial role of support and assistance for both the family unit and its individual members. According to Mak and Ho (2007), support serves as a vital determinant in shaping the impact of stressful events on personal well-being. It acts as a protective mechanism, offering a cushioning effect that can influence the overall well-being of the family, the quality of parenting, and the resilience of children, particularly during critical situations. Hromková et al. (2018) research highlights that parents frequently express a need for support, while Luther et al. (2005) underscore in their study that seeking social support from parents is one of the most commonly employed coping strategies.

Extensive research has explored the numerous benefits of nurturing and supportive relationships. Many of these studies highlight social support as a vital factor that contributes to a higher quality of life, essential for enhancing adaptation and alleviating stress. Such support plays a crucial role in reducing burdens and effectively managing challenging situations. In line with this, Shuval et al. (1984) highlights the noteworthy finding that social support has the potential to alleviate negative perceptions of problems and proves valuable when individuals subjectively perceive their situation as problematic.

Effective support can empower parents to cultivate positive and enriching interactions with their child, enhance problem-solving skills, and create a safe and nurturing environment. Strong social support is linked to improved mental health and overall quality of life. Conversely, inadequate social support is associated with increased depression and anxiety among mothers of children with autism (Boyd, 2002). Assistance from professionals and supportive social environments plays a pivotal role in enhancing the well-being of both the child with an illness and their family.

### 3. **Research methodology**

*The objective* of this research is to examine the adequacy and sufficiency of resources and support accessible to families with children with disabilities, aiming to assess their impact on the quality of life. Additionally, the study seeks to understand the perspectives of parents regarding these resources and support systems.

For the research, a customized questionnaire comprising 21 questions was employed as a survey tool. To streamline the analysis process, the questionnaire was divided into distinct sections: formal support (institutional support), informal support, education, and the individual experiences of parents. While a majority of the questions were structured as closed-ended, allowing for straightforward responses, we incorporated open-ended questions to delve into the nuanced individual experiences of the participants.

The questionnaire was disseminated to families having a child with any form of disability via a Google form. To facilitate its distribution, social networks were utilized alongside the assistance of institutions and associations dedicated to supporting individuals with disabilities.

The research sample, obtained through a convenience sampling technique utilizing the snowball method, consists of 250 parents who have a child with a disability. The substantial size of the sample enhances the significance of the findings and enables potential generalization of the conclusions drawn from the study.

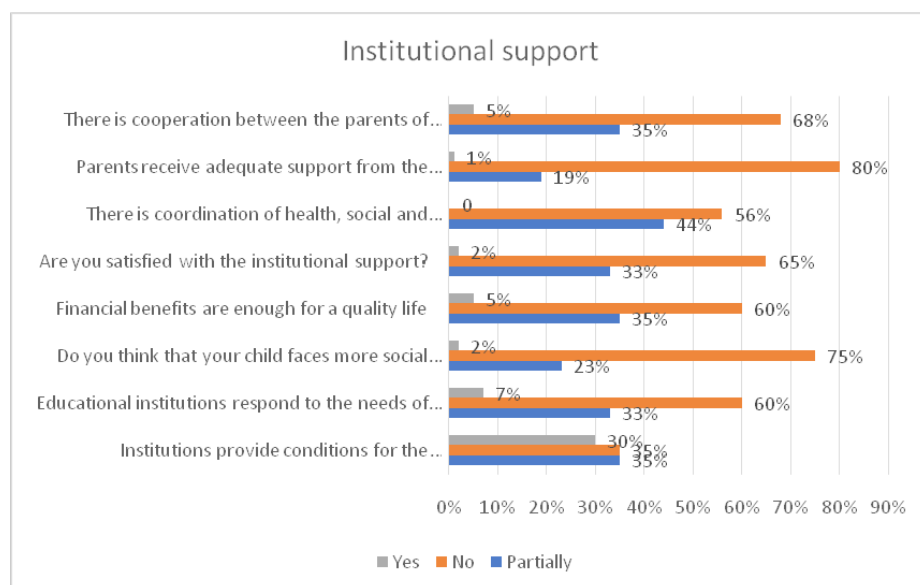
Table 1: Overview of research sample:

Characteristics of respondents		N	%
Gender	Female	232	93
	Male	18	7
	Total	250	100
Age	18-24	23	9
	25-34	53	21
	35-45	123	49
	over 45	51	21
	Total	250	100

According to the data obtained, the majority of respondents who answered the questionnaire are between 35-45 years old, a smaller percentage of about 21% are aged 25-34 years and over 45 years, and the smallest percentage are in the 18-24 age group. Of them, most (93%) are female respondents, while a small percentage of 7% are male respondents.

#### 4. Results

##### 4.1 Formal /Institutional support



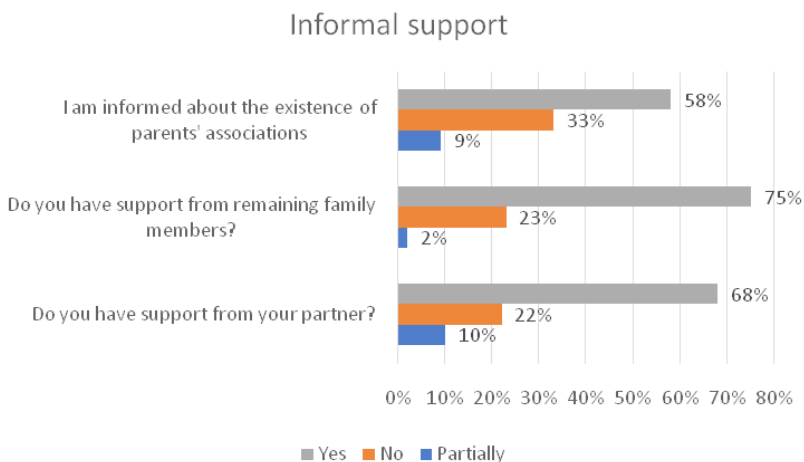
According to the obtained data regarding the institutional support, we can notice that in all the examined segments the dissatisfaction of the parents is evident. On table 1, we can see that 80% of parents do not receive adequate institutional support, only 1% of parents receive it. Accordingly, 65% of parents are not satisfied, and 33% are partially satisfied with what the institutions offer. The financial benefits allocated by the state are not sufficient to meet the needs of 60% of parents, and are partially sufficient for 35%.

In addition to the series of changes in the educational process of children with disabilities, especially the concept of total inclusion and transformation of special schools into resource centres, parents still believe that educational institutions are not at the required level to meet the needs of their children, a high 60% show dissatisfaction from educational institutions, and 33% are partially satisfied. We must see the disability in the functioning of the child as a multi-sector problem that affects the daily functioning of all family members, that is, medical, educational and social institutions must be interconnected and coordinated to offer appropriate services to support families. But in practice we detected a serious problem with this coordination. Namely, not a single parent showed satisfaction with their coordination, 56% are dissatisfied, and 44% are partially satisfied.

We obtained the most optimistic results regarding whether the institutions generally offer stimulating opportunities for the development of children's potential. According to the results, 30% of parents agree with that, while an equal percentage of parents - 35% are partially satisfied, that is, dissatisfied with the conditions in institutions for children with disabilities.

#### 4.2 *Informal support*

Chart 2: Displaying the level of parental satisfaction regarding informal support



According to the results, we can notice that more than half of parents (58%) are familiar with the existence of associations for their support, but still the percentage of parents (33%) who do not have any information about the existence of associations of such a nature is still high. Definitely, the greatest support that family members receive comes exclusively from mutual support. In 75% parents receive support from other family members (siblings, grandmothers, grandfathers and other relatives), and in 68% parents receive support from their partner (in relation to the structure of our sample, the mother receives support from the child's father).

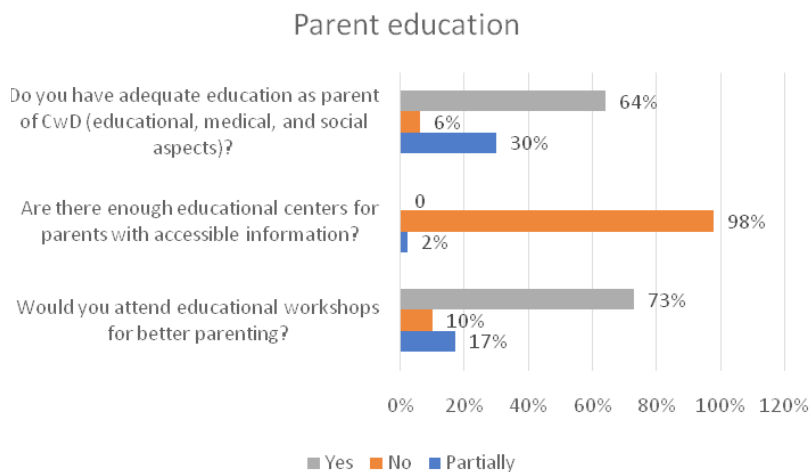
Regarding the analysis that is not shown graphically, we would point out that only 18% of parents are part of a parents' association, and 22% are not currently, but they have a desire and think it would be beneficial for them to join an association. The parents singled out the following associations as the most relevant: Dyslexia-Einstein Association, Association for People with Cerebral Palsy and Other Disabilities, and Sunflowers/Down Syndrome.

However, parents are aware of the importance of formal and informal support, a high 87% confirm and 10% partially confirm, that such support has a key role in overcoming daily challenges and reducing the stress experienced by parents.

#### 4.3 *Parents Education*

Based on its relevance, we singled out education, i.e., parents' awareness, as a separate segment for analysis, although it could belong to the segment of institutional support, when education is realized through formal courses organized by a public institution, or it could belong to the section of informal support when it is organized by a parent association or a parent support group.

Chart 3: Presentation of parents' attitudes regarding their need for education in relation to their child's needs



According to the results, we would notice that 64% do not have adequate education regarding the needs of their child, while 30% consider that they are partially informed. It is important to mention that not a single parent thinks that we have enough education centres, 98% answered negatively to this question, and only 2% think that the number of education centres is partially sufficient. Realizing the importance of education and the feeling of reluctance when having to accept, grow and stimulate a child with a disability, 73% of parents would attend educational workshops/courses to improve their parenting skills, while 17% are hesitant about this decision and decided on the option partially.

#### 4.4 *Individual experiences of parents*

This part of the analysis consisted of open-ended questions. Although we are talking about individual experiences, according to the analysis we can generalize the results. In this section, parents talked about who they first turned to for help and where they get information about their child's development and needs in conditions where there are no official centres for their education.

According to the qualitative analysis, we determined that most of the time the parents consulted a family doctor, experts, and family members for the first time. For help in everyday life and information about the condition of their child, parents look to doctors, but a large part of parents look for their answers on the Internet and social networks. We should understand this information as an alarm for a more serious approach in the organization of support for these families.

Regarding their needs, most of the families agreed on the need for: (1) Greater financial resources and greater financial assistance from the state; (2) Greater cooperation with all health, educational and medical institutions; (3) Development of institutions and their modernization in the direction of the needs of children with disabilities; (4) Greater social acceptance of persons with disabilities in all social aspects; (5) Greater number of day care centres for children with disabilities; and (6) providing counselling and support to parents and children with disabilities themselves in order to preserve their mental health.

In the last part of the questionnaire, the parents revealed to us the biggest fears they face on a daily basis. Generally, these fears were about their child with a disability, not themselves. According to the analysis, parents are most afraid of the uncertain future that results from the disorganized support system that we offer them and their children, specifically they fear for the health of their child in the future, for the quality of life that awaits them in the future and what would happen to their child after their death.

### 5. **Discussion and recommendation**

The obtained data sheds light on various aspects of institutional support, informal support, parents' education, and individual experiences of parents



regarding the challenges they face while raising a child with disabilities. The results indicate a significant level of dissatisfaction among parents in multiple areas, emphasizing the need for improvements and interventions.

In terms of institutional support, the findings reveal a widespread lack of satisfaction among parents. The majority of parents (80%) reported not receiving adequate institutional support, with only a small percentage (1%) expressing satisfaction. Financial benefits provided by the state were deemed insufficient for the majority of parents, while educational institutions were criticized for their inability to meet the needs of children with disabilities. A substantial proportion (60%) expressed dissatisfaction with the level of support provided by educational institutions, while 33% reported partial satisfaction. This highlights the importance of comprehensive coordination and interconnection between medical, educational, and social institutions to deliver appropriate services that support families effectively.

Mutual support from family members emerged as a vital source of assistance for parents. Approximately 75% of parents reported receiving support from other family members, while 68% received support from their partners. However, awareness about associations offering support was lacking for some parents (33%).

The importance of formal and informal support was recognized by a majority of parents, with 87% acknowledging its pivotal role in overcoming daily challenges and reducing parental stress. These findings emphasize the significance of developing and strengthening support networks and resources for families raising children with disabilities.

Insufficient parental education regarding their child's needs was highlighted, with a lack of available education centres. Sixty-four percent of parents reported inadequate education on their child's requirements, while only 30% felt partially informed.

The qualitative analysis highlighted the need for greater financial resources, improved cooperation between institutions, modernization of existing institutions, increased social acceptance, expanded availability of day care centres, and counselling and support for parents and children. Parents expressed fears about their child's uncertain future within the current disorganized support system.

Based on the findings of the study, we propose several recommendations that can be made to improve the support and services provided to families of children with disabilities:

- *Enhancing institutional support:* It is crucial to address the evident dissatisfaction among parents regarding institutional support. Efforts should be made to increase the availability and accessibility of support services, such as counselling and information resources, through collaboration between healthcare, education, and social welfare institutions.

- *Improving coordination between support systems:* The lack of coordination between different support systems was a notable concern raised by parents. Establishing effective communication channels and collaborative networks among healthcare professionals, educators, and social workers can ensure a comprehensive and integrated approach to supporting families and meeting the diverse needs of children with disabilities.
- *Expanding parental education programs:* Given the high percentage of parents lacking adequate education regarding their child's needs, it is essential to develop and implement educational programs specifically designed for parents of children with disabilities. These programs should cover various aspects, including understanding disabilities, effective parenting strategies, accessing available resources, and fostering their child's development.
- *Increasing awareness about support associations:* While a significant number of parents were familiar with support associations, there were still parents who lacked information about their existence. Efforts should be made to raise awareness about these associations and their services through targeted outreach campaigns, collaboration with institutions, and their inclusion in information resources provided to parents.
- *Allocating more financial resources:* The study revealed that many parents perceived the financial benefits provided by the state as insufficient. It is recommended to allocate additional financial resources to support families of children with disabilities, ensuring that they have adequate financial assistance to meet the diverse needs of their children.
- *Promoting social acceptance:* Parents expressed the need for greater social acceptance of persons with disabilities. Raising public awareness, promoting inclusivity in community settings, and combating stigma and discrimination can contribute to creating a more accepting and supportive environment for families and their children with disabilities.
- *Improving availability of day care centres:* The study identified a demand for a greater number of day care centres catering specifically to the needs of children with disabilities. Expanding the availability of such centres will provide parents with respite, space for personal care, and individual development.
- *Prioritize mental health support:* Given the fears expressed by parents regarding their child's future and their own mental well-being, it is crucial to prioritize mental health support for both parents and children. Providing counselling services, peer support groups, and accessible mental health resources can help alleviate stress and enhance the overall well-being of families.

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