

## THE DESCRIPTION OF THE CURRENT SITUATION OF THE FAMILIES WHO HAVE CHILDREN WITH DISABILITIES

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**Abstract:** *The present study will examine the quality of life of families who have disabled children. Identifying ways for supporting the families who have disabled needs is important and relevant because later the professionals will be able to create and design proposals to improve support programs adapted to the needs of families.*

**Keywords:** *disability, quality of life, the needs of the families*

### **Introduction**

This research is focusing on the quality of life of families who have disabled children in Romania.

To improve the quality of life of these families is necessary to improve certain services such as: multidisciplinary assessment of children with disabilities, rehabilitation of children, parental counseling, training staff and parents, collaboration with educators, teachers, schools and kindergardens, forming support groups, parents associations and creating support materials for both children and parents.

In most cases, parents are confronting with confusing situations caused by lack of coordination and co-responsibility between institutions and services such as social services, rehabilitation, health and others that affect children with disabilities.

Also, in Romania, the integration of persons with disabilities in the world of work is still very difficult. Therefore, I believe that our society should be more concerned by this problem because the integration of these people, from the earliest age to their incorporation in the social system to become reality. This is one of the most important aspects in improving the quality of life of these families. The education and training that disabled children and

young people receive today will directly influence their personal and social future perspectives. For being possible that young children with disabilities

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could become independent and autonomous individuals and to be incorporated into the social system, it is necessary that each person can get what he needs in place and at the right time, considering all aid needed, both in terms of human resources and the materials and eliminating any barriers: social, physical, communication, transportation and others.

Identifying the ways of support that the families with disabled children need is important and relevant because later it will be possible to create and design proposals to improve the support programs adapted to the needs of families.

### **Material and Methods**

In this research, I used both quantitative and qualitative research. The quantitative research will be useful for describing the current situation of families with disabled children, to analyze a large sample of subjects to identify resources available to support families. At the same time, the qualitative research will help me to identify the support measures in exploring proposals for improvement that families need and that will lead to improved quality of life. In this case I will use interviews and focus groups as investigative tools. This will be done both with families who have children with disabilities, and people with disabilities. The purpose of using this method in the second phase of the research is to deepen the identification of needs and outcomes, and clearly know the proposals for improvement.

These techniques will enable participants to speak openly about what they believe, so it is possible to obtain more complete and richer information to understand their motivations. Therefore, I believe that the use of qualitative methods with quantitative will be necessary to deepen the knowledge and experiences of parents and siblings relationships with people with disabilities, so that to allow analysis of their needs and to identify suggestions for improvement to enhance quality of life of these families.

Finally, the design of appropriate aid programs that have real needs these families can be achieved through panel discussions with the participation of specialists working within various organizations, and government representatives. The sample of this study consists of: families with disabled children and persons with disabilities. Given that this project is open to all families who have children with disabilities both in Bucharest and in other regions from Romania, in the first phase, the questionnaires will be sent to all these families. Subsequently it will be selected a representative number of these families, who will be required to form various discussion groups.

Regarding the questionnaire, this is formed by two parts:

1. Information regarding the families.
2. Families situation.

### Literature review

According to Vrăsmaş (2008), the family is an important factor in regulating the relationship between the child and society. Children develop physically, mentally, morally and spiritually at home.

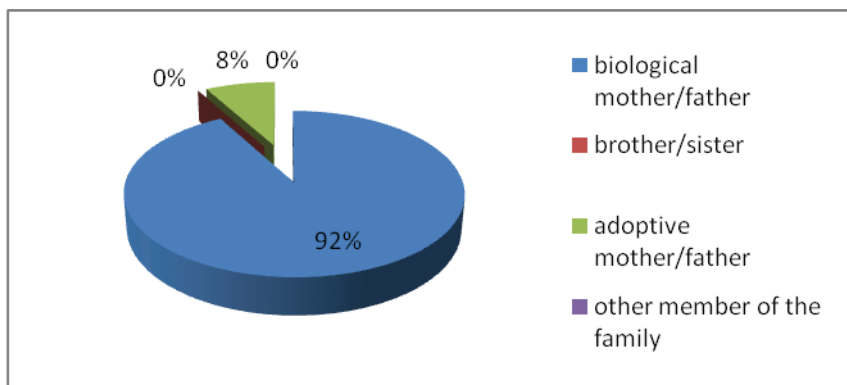
For children with disabilities, the family is much more: a special and great guidance in making important decisions in their lives.

The birth of a child with disabilities always causes a situation full of concerns, questions and new needs which is characterized mainly by: psychological and emotionally powerful impact, adaptation and redefinition of family functioning, need for information, assistance and counseling in education, health, psychological and others. Every child has the right to belong to a community and its members to share different experiences of everyday life. Each child has a contribution to society, and children with disabilities should not be less valued than others and their achievements should be seen and supported equally with other children.

Knowing the family environment of children is very important, because the family represents the first context of development of any child.

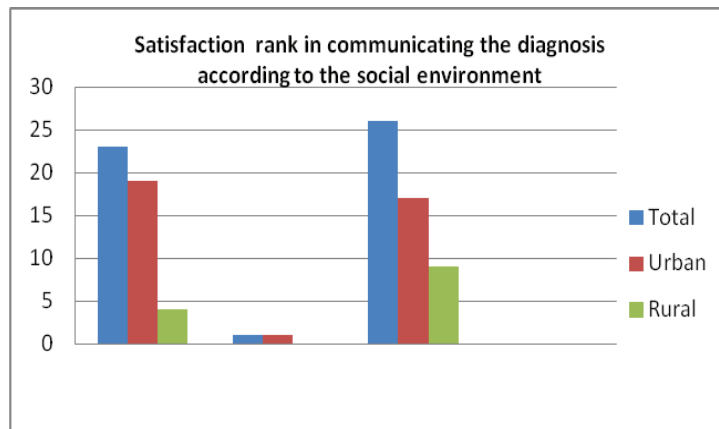
### Results and Discussion

Next, I'd like to present you some of the results of the research that I realized. Of the fifty respondents, forty-six are biological mothers of children with disabilities, and four of them are adoptive mothers. In the chart below, these relationships are represented as a percentage.

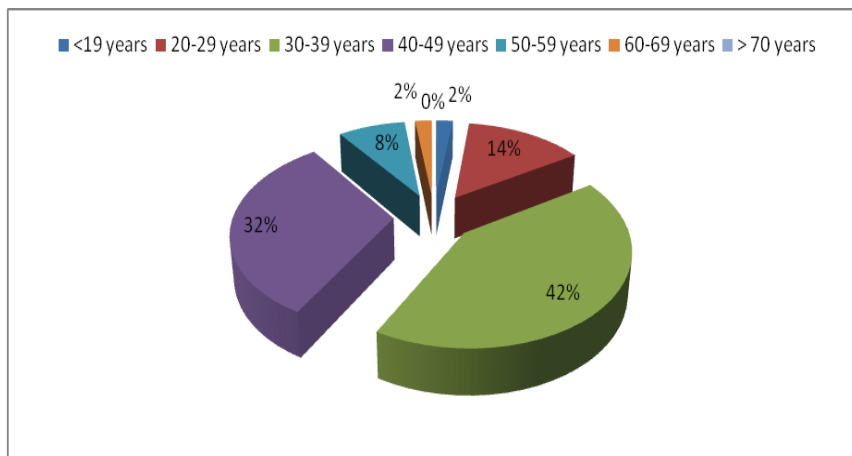


**Fig. 1** Graphical representation of subjects according to the relationship of people with disabilities

Thirty-eight subjects are from urban areas, while the other twelve are from rural areas. In figure two we can see the graphical representation of respondents according to social environment.



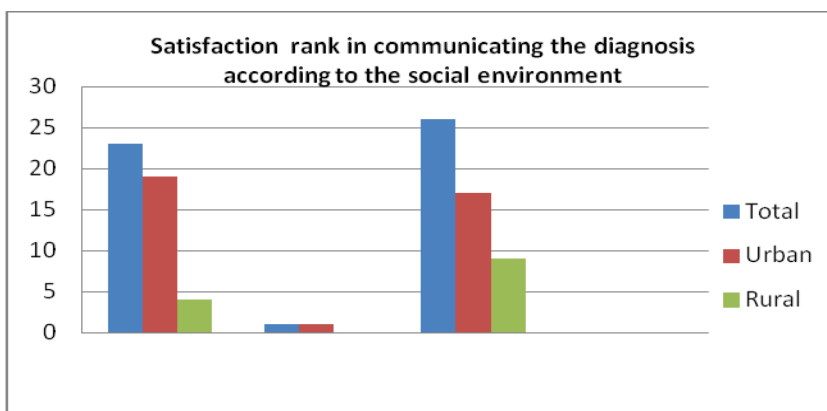
**Fig. 2** Graphic representation of the subjects according to the social environment



**Fig. 3** Graphic representation of the subjects according to age

Regarding respondents' age, a person is less than 19, seven are aged between 20 and 29 years, twenty-one are aged between 30 and 39, sixteen between 40

and 49 years, four between 50 and 59 years and a person is older than 60 years. Regarding the category "emotional welfare", twenty-six of respondents believe that family atmosphere was marked by problems created by the appearance of the person with disabilities, twenty-two of the respondents believe that family atmosphere was marked in a certain way and only two people do not believe that the appearance of people with disabilities in their family marked the family atmosphere. Twenty-three of the respondents believe that the way that the diagnosis of their children was told was adequate, twenty-six don't agree with this aspect, and only one respondent agrees to a certain extent.



**Fig. 4** Graphic representation of the subjects according to the satisfaction rank related to the diagnosis

Forty-six of the parents who responded to the survey believe they have enough information about existing support services, two of them believe that they have enough information and the other two parents hold this information in a certain way. Twenty-six of the respondents believe that they could find out more and more the features of their children, twenty-four disagree with this statement. Instead, all respondents believe they have where to go when they have any queries about what would be best for the person with disabilities from their families.

### Conclusion

The conclusions that I'd like to mention are actually some proposals to improve the quality of life of families of children with disabilities that I could observe that would be necessary through this research.

These are some of the proposals that I wanted to mention:

1. Providing even more information about the characteristics of disability and how people with disabilities can evolve.
2. Develop communication strategies for an appropriate communication with families of disabled children and informing the families about the diagnosis of their children in a very short time.
3. Creating support groups for parents who have disabled children so that they can speak with professionals about the various problems they have.
4. Creating awareness campaigns towards people regarding the people with disabilities and their families.
5. Creating united group of parents who have a disabled person in the family to share experiences.
6. Improving offers for leisure and sport activities that concern people with disabilities.
7. Improving offers for jobs that concern people with disabilities.
8. Promoting different policies related to the time of work realized by the persons who have a person with disabilities at home, their possibility to be allowed greater flexibility and to be considered other ways of working.
9. Providing support and guidance to promote responsibility and autonomy of the person with disabilities at home.

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