

10<sup>th</sup> International Conference:  
Research in Education  
and Rehabilitation Sciences

**ERFCON**23

May 5-7, 2023  
Zagreb, Croatia

# CONFERENCE PROCEEDINGS

Vol. I



10<sup>th</sup> International Conference:  
Research in Education and Rehabilitation Sciences

**ERFCON 2023**

May 5-7, 2023  
Zagreb, Croatia

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10<sup>th</sup> International Conference:  
Research in Education and Rehabilitation Sciences

## ERFCON 2023

May 5 -7, 2023  
Zagreb, Croatia

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## Introduction

Welcome to the Conference Proceedings for the 10<sup>th</sup> International Conference: Research in Education and Rehabilitation Sciences - ERFCON2023, Volume 1. This milestone event brings together scholars, researchers, educators, and practitioners globally, facilitating profound discussions, the exchange of innovative ideas, and the presentation of groundbreaking research in the fields of education and rehabilitation sciences.

The themes of ERFCON2023 signify our dedication to exploring uncharted territories and pushing the boundaries of knowledge in special and inclusive education, rehabilitation, speech-language pathology, social pedagogy, and criminology. As we collectively explore new horizons, this conference provides a platform for intellectual exchange, fostering collaboration and inspiring transformative developments.

The Conference Proceedings underscore the importance of diverse perspectives and interdisciplinary collaboration in addressing the multifaceted challenges within education and rehabilitation sciences. By assembling experts with varying backgrounds, our aim is to weave a rich tapestry of insights contributing to the holistic advancement of these critical fields.



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## First reactions and future expectations of parents of children with developmental disabilities

### SUMMARY

The birth of a child in the family is usually a period filled with joy and the formation of new feelings such as immense happiness, pride, self-realisation, success, and confirmation of identity. However, the birth of a child with developmental disabilities represents a strong challenge and a threat to the disruption of family life. The main aim of this study was to examine the reactions and feelings of parents as part of a family unit with a child with special needs. Several stress factors, positive and negative emotions, impact of disability on family members, and expectations for the future were investigated. Data were collected by surveying a group of 77 respondents who were parents of children with developmental disabilities.

The results of this research indicate that, although all parents faced similar challenges, emotions, and struggle with similar problems, to a large extent the emotions that dominated, the time needed to accept reality, and the challenges they faced were directly associated with the type of disability of the child. A total of 52% of respondents experienced some changes in marital relations after the arrival of a child with a disability in the family, 45.5% of respondents answered that someone from the family was forced to leave the workplace, 49.35% of parents answered that they neglected their own social life, and 51.94% of parents pointed out that the biggest challenge they were currently facing was psychological stress. In fact, parenting a child with a disability can present a unique and complex set of challenges.

**Key words:** *disabilities, families, first reactions and expectations*

## Introduction

Before giving birth, it feels like you're getting ready for a wonderful trip to the place you've been dreaming about all your life. You buy a bunch of travel guides and make wonderful plans, what to see and visit, where to go, everything is so exciting. After months of excited anticipation, the big day finally arrives, and the birth of a child with a disability suddenly takes you in a completely new direction, to a completely unknown place.

Regardless of the type and degree of disability, it always represents a complex triad of interactions, on the one hand including the child with a disability, and on the other hand the affected family, as well as the environment in which the disability manifests itself (Heiman, 2002).

When a child with special needs is born into a family, all aspects of the family are affected, including parents, brothers, sisters, friends, and close relatives. Many researches indicate that birth of a child with developmental disabilities undeniably causes a stressful change in the family and often changes its daily functioning, thereby determining the direction of its further development. There are great and difficult demands placed on the family, that is, on all its members, placing them in front of serious challenges and temptations, which can endanger not only each of them individually but also the family as a whole (Chichevska-Jovanova N., 2015).

How parents or other family members react to their child's disability, cope with the new situation and expectations for the future will largely depend on how they find out they are a parent, grandparent, sibling, or other member of the family to a child with a disability. Parents faced with the immediate crisis of preterm birth, or the initial diagnosis of a developmental disability mobilize their resources to cope with the crisis, albeit sometimes in ways that can affect them emotionally for years (David, 2013). Greater difficulties and consequences, in general, have parents and families of children whose disabilities begin to manifest in later development, and not immediately after birth or in the first months of life (Chichevska-Jovanova, 2023). In many cases, the initial reactions of the parents will be negative, similar to those related to sadness, anger, and rage. Some families flexibly adapt and mobilize for effective action, while others freeze in varying degrees of rigid, ineffective reactions, or tend to resist or even deny the diagnosis itself (Falik, 1995). Parental acceptance of children affects children's development, social behaviour skills, and adaptability (Carrasco, 2019).

Many studies have investigated the difficulties they encounter parents in raising children with developmental disabilities (Lučić, 2019). Research points to several important risk factors that parents of children with disabilities face. They are more likely to experience major life changes, including divorce, surgeries, and frequent moves. They also experience stress during the day much more often than other parents. Such anxieties often become a source of cumulative stress, which in combination with various life events leads to problems for themselves. According to VanLeit and Crowe (2002), mothers of children with developmental disabilities neglect

their own needs. In most cases, they do not find time for other activities, including family walks, socializing with other family members, and household chores. Mothers of children with multiple disabilities spend 39.7 hours per week nurturing their child, mothers with children with Down syndrome need 32.8 hours, while mothers of typically developing children spend about 33 hours per week (Crowe, 1993). In a study conducted at a pediatric clinic in Taiwan, it was determined that 44% of parents of children with physical disabilities have poor mental health, and 41.8% of mothers of children with cerebral palsy have an increased risk of developing psychiatric disorders diseases (Jen-Wen Hung, et al., 2010, Chichevska-Jovanova, Rashikj-Canevska, 2015).

Parents' perceptions of children with disabilities determine how parents educate and care for the child. Perceptions and expectations of parents of children with disabilities depend to a great extent on the socio-cultural arrangement, moral values and traditions, organization and accessibility to services and support, as well as the economic status of the parents. Very often we can see negative perceptions, including feeling pessimistic, embarrassed, withdrawn, and even rejecting the existence of children with disabilities (Junaidi, Dewantoro, 2020).

## **Objective**

The main goal of our research was to determine the first reactions of parents upon learning about their children's disability, as well as their plans and expectations for the future. To determine if there is a difference in the reactions between parents of children with different types of disabilities, what changes happened within families after having a child with disabilities, what challenges parents faced and what are their biggest fears for the future.

## **Research Problems and Hypotheses**

Our previous experiences and the analysis of literature made us start from the assumption that the birth of a child with a disability causes major changes in the life of the parents, more precisely in the social life, the time set aside for themselves, commitment to other brothers and sisters, psychological stress, work status, marital relations, etc. In correlation with the main hypothesis and its precise explanation, we also set auxiliary assumptions, that is, in the largest number of cases, negative emotions will dominate among parents, and in the largest percentage, expectations and fears for the future will be related to the independence of children, i.e. adults with disabilities.

## **Methods**

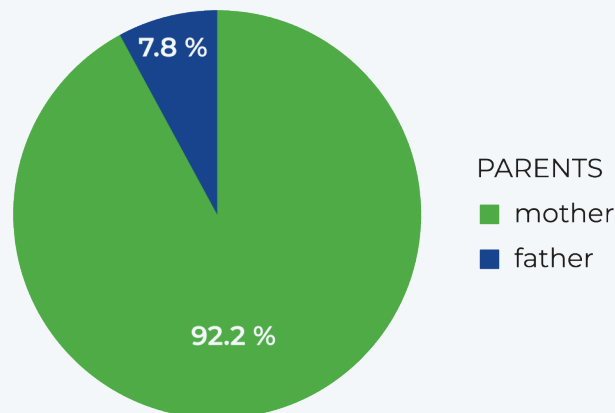
For the purposes of this research, the methods of descriptive analysis and comparison were used, as were the techniques of documentation analysis and surveying, and as an instrument, a survey questionnaire was used, which was answered by parents of children with de-

velopmental disabilities. The survey consists of 4 parts and a total of 41 questions. The first part consists of general questions related to the gender of the parent, gender, age and type of disability of the child. In the second part of the questionnaire, there are 17 questions related to the past, that is, how the parents found out about the disability in their child, their first reactions and the impact of the disability on part of their life. The third part of the questionnaire consists of 13 questions, 12 of which are in the form of statements, and parents have to rate their agreement or disagreement with the statements according to a 5-point Likert scale: 1 – do not agree at all, 2 – do not agree, 3 – neither agree nor disagree, 4 – agree, 5 – completely agree.

A total of 77 parents of children with developmental disabilities were included, of which 92.2% (71) are female, and 7.8% (6) are male (Figure 1).

The main limitation of the study is that it is a convenient sample with a small number of respondents, that is, respondents who were available in the field and agreed to participate in the research.

Figure 1 *Distribution of parents by gender*



## Results and Discussion

Considering that the group of respondents consisted of parents of children of different ages and with different disabilities, we will first give an overview of the demographic data. From Figure 2 we can see that 28.60% of the respondents' children are female, while the majority or 71.40% are boys. In terms of age, the largest percentage or 31.2% are in the category from 6 to 10 years old, 28.6% from 10 to 18 years old, 22.1% are aged from 3 to 6 years old, 13% are over 18 years old and 5.2% are aged from 0 to 3 years (Figure 3).

Regarding the type of disability of the children, the representation of children with an autistic spectrum disorder and children with multiple disabilities is equal, or 18.2% of the respondents' children, 15.6% are children with speech and language disorders, 13% are children with

Figure 2 *Distribution of children by gender*

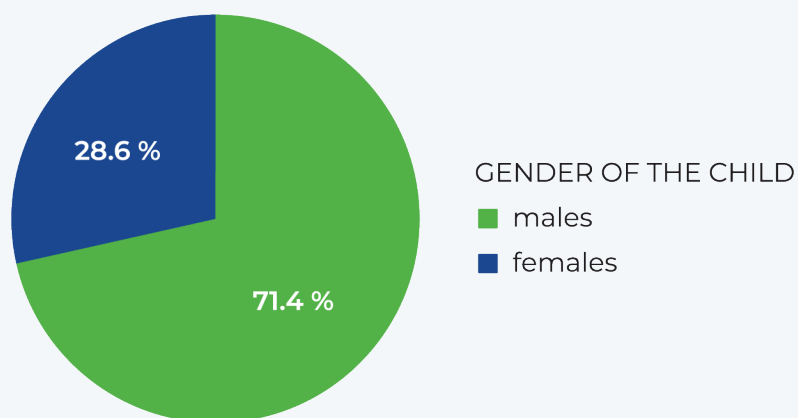
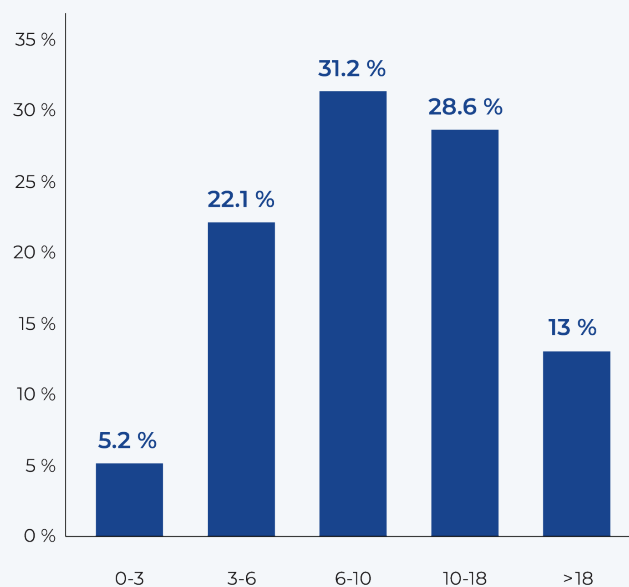


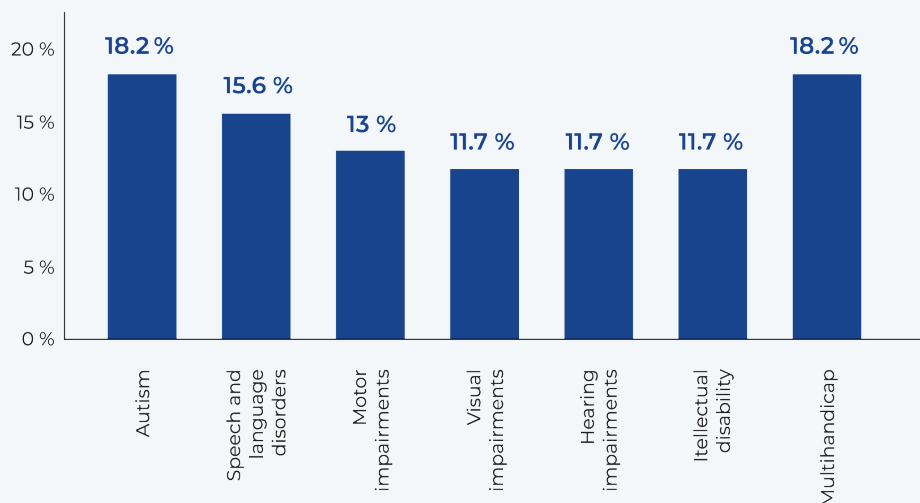
Figure 3 *Distribution of children by age*



motor impairments and there was also an equal distribution of children with visual impairments, hearing impairments and children with intellectual disability, i.e. 11.7% each (Figure 4).

Given that the first reactions, acceptance and expectations for the future depend on the way and time of discovering the disability in one's child, as well as on the availability of services and support, we will briefly focus on the analysis of respondents' answers related to

Figure 4 Distribution by type of child's disabilities



the discovery of disability in their children. Unfortunately, and contrary to all efforts for early childhood intervention, the largest number of respondents, 17 (22.1%) indicated that their child's disability was determined around the second year of life. In 16 respondents (20.8%), the diagnosis was made around 18 months of age, and the smallest number of respondents indicated that the disability was determined during pregnancy, 3.9% (Table 1). In correlation with the time of determining the disability with the age of noticing the first symptoms, 15 respondents answered that they noticed the first symptom of deviations in development around the first, that is, around the second year of life. As many as 14 respondents or 18.2% noticed the first symptoms immediately after birth. The most suspected signs, 44.2% of the parents (34 respondents) noticed in the area of Communication (social smile, eye contact, turning on sounds, reaction to own name), 31.1% or 24 examinees noticed a delay in motor development (lying on stomach, crawling, first steps...), seven parents (9.1%) pointed about the lack in their children's play (lack of imagination, imitation, disinterest...). Some other signs that were listed by a few examinees were lack of eye tracking, missing laughing for up to 8 months, hearing problems and reaction to voice etc. In addition to the ever-increasing awareness of the importance of early diagnosis leading to appropriate support and intervention for children showing developmental delays, in many countries the determination of the first signs of delayed development still takes place after the age of 18 months or two years. Similar to our findings are the results from Sidney obtained by Boulton and coworkers (2023). They found out that the average age at which caregivers identified developmental concerns was 3.0 years of age, but the average age of receiving a developmental assessment was 6.6 years. Only 46.4% of children received a diagnostic assessment by 5 years of age, even though 88.0% of caregivers were concerned about their child's development by that age. A popula-

tion-based cohort study provided in the USA (2022) by Straub and associates reported that the incidence and timing of neurodevelopmental condition diagnoses varied by insurance type, with diagnoses made earlier for privately insured children, relative to publicly insured children (Boulton, 2023).

Table 1 *Discovering the disability and noticing first signs*

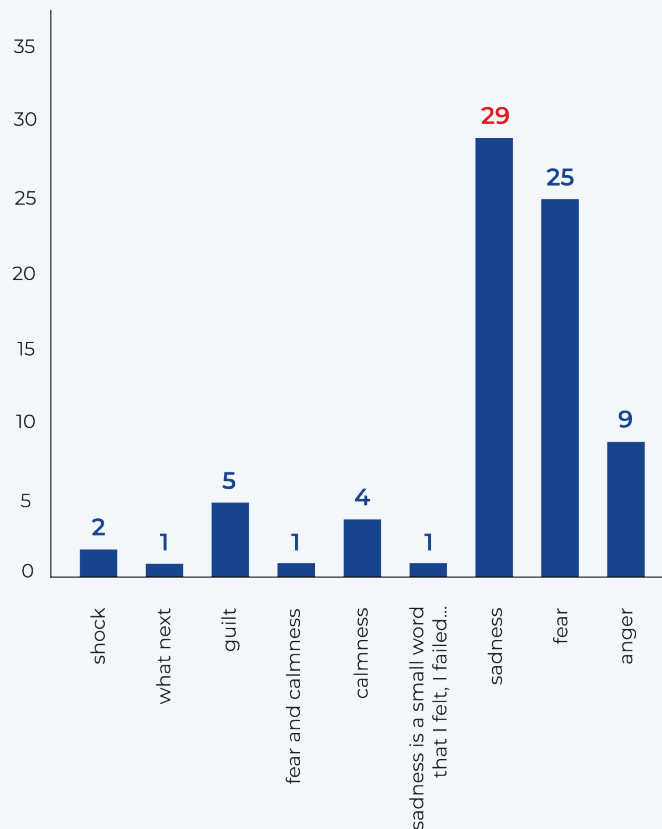
When you officially found out about your child's disability?			When did you notice the first sign?	
	N	%	N	%
During pregnancy	3	3.9	/	/
Immediately after birth	7	9.1	14	18.2
Up to 3 months	8	10.3	8	10.4
From 3-6 months	11	14.3	12	15.6
Up to 1 year	9	11.7	<b>15</b>	<b>19.5</b>
Up to 18 months	16	20.8	8	10.4
Up to 2 years	<b>17</b>	<b>22.1</b>	<b>15</b>	<b>19.5</b>
After 2 <sup>nd</sup> year	6	7.8	5	6.5

In the largest number of cases, delays in development were noticed first by the mother, i.e. 55 respondents or 71.4%, in 11.7% (9 respondents) the family pediatrician first noticed developmental disabilities, and in 3.9% of cases it was the father and the same number of grandparents. Based on the data from many studies we can state that the diagnostic process is rarely a positive experience for families and might therefore contribute to the stress felt by families of children with disabilities. Smith et al. (2010) also pointed out that in their study, in the largest number of cases, deviations in children's development were noticed and reported by mothers, especially in families where the child with a disability is the second child. Mothers in Smith's study reported that very few eligible children (2% at 12 months and 9% at 24 months) were identified by medical professionals as having any problems that could interfere with development.

The second part of the questionnaire referred to the emotional state of the parents and facing the disability, so to the question "What was the first thing you felt when you found out about your child's disability?" with the possibility of multiple answers, twenty-nine parents or 37.7% of the respondents answered that felt sadness, 25 parents (32.5%) had a huge fear. Anger

as the first feeling appeared in 9 respondents (11.7%), 5 (6.5%) respondents felt guilty, and 4 (5.2%) respondents felt calm (Figure 5). Starting from the fact that a large number of families break up after the birth of a child with developmental disabilities, and, it even leads to the separation of the spouses. The respondents were asked to answer what was the reaction of their partners when facing the disability. Forty-two parents (54.5%) pointed out that they talked openly with their partner and approached the best possible solution for their child, 13 parents (16.9%) faced distancing from their partner and going to work more often, 11 (14.3%) indicated that it took longer for the partners to accept the situation, and eight of the respondents, i.e. 10.4%, wrote that the partner still could not face the problem. Regarding support from relatives and friends, 70.1% (54) of the respondents had constant support from those close to them in every field, on the contrary, 15.6% (12) of them faced distancing by the close people around them, and 10.4% (8) of the parents answered that the people around them were scared and only came at their request.

Figure 5 Emotional state of parents when encountering a child's disabilities





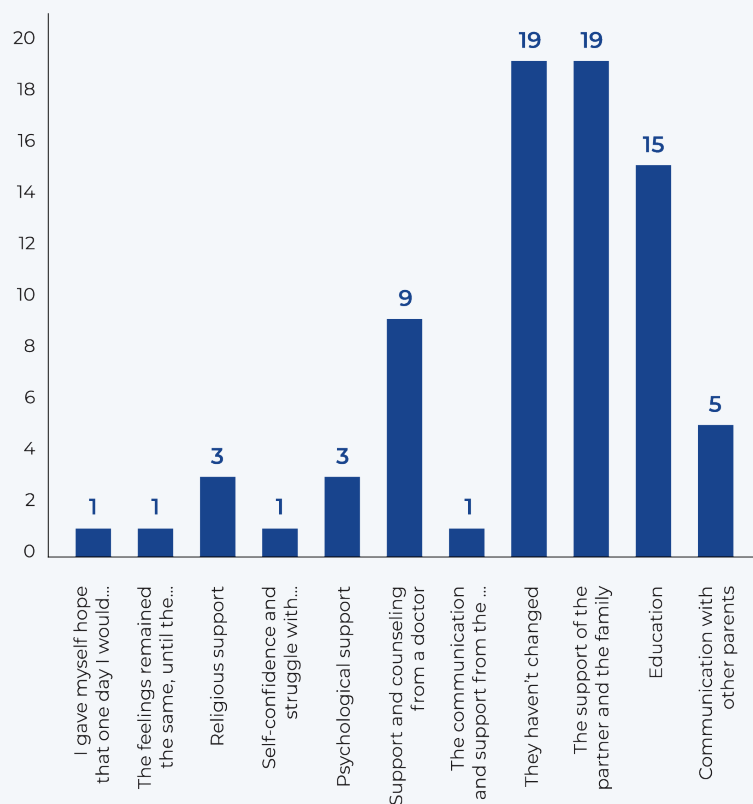
Regardless of gender, race, ethnicity, or nationality, parents when faced with information about their children's disability go through a range of emotions, starting from the most negative to complete acceptance of the new situation. In correlation to our results, Haiman (2002) found that most parents had to make changes in their social life and expressed high levels of frustration and dissatisfaction, although many try to maintain their routine life. In 1993, Tunali determined in his research that parents of children with disabilities face a series of problems, primarily financial, but also emotional, namely a sense of guilt, blaming each other, shame and a feeling of rejection by other family members. He also identified changes in family goals and expectations, related to the need for intensive care of children with disabilities, which often interferes with the work, and careers of parents, and some even leave work to care for children with disabilities. All these data were also confirmed by the respondents included in our study, although exactly 3 decades have passed since 1993 and things should be getting better with the progress of science and technology, but also of social order. Interestingly, religion and society have a great impact on parent's view of their child's disability, so in Indonesia, parents of children with disabilities consider that having a disability is God's will (Junaidi, Dewantoro, 2020)

The following open-ended question made the parents think and indicate what was the biggest concern that affected them at the moment when they found out about their child's disability. Most of them declared that the question "What to do next?" was a huge burden for them, they were worried about what would happen to the child after they were gone whether he would be able to manage, and who would take care of him if he cannot do it himself. A large number of parents also emphasized that they were most worried about the future of their child, whether he would be able to become independent, whether he would walk, whether he would start to speak, etc. Among other things, the parents indicated the fact that there are not enough professional staff, resources and centers in our country and that there is no one to provide them with help and professional support. Some of them pointed out that their biggest concern was that there was no cure for their condition, while others wondered if there would be an improvement in the condition with the current treatments or if the condition would last a lifetime. The parents were asked to answer whether there were changes in the initial emotions and feelings over time, but also to indicate the reason for the changes. Nineteen parents (24.7%) answered that there was no change in emotions at all and that they still faced the same difficulties. The same number of respondents answered that they face positive changes thanks to the support of their partner, 19.5% (15) pointed out that their feelings changed as a result of personal education, and 11.7% (9) said that they changed their negative feelings as a result of support and counseling from a doctor (Figure 6).

Naturally, the future brings great uncertainty and fear of the unknown, but for parents of children with special needs, the worry and anxiety are stronger. The analysis we made of

the literature led us to the conclusion that the same questions and worries about the future are everywhere, among our respondents, that is, parents are worried about the moment when they will not be able to take care of their children with disabilities. Parents expressed their concern about their child's ability to function in a less restrictive environment or less sheltered settings. Comparing ours with the social order in developed countries around the world, we can point out that parents of children with disabilities in countries in transition like ours have a greater burden on organizing the future of their children, as a result of the lack of sufficient service and support for independent living of persons with disabilities, as well as the realization of personal income (Kochovska et al, 2018, Rashikj-Canevska, 2023). Green, Darling and Wilbers (2013) made a meta-analysis of qualitative studies of parents of children with disabilities from 1960 to 2012 and like our findings pointed out that some aspects of the parenting experience have changed very little. Parents continue to experience negative reactions such as stress and anomie, especially early in their children's lives, and socially imposed barriers such as unhelpful professionals, and a lack of needed services continue to create problems and inspire an entrepreneurial response.

Figure 6 *Reasons for the change in initial feelings*



When it comes to changes, the respondents were asked if after the birth of a child with a disability, they were forced to make changes in their work status, i.e. if one of the parents was forced to leave their workplace, with as many as 39% (30 parents) answering that they were forced to leave the workplace, and 6.5% (5) answered that their partner left the workplace.

The third part of the questionnaire consisted of 12 questions conceptualized as statements graded according to the Likert scale, to which the parents had to express their agreement or disagreement with a score from 1 to 5. In this part, most of the questions are related to the difficulties that respondents face as parents of children with developmental disabilities.

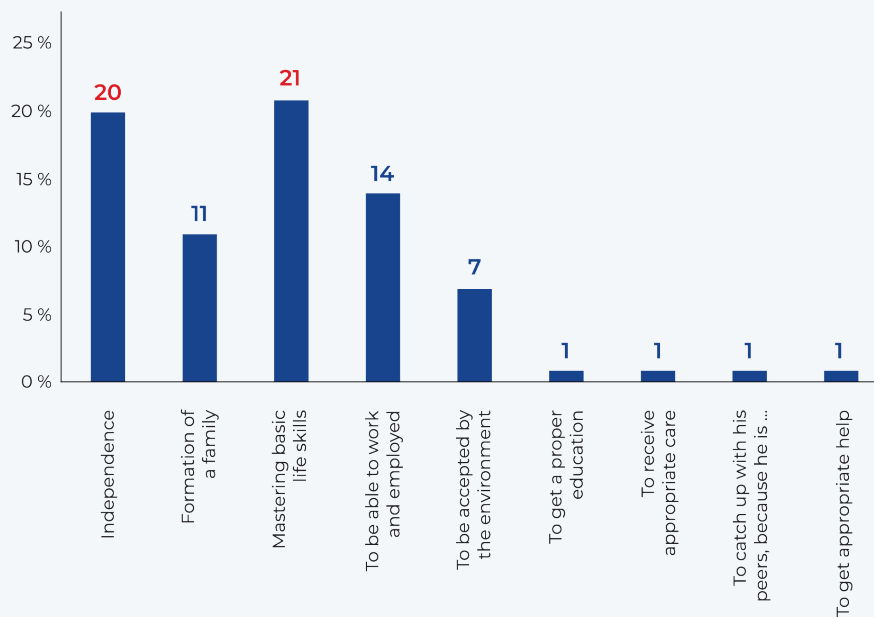
From the answers shown in Table 2, it can be concluded that the largest number of parents, 53 agree that the biggest challenge they are currently facing is finding the necessary institutions and services that will be appropriate for their child's needs. Forty-eight pointed out that the biggest challenge they are currently facing is the shortcomings in the educational process, 47 parents agreed that they experienced a great personal transformation as a result of caring for a child with a disability. A large number of parents (43) agree with the statement that they do not devote enough time to themselves and that they give up their social life. They least agree with the statement that they feel like they don't pay enough attention to the siblings of a child with disabilities (33 parents) and that they feel constant judgment from the surroundings (32 parents).

Table 2 *Parental statements*

N	Statements	1 – Do not agree at all	2 – Do not agree	3 – I neither agree nor disagree	4 – I agree	5 – I agree at all
1	My child needs constant supervision and support, and therefore I need to devote all my time to him.	12	3	20	13	29
2	I am having difficulty in providing full day supervision for my child.	20	6	17	10	24
3	I feel like I don't pay enough attention to his/her siblings.	<b>33</b>	3	17	6	18
4	I feel that I don't pay enough attention to myself.	13	4	6	11	43
5	I feel like I'm neglecting my own social life.	13	4	9	13	38
6	I feel constant judgment from the surrounding.	<b>32</b>	9	20	5	11
7	The biggest challenge we are currently facing is the financial part (lack of funds for therapies, medicines, etc.)	16	9	12	11	29
8	The biggest challenge we are currently facing is psychological stress.	12	4	15	6	40
9	The biggest challenge we are currently facing is my employment status.	27	11	18	3	18
10	The biggest challenge we are currently facing is finding the necessary institutions and services that will be appropriate for my child's needs.	5	6	8	5	<b>53</b>
11	The biggest challenge we are currently facing is the shortcomings in the educational process.	6	2	13	7	48
12	I believe that I experienced a great personal transformation as a result of caring for a child with a disability.	9	2	12	7	47

The last part of the questionnaire consisted of 7 questions, several of which were related to the plans and wishes for the children's future. Regarding the biggest wishes for their child about the future, most of the respondents, 27.3% (21) pointed out mastering of basic life skills as their biggest wish, 20 respondents (27%) highlighted the desire for independence of their children, 14 respondents (18.2%) have a desire for their child to be trained and employed according to their characteristics and abilities, and 14.3% (11 respondents) marked forming their own family and good quality of life for the child as their greatest desire (Figure 7).

Figure 7 The most important wishes for the child's future



## Conclusion

Understanding the first reactions and expectations for the future among parents of children with developmental disabilities is vital for providing appropriate support and intervention. By recognizing the range of emotional reactions, addressing the unique needs of each family, and promoting resilience, professionals can better support parents as they navigate the challenges and joys of raising a child with a developmental disability. Strengthening family relationships, providing accurate information and resources, and advocating for disability rights are essential components of this support.

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