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Research Insights
Изследователски проникновения

PARENTS' REACTIONS AND FIRST ACTIONS TOWARD THEIR CHILDREN WITH MULTIPLE DISABILITIES

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Abstract. The research focused on the reactions and first actions among 52 parents of children with multiple disabilities in Bulgaria. The results showed that most of the parents went through stages of denial, anger, bargaining, depression and acceptance. Most of the parents did not receive in-time support upon the news of having a child with multiple dishabilles. Many parents were not fully satisfied with the educational options and placement of their child and believed more can be done, as well as they did not have enough knowledge about the specific methods, strategies and approaches used in the education offered to their children.

Keywords: multiple disabilities; parents; reactions

All parents play significant role in their child's life. They raise him/her, they are part of his/her education, they provide support in every aspect of life on everyday basis. Parents are parents for as long as they live.

All parents are hoping and dreaming for a healthy, smart, beautiful and successful child. This is part of the human nature. In some cases a child with disability may be born. Every disability – expected or unexpected, causes shock, anxiety, grief, stress and tension in the family. The hopes and dreams are broken, the future is unknown.

Families of children with special needs have specific identity. They often experience feelings of insecurity, high levels of stress and confusion. The presence of a child with special needs in the family may cause negative emotions and is considered as very stressful event for the family (Chang & McConkey 2008).

Blacher (1984) defined three periods of adaptation of parents toward the news of their children being with disability:

– first parents experience emotional crisis, which includes shock, denial, and mistrust;

– the second period includes anger, guilt, depression, shame, low self-esteem, rejection of the child or overprotection;

– in the third period parents accept the child.

Anderegg, Vergason & Smith (1992) did a significant research on 130 parents from 2 support groups and developed a model of the grief process experienced by parents whose children had disabilities. The intention was the model to be used in working with parents to facilitate the process of passing through the stages of grief and to turn the negative feelings and reactions into more positive behavior. Behaviors from traditional models of grief were organized into 3 clusters: confronting, adjusting, and adapting.

Other studies on the emotional reactions of parents of children with special needs have shown that parents go through an adjustment process of their emotions. The adjustment time required is different for every family. One of the reasons may be the difference in the parental roles (Norlin & Broberg 2013), but probably the efforts to ensure a stable environment and daily routine in the child's life was also of significance.

Tsimbidaki (2006) investigated the emotional reactions of parents toward their children's disability and their development, from the time of giving the diagnosis until the age of 12. The author noted that most parents considered the disability of their child as a very difficult situation. Some parents described it as a constant struggle and a smaller percentage as a drama or even death of expectations and dreams, while few described it as a test from God. For this reason the early start of work with families of children with disabilities by educators is crucial, because it can spare lots of doubts, stress and misunderstandings and will provide positive views and solutions for the future (Hornby 1995).

Fareo (2015) reported that one of the biggest challenges for parents was the ignorance they felt or the lack of specific knowledge about the nature of their child's difficulties, the cause, the impact and eventual prognosis of disability.

In Greece, a large percentage of stress experienced by parents, according to Alevriadou & Giaouri (2009), came from the lack of enough resources and services such as: psychosocial support systems, early intervention programs, day care centres, strong parents' groups or organizations. It was also found that the most important factors that help families raise children with special needs were: good financial situation, good family relationship in the forms of coexistence of both parents in the family, successful marriage and high-level of social support (Collara & Alevriadou 2016).

One of the most significant research on grieving was done by the Swiss psychiatrist Elisabeth Kuebler-Ross, who developed in 1969 a model or cycle with five stages of human grief in her book *On Death and Dying*. The model was based on her work with terminally ill patients. Later the stages and the model were introduced to psychology, education etc. and the researchers mentioned above used them for explaining other forms of grief – for instance if a child with disabilities was born. The five stages are: Denial, Anger, Bargaining, Depression, Acceptance.

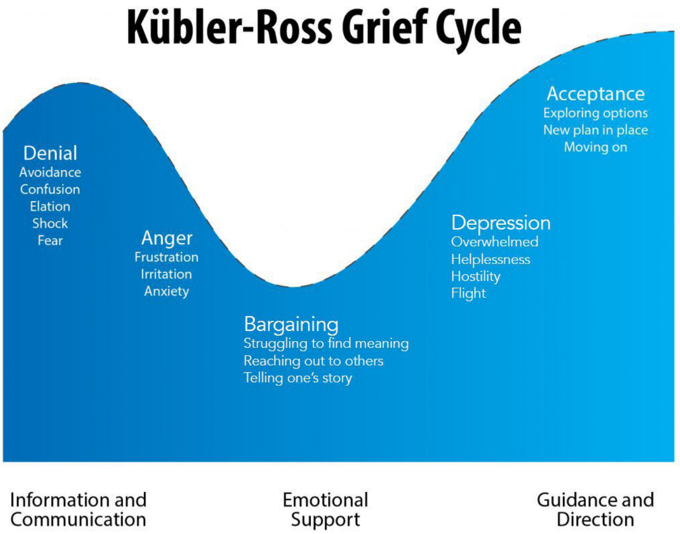

Figure 1. Kübler-Ross' model of human grief[1]

The model has received much criticism in time, because for long years its interpretation was that the stages followed a specific order and that all people would go through all stages. It is well understood now that some people may not experience any of the stages, while others might only undergo two stages rather than all five. It is also agreed that the five stages of grief are the most commonly experienced by any grieving person or population.

In the stage of a ***denial:*** Parents may loose reason for living, may wonder what to do, will be in a shock, may doubt if the news is true. It is important in this stage to try to overcome the shock, because only then process of healing begins.

In the stage of ***anger:*** parents may think and wonder why it happened to them, did they really deserve it, they may start blaming one another or other people. Sometimes belief in God is broken. Professionals suggest parents to talk about the anger and express it freely.

In the stage of ***bargaining:*** parents will start trying to negotiate the situation virtually or spiritually and to hope for a miracle. They may think of bargaining with God, of promising themselves major life changes in the attempt to gain their usual life again. Guilt is a common feeling in this stage.

In the stage of ***depression:*** parents may feel emptiness, may want to withdraw from life and be alone, may not want to talk about anything and feel hopeless.

In the last stage of ***acceptance:*** parents will understand and accept the new reality and will be ready to continue their lives. They will however feel sad sometimes, but are ready to move on.

The sooner the parents pass the stages of grief, educational options, educational specialists and educational interventions would be sought for. The active parental involvement in every stage of the development of their child and in every age, plays significant role and contributes to the cognitive development of the children and supports later their school performance and achievements (Rodrigues et al. 2015). Parents' expectations, hopes and desires influence the decisions taken for the child with disabilities, his/her educational placement and educational process. The parental reactions, attitudes and involvement influence the whole life-span of their children with disabilities.

Design of research

In order to learn more about the reactions of parents of children with multiple disabilities, and especially about their actions when learning the news of having a child with multiple disabilities, we developed a questionnaire. It was distributed widely in Bulgaria through Google forms to parents' organizations, schools, educational centres etc. Approximately 250 people were reached and kindly asked to fill in anonymously the questionnaire. We got back 52 filled in questionnaires, some were incomplete, however, we accepted them. Some of the parents who were contacted directly, said they did not want to answer the questions, some promised to answer them, but did not do so. The overall conclusion was that many families still are very sensitive to the issue and even though years have passed since the birth of their child with multiple disabilities, many of them were not ready to share their thoughts openly and without hesitation. No matter that we intentionally did not include a demographic question in regard with town/city/village the parents were living in, to keep their confidentiality as much as possible, many parents did not feel ready to participate in the study. The Questionnaire consisted of 25 question divided into 2 sections:

- 8 questions with demographic context;
- 17 questions in regard with the parents' reactions and actions.

Most of the questions were with multiple choices, some were open-ended. The research happened between February and May 2022.

Analysis of the data gathered

All of the participants were mothers of a child with multiple disabilities. This is a trend in Bulgaria that mostly mothers are actively involved with any initiative connected with their child. Regarding the marital status of the parents:

- 31 (59,6%) were married;
- 11 (19,2%) were single parents;
- 9 (17,3%) were divorced;
- 2 (3,8%) were widowed.

We did not dare to ask whether there was a change in the marital status after the birth of the child with multiple disabilities, although we may suspect separations and divorces happened in some of the families.

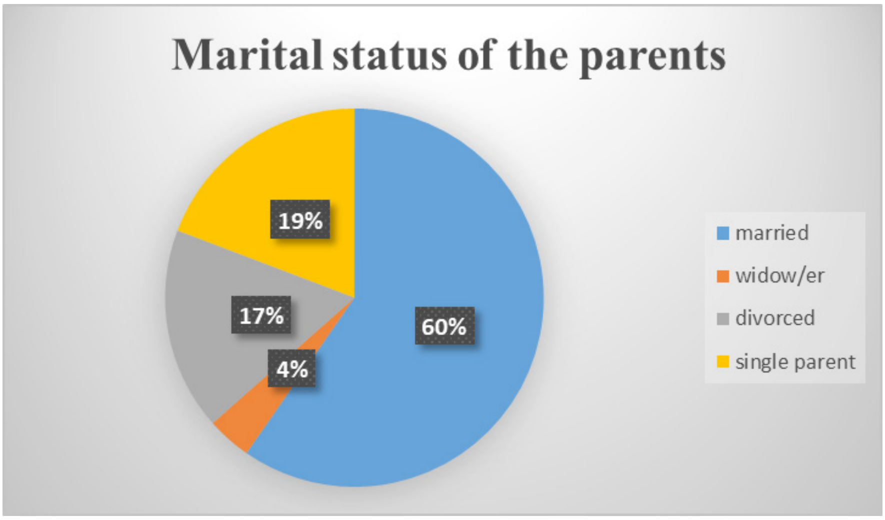

Figure 2. Marital status of the participants

In regard with the educational background of the parents:
– 30 (57,7%) had university education;
– 17 (32,7%) had secondary school education;
– 5 (9,6%) had completed 8th school grade.

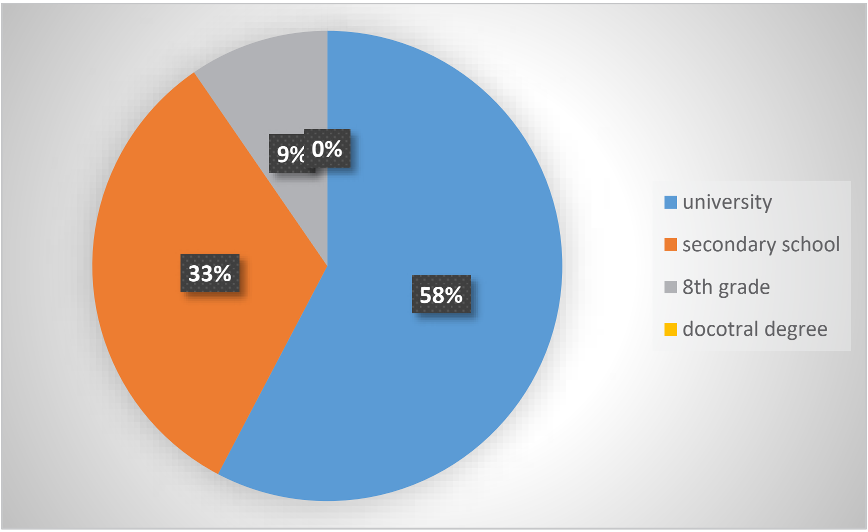

Figure 3. Educational background of the participants

All the children had multiple dishabilles in a variety of degrees and forms. The most commonly reported was communication disorder – in 50% of the children, followed by motor disability – in 48,1%. 19 children (36,5%) had intellectual disability, 17 children (32,7%) had Autism Spectrum Disorder (ASD), 16 children (30,6%) had visual impairments, 15 children (28,8%) had seizures, 5 children (9,6%) had hearing problems, one child had specific genetic disorder, 1 had hydrocephaly and 1 was reported to have behavioural issues.

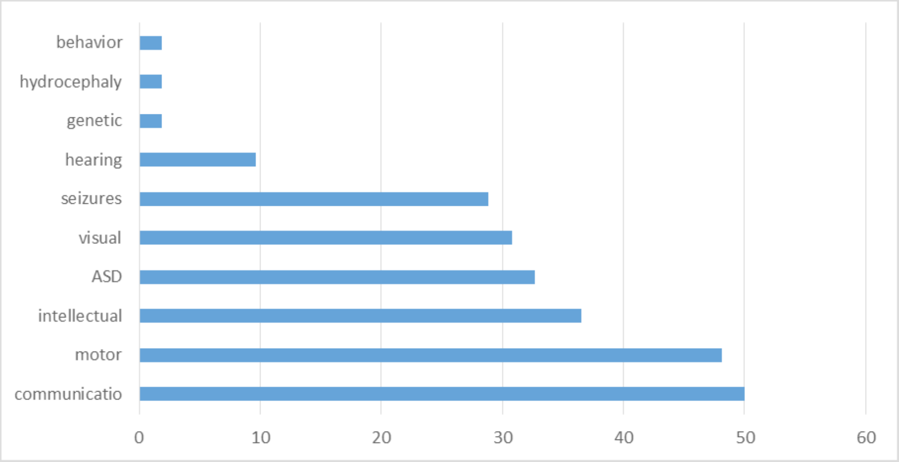

Figure 4. Types of disabilities of the children

As we contacted parents of children of different ages, we asked about the current age of their children. It turned out that many families actually had older children who were in teen age or even older. Here we got 28 answers. Obviously some of the parents intentionally did not want to reply to this question, maybe in order their children not to be recognized by their age.

Table 1. Age of the children

4 years	5 years	6 years	7 years	8 years	9 years	10 years	11 years	12 years	13 years	15 years	16 years	17 years	21 years
3	2	1	3	2	2	2	1	1	2	1	1	2	5

The next question was connected with the educational setting the children were placed in.

– 13 children went to a regular kindergarten;
– 2 were placed in special kindergarten;

- 12 were in special schools;
- 15 were in a regular school;
- 9 were in a day centre;
- 1 was in university.

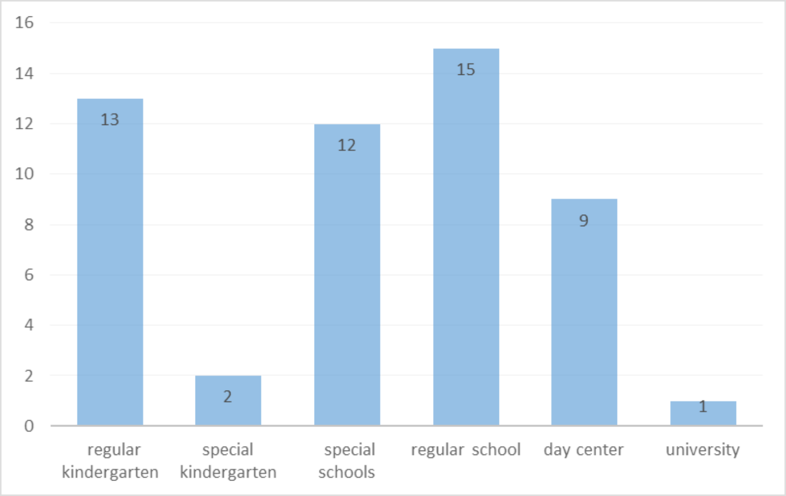

Figure 5. Educational placement

A question about other children in the families showed that 37 of the parents (71,2%) had other children and 15 (28,8%) did not.

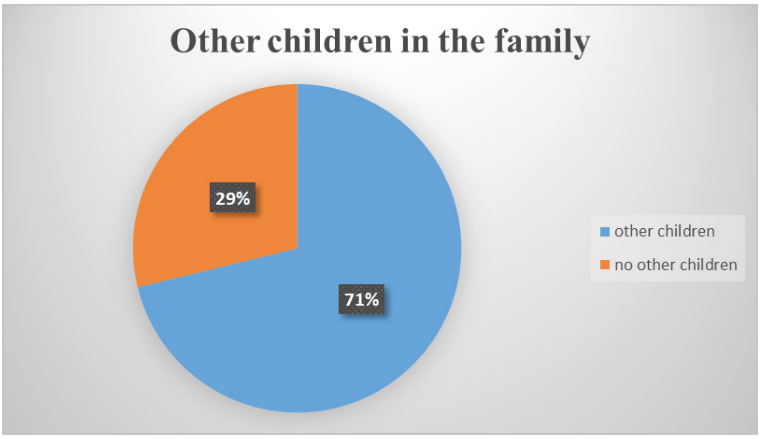

Figure 6. Siblings in the family

35 (89,7%) of the siblings did not have any disability and in 4 of the siblings (10,3%) there were disabilities.

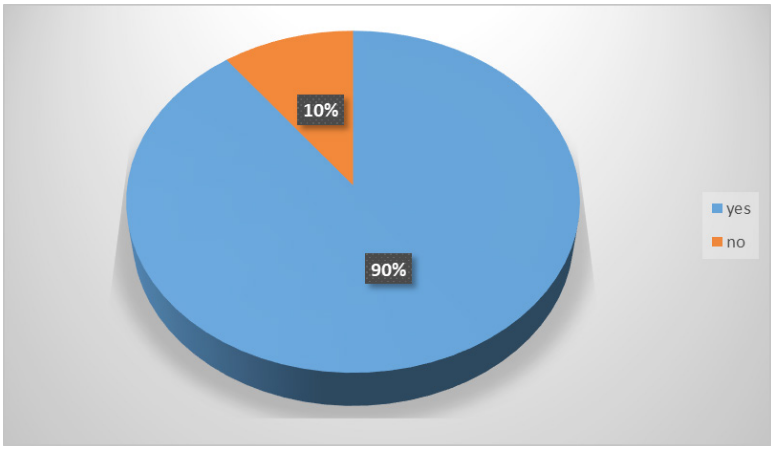

Figure 7. Disabilities in the siblings

We also asked the parents with siblings what was the attitude toward the child with multiple disability. The parents reported that 31 of the siblings (79,5%) were tolerant, 5 siblings (12,8%) had no interest in their multiply disabled brother or sister, 1 sibling was very compassionate, 1 had a regular attitude without any peculiarities and 1 sister was reported as too young to understand the multiple disabilities of her sibling.

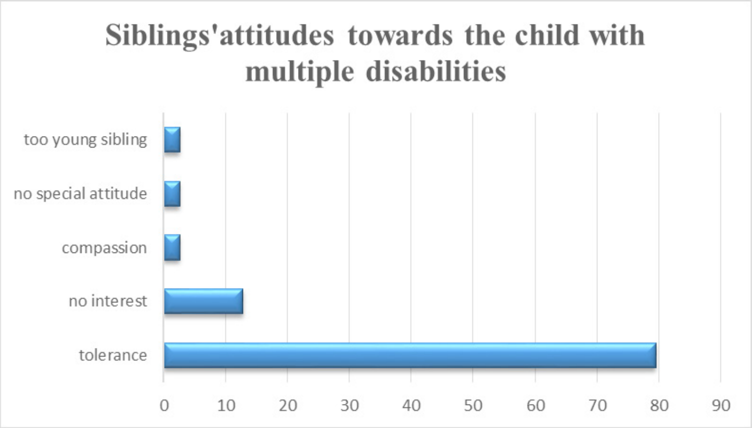

Figure 8. Attitude of the siblings toward the multiply disabled child

Then we asked several questions in regard with the pregnancy. All mothers reported they did not have any idea about carrying a child with disability. For this reason on the next question whether genetic testing should be done, we had 51 answers. The majority of the parents – 37 (72,5%) replied that genetic testing should be done. 9 mothers (17,6%) replied negatively to the same question, 2 said they did not know, 2 said it depends on the situation and 1 replied that maybe before marriage such testing may be beneficial.

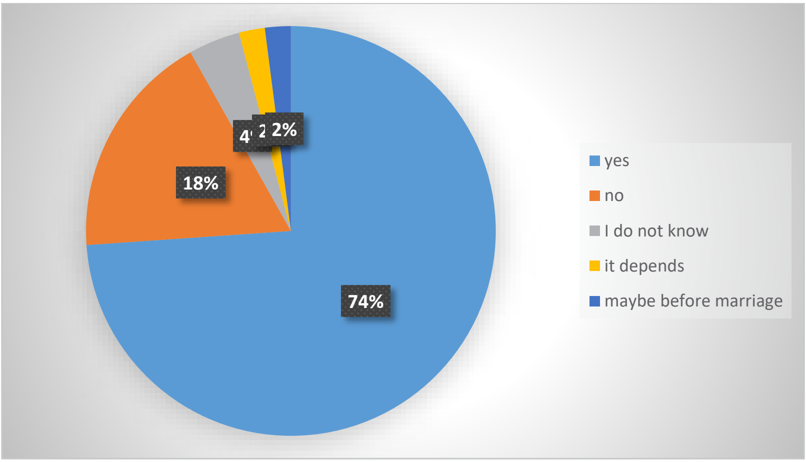

Figure 9. Need of genetic testing

The next question was about when the first symptoms of the disabilities were evident and when the child was diagnosed with multiple disabilities. We got 51 answers. In 16 cases (30,7%) the child was diagnosed in the maternity hospital, in 6 cases (11,5%) the general practitioner diagnosed the child, in 26 cases (50%) the parents themselves recognised the issue and searched for medical specialists, in 3 cases (5.7%) a neurologist diagnosed the child, in 1 case (1,9%) a paediatrician diagnosed the child.

We also asked about the mothers' first reactions. Many mothers marked not just one reaction but few. This shows that many of them went through different stages of emotions and reactions.

- – 34 were confused;
- – 27 were scared;
- – 12 were angry;
- – 5 did not believe it;
- – 3 wanted to escape;
- – 18 felt guilty;

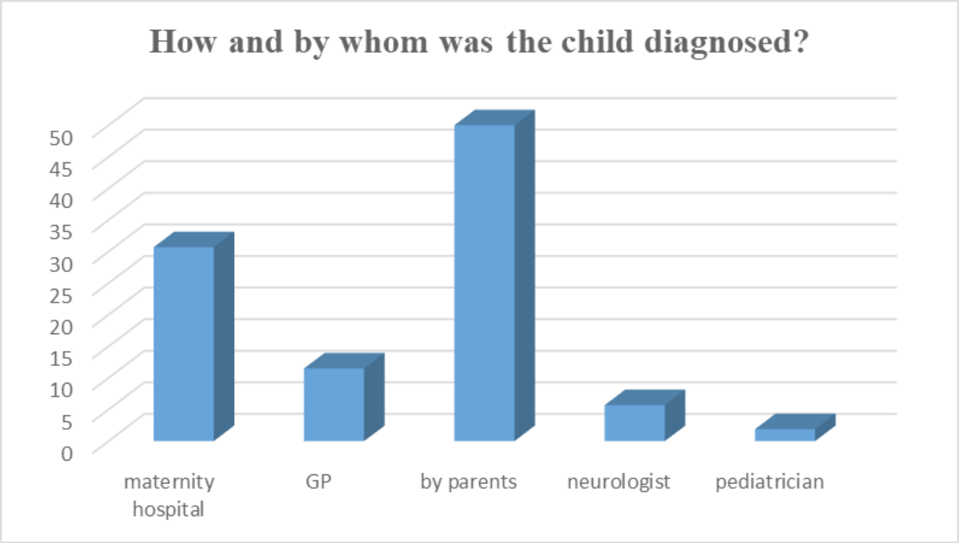

Figure 10. How and who diagnosed the child

– 10 went through depression;
– 4 were complaining and rebelled;
– 1 felt helpless;
– 1 was shocked;
– 2 started to look for information;
– 1 thought she would find a solution.

Then we asked about what happened after getting the news that the child had multiple disabilities. Again the parents provided more than one reply. This shows the different levels of reactions they went through.

– 34 parents started to look for other opinions by other medical specialists;
– 29 looked for solutions (without specifying of what kind);
– 19 started to think of surgeries and treatments;
– 4 became religious in the hope for healing;
– 3 searched for help by psychics;
– 2 started to drink.

A question was asked especially with a focus on having hopes for healing or recovery.

– 27 parents (51,9%) were hoping deeply insight for recovery;
– 9 (17,3%) did not have such a hope;
– 14 (29,6%) had a hope for recovery for their child;
– 2 (3,8%) were not sure.

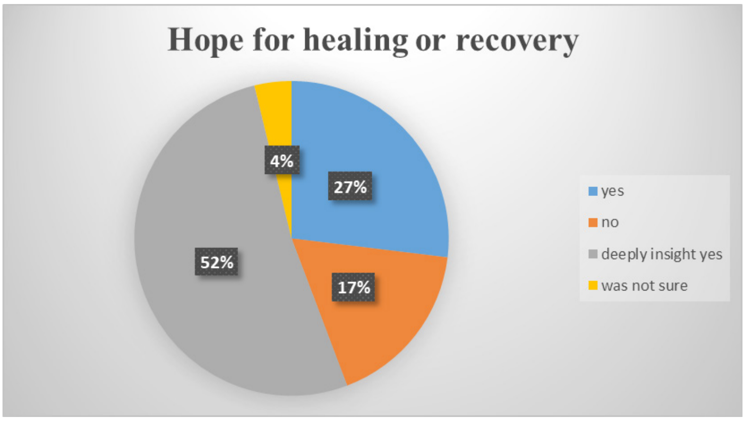

Figure 11. Hope for recovery of their child

After that we focused on the educational solutions and specialists and asked the parents when they started to search for such.

– 24 (46,2%) said that this happened immediately after they heard the diagnosis;
– 12 (23,1%) said that shortly after the child being diagnosed;
– 3 (5,8%) – an year after being diagnosed;
– 3 (5,8%) – more than an year after the child was diagnosed;
– 7 (13,5%) – few years after the diagnosis;
– 3 (5,8%) – when the child turned school age.

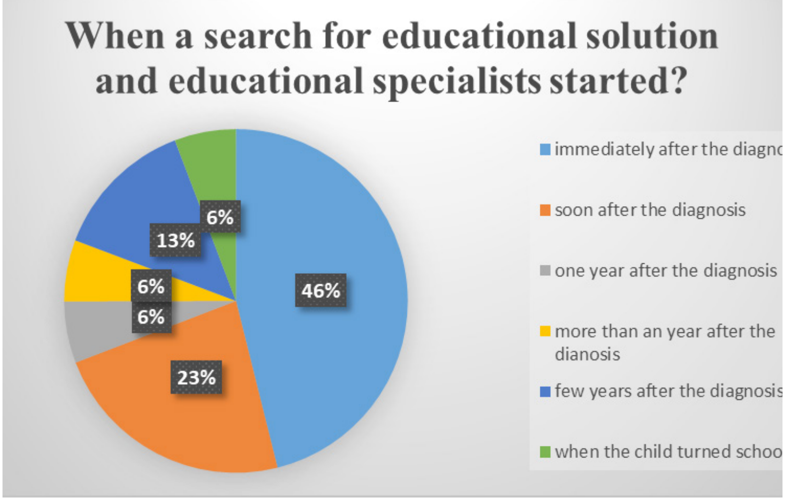

Figure 12. Search for educational solutions and specialists

On the next question in regard who guided the parents in search for educational solutions we got 50 answers. The parents were able to give open-ended answers.

– 11 parents reported that it was them who started to search for proper education and educational specialists;

– 14 said that the medical specialists, especially neurologist, paediatrician and the GP suggested it;

– In 2 cases this was the psychologist;

– In 2 other cases the speech therapist;

– 16 answers were toward the nursery school or kindergarten, which actually shows that the parents placed the child in such setting and this actually does not provide answer to the question how and who guided them to search for kindergarten in first place;

– 3 mothers said that other parents of children with multiple disabilities helped them;

– friends was one of the answers;

– one answer was connected with reading scientific articles.

As some of the mothers had older children with multiple disabilities, we asked them whether they would have done something differently now in the same situation. We got 47 answers and again the answers were open-ended and varied a lot. We will quote here only some of the answers.

– 12 answers were that the parents would not change anything;

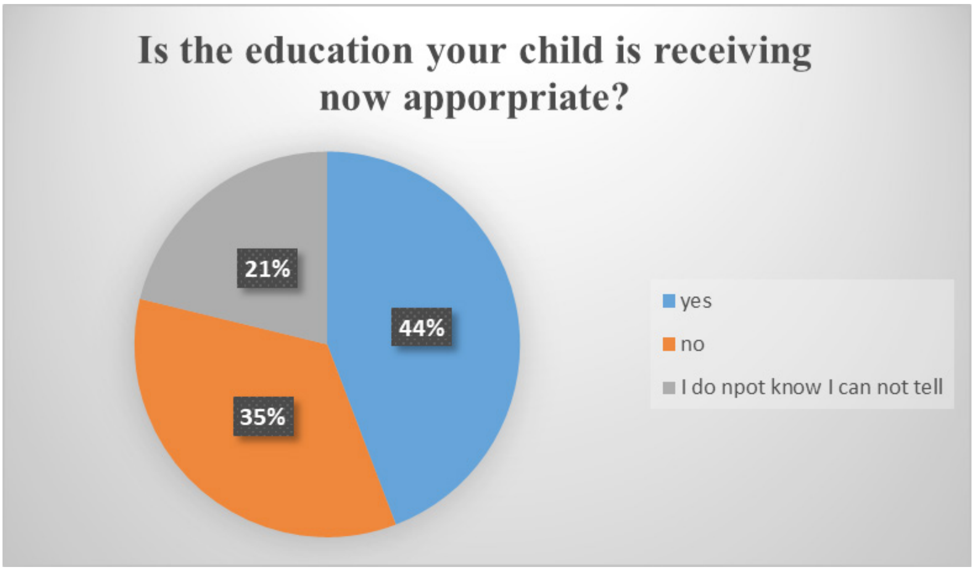

Figure 13. Appropriateness and quality of the education

– 5 said that they would have done things differently. Among them: two mothers said they would have looked for surgeries or help abroad;

– 1 answer was that the question was not appropriate;

– 1 answer was that this is impossible and what was done, was done;

– 1 answer was that the mother would have started educational interventions earlier;

– Few parents replied they did not know.

In regard with the contemporary education options for children and students with multiple disabilities we asked the parents whether they think their child's educational process was appropriate. 23 parents replied positively, 18 – negatively and 11 said they did not know or could not tell.

Those who gave a negative reply to the previous question were asked to share what should be done. We expected 29 answers to this question, but got 35, which means that some of the parents who reported they were satisfied of the educational process of their children, decided to share additional thoughts. Many parents actually pointed out few things to be worked on. Some just confirmed they were satisfied with the education of their children.

Table 2. Need for changes

Better educational materials	Lots shall be changed = 3	The IEPs
Technological solutions, AAC (Alternative & Augmentative communication) = 3	I am satisfied = 5	More and better prepared specialists = 5
Home visits	Everything shall be changed	Special classes in the regular schools
Early acceptance of the situation by the parents will cause early educational start	I do not know = 4	More special educational centres
Information, attitudes, empathy = 3	Vocational training	The methods and strategies of education

We also asked if in the educational process some specific strategies, methods and approaches were used and whether the parents were aware of them. We got 50 answers.

– 31 parents said Yes;

– 11 parents said No;

– 8 parents said they did not know.

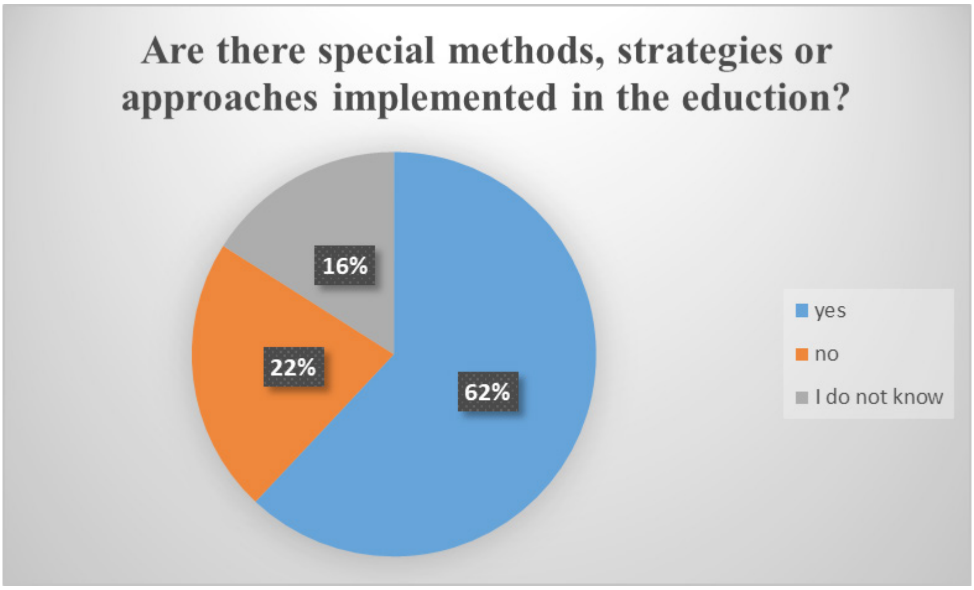

Figure 14. Implementation of special methods, strategies and approaches that parents are aware of

Then we asked what were these methods, strategies and approaches used in the educational process. We got only 36 answers to this open-ended question.

Table 3. Strategies in the educational process

Individual approach and work = 9	Resource support by resource teacher = 9	Additional work with specialists: speech therapist, psychologist = 4
AAC	Activities of daily living, low vision training	More and better prepared specialists = 5
I do not know = 6	PECS	They make flags

The answer about making flags may be accepted somehow as ironical or it can be also the real understanding of the parent as special method.

Then we asked if parents were happy and satisfied with the education of their children and got 49 answers.

– 34 parents replied positively;
– 8 parents gave negative reply;
– 7 parents said they did not know.

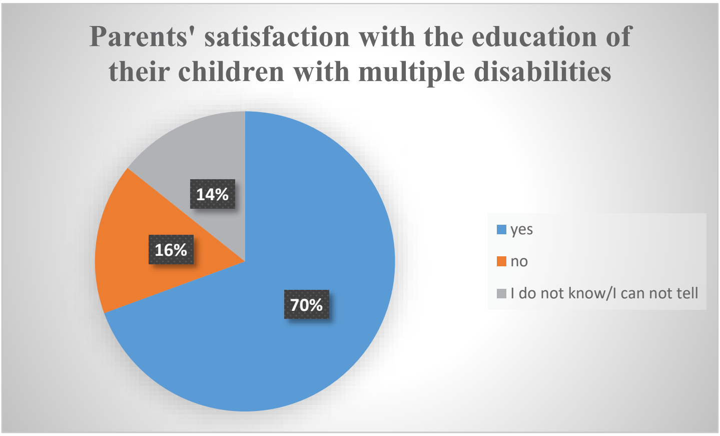

Figure 15. Are parents happy and satisfied with their children's education

The next question focused on how the parents got information and were referred to any education for their children with multiple disabilities. This was an open-ended question, so we got different replies and many parents indicated more than one answer.

– 26 parents reported they found and selected on their own educational options;
– 26 parents searched for information;
– 27 parents were helped by other families with multiply disabled children;
– 11 parents got information from the mass-medias;
– 2 parents went to university and got special education major;
– 2 parents were advised by specialists.

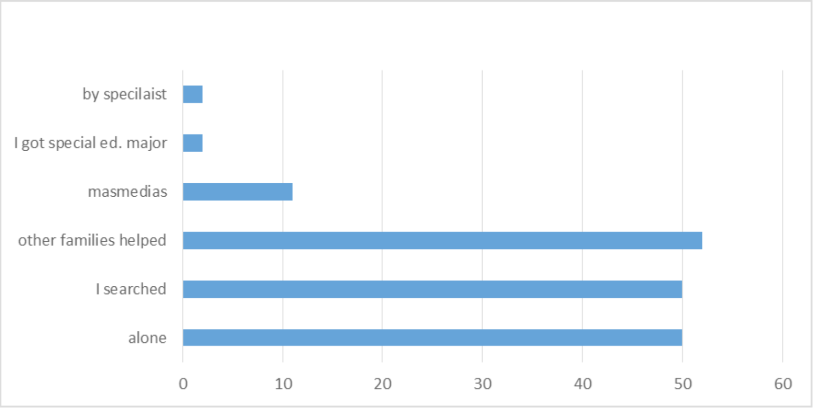

Figure 16. Way of getting information about proper education

Last but not least we asked the mothers to share if they would help and support another family in similar situation.

– 47 parents were ready to provide help and support;
– 3 parents did not know;
– 2 parents were not sure if they could help.

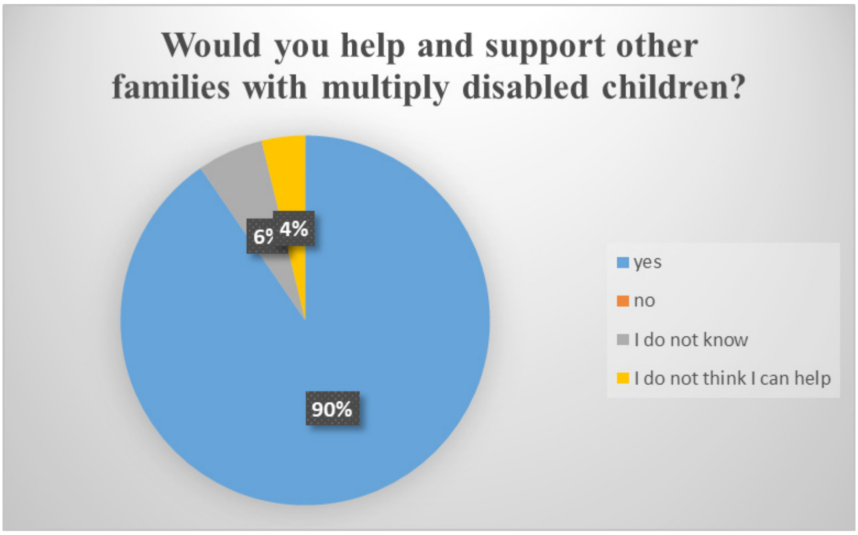

Figure 17. Readiness of parents to support other families with children with multiple disabilities

What are some of the most significant findings and ***conclusions*** from this research?

1. Many families of children with multiple disabilities are not ready, even after years, to talk and discuss freely issues in regard with their child.

2. Most of the parents did go through some or through all of the stages of grief developed by E. Kuebler-Ross.

3. Most of the parents did not receive in-time and adequate support upon the news of having a child with multiple dishabilles. In addition, some shared that they were advised by medical specialists to abandon their child and to leave him/her for adoption.

4. Many parents felt alone and had to struggle in their search for what to be done for their child in terms of education, psychological, emotional, social help and support.

5. Many parents were not fully satisfied with the educational options and placement of their child and believed more can and needs to be done.

6. Many parents did not have enough awareness about the specific methods, strategies and approaches used in the education of their children.

It is always worth and important to ask parents about what they think, about their wishes in regard to their children with multiple disabilities, to know about their feelings, however, it is not easy to do so. We – the special educators, shall do our best to reach the parents as soon as possible after the official diagnosis, to work as closely as possible with them, to offer them different educational solutions and options, which suit the best the individual educational needs of their children, and make parents real and integral part of the evaluation and educational processes. This way a good and smooth contact and later good collaboration between parents and teachers will be built (Koller 2008), based on mutual respect and support, shared expertise, joint decision-making and effective communication (Hornby 2002). All this shall be done in a tactful way, with tolerance, with understanding and with careful listening to the parents.

On the Balkans lots more needs to be done for the parents of children with special educational needs, including those with multiple disabilities and more support should be provided to them. Our cultural peculiarities, traditions, stereotypes and society's awareness are often an obstacle for an easier acceptance of the disability by the family and for an early start of the educational process and interventions.

NOTES

1. Source: https://www.psycom.net/depression.central.grief.htm

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