SUPPORT FOR FAMILIES WITH HEALTHY DISADVANTAGED CHILDREN. ANALYSIS OF THE RESULTS OF QUALITATIVE RESEARCH

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Abstract: The article analyzes the needs of families with children with disabilities through qualitative research based on the focus group method. The results show that these families need customized educational programs, social integration and support in the form of self-help groups. Parents emphasize the importance of special classes and pedagogical teams, as well as the lack of day care centers. These services would help them better manage childcare and attend to their own needs. According to the findings, supporting parents through self-help groups is crucial. The research brings recommendations to improve the quality of life of these families.

Keywords: focus group, families with disadvantaged children, quality of life, support services

1 Introduction

Support services play a key role in the daily lives of families facing the challenges of raising children with disabilities. The paper not only focuses on the current availability and quality of these services, but also identifies gaps that could be filled to improve the quality of life of these families. The research focuses on identifying support services that parents of children with disabilities use, but also on those that they would like to use, but are not available to them for various reasons.

When focusing on families with a disabled child, it is undeniable that this is a specific situation and experience that affects all aspects of the family. Raising and caring for a child with a disability also brings a number of negatives - significant financial and time costs, increased emotional, psychological and physical demands, the search for logistical options, information, financial resources, the search for social support, as well as a sense of understanding and belonging or other necessary help. These negative effects depend on the type and severity of the child's disability, as well as on the physical, emotional and financial resources of the family (Šmidová, Kollárová, Šmid, 2019).

In 2018, as part of the project APVV-15-0189 entitled "Selected factors of a pro-family strategy and support of a stable family in a multicultural environment", quantitative research was carried out, the focus of which was to present the quality of life of families with a child with specific needs, with an indication of possible solutions for assistance to these families in the conditions of the Slovak Republic.

The aim of the quantitative research "Application of counseling in Slovakia within selected helping professions", which was carried out as part of the KEGA project "Distance module of education in the field of pastoral counseling", was to focus on investigating the need and possibility of using counseling in selected helping professions. One of them is the need for the position of counselor when accompanying families with a child with a disability.

It was also important to ask the respondents a projection question regarding whether they would be willing to contact a specialist for guidance if they were to experience a difficult life situation in the future. Other findings focused on the imaging and concretization of various life situations in which the respondents would be willing to contact a specialist for guidance. The results of the research show that they would be most willing to contact a specialist for guidance when experiencing a crisis in their personal life, i.e. in a burden related to a close person. The research dealt with the following questions: How is a child with a severe disability accepted into his/her family? What affects the optimal quality of life of a family if their child has a disability? What needs to be done and how to help such families to use their own possibilities, the capacities of their informal social environment, communities, organizations, public institutions, as well as municipalities so that they not only cope with the given situation, but also prosper despite many problems and challenges? (Šmidová, Žuffa, Nemčíková, 2022). It turns out that counseling at the level of the content of counseling activities can significantly help parents of children with disabilities to manage a wide range of situations and problems that they encounter on a daily basis (Urbančok, 2023).

In order to obtain a more detailed view of the quality of life of families with a child with a disability, a qualitative research was carried out by a group of researchers at the Faculty of Theology of the University of Trnava. This research, conducted in the form of a focus group, provided new insights into the experiences and needs of families with children with disabilities. Focus groups are an effective tool for gathering quality data because they allow for in-depth discussion and exchange of views between participants, resulting in detailed information. It is a group form of interview, an in-depth qualitative interview. Group interaction is used when collecting data (Bačíková, Janovská, 2018). This method provided a space for parents to share their experiences, opinions and suggestions for improving services that are crucial for them and their children.

2 Research focused on supporting families with disabled children

2.1 Research methodology

The main focus and research problem was to find out the needs of families with a disabled child. This research problem is crucial because families with children with disabilities often face specific challenges and needs that require specialized services and supports. The main goal was to identify and understand the needs of families with a child with a disability and thus create effective recommendations for practice. A focus group was chosen as a qualitative research method. This method is a commonly used tool in qualitative research that allows for a deep and nuanced understanding of participants' experiences and perspectives (Barbour, 2007). It is suitable for investigating complex social and health issues, as it enables direct and interactive data collection through discussion between participants.

The preparatory phase of the research process was carried out in the first half of 2024, the actual data collection and subsequent processing of the research results was carried out in June 2024. The focus group was carried out with 11 respondents who were selected on the basis of voluntary registration for an email sent to the organization covering families with children with special needs stemming from their health handicap. This selection ensured that all participants had personal experience of raising a child with a disability, which ensured relevance and a deep understanding of the topics discussed (Kitzinger, 1995). The number of respondents was chosen in such a way as to ensure a sufficient diversity of opinions, but at the same time it enabled an effective and controlled discussion. The participants were both men and women, men (fathers of children with disabilities) – 3, women (mothers of children with disabilities) – 8. It is also necessary to mention the specific type of disadvantage of children. The focus group participants were most often parents of children with moderate intellectual disabilities, Down syndrome, and in two cases of children with combined disabilities (mental disabilities and physical disabilities). The

results of the findings must therefore be perceived in the context of the selected target group's perspective.

Data collection through a focus group was carried out in an informal environment of a recreational type of facility in a neutral space of the common room. The environment in which data collection takes place is important to ensure an open and confidential atmosphere that supports honest discussion (Stewart, Shamdasani, 2014). The participants were informed about the anonymous processing of the research data, which gave them the assurance that their contributions would not be linked to their identity and could thus freely share their thoughts and experiences (Hennink, 2013).

Research objectives

O1: To identify support services used by families with children with disabilities.

O2: To find out which support services for this type of family are missing or insufficiently covered. The goal includes identifying gaps in the current support system.

O3: To determine specific proposals for support services for families with a child with a disability.

O4: The ultimate goal is to contribute to improving the quality of life of families with children with disabilities by identifying and addressing their specific needs and problems.

These research goals aim to provide a comprehensive view of the situation of families with children with disabilities and to propose practical and effective solutions for their support.

The discussion was divided into three main topics, which were also research questions:

RQ1: Which services (social, health) and forms of support are important to you and why? Which services are available to you and do you use them?

RQ2: Which important services and forms of support are you missing?

RQ3: What changes would you like to see in the community in which you live or the local church due to the increase of your support and availability of services?

Each topic was discussed separately, with the group moderator asking questions and encouraging participants to share their experiences. All discussions were recorded and subsequently transcribed for detailed analysis. The chosen research methodology made it possible to gain deep and personal insights into the everyday life of families with children with disabilities and to identify specific areas that need improvement..

2.2 Analysis of research results

Analysis of the first research question: Identification of support services used by families with children with disabilities.
The main goal of this part of the research was to find out what specific needs they have and which support services are used by families with children with disabilities. Based on the results of the focus group, several key support services were identified, which cover several areas from education, to day care, to self-help groups and social integration. A more detailed summary and specification of these areas follows.

Education of children with disabilities is the first important need and perceived area of support. All parents participating in the focus group agreed that school integration (inclusion) is not suitable for the effective education of their children, as they not only need special educational methods, but also a smaller class group, barrier-free spaces, a special pedagogical support team and the same target group of children, such as their child. The participants gave the following explanations of their opinions: "Our son is very happy to be around people from his group, from his circle. He recognizes a child with Down syndrome even in a crowd on the street, in a TV commercial, and at the swimming pool, which I, as an adult, do not notice at all, because not all these children have specific external signs of their handicap. Children with Down syndrome form one family with each other, they may not even know each other, but they know that they belong together. They immediately hug and call each other siblings. For this reason, it is important that they are given special education, which school integration would not allow, or our children would be in a classical education environment more than in the background." Another participant adds: "I agree, our children need their own protective zone where they can be themselves. They need to create their own communities, which is possible within special education." The starting factor in the education of children with disabilities is therefore targeting the needs and possibilities of children with disabilities. For this reason, the participants prefer special education rather than inclusion in a classic school environment.

Social integration and social support are the second important supporting factor for these families. The participants agreed that inclusion in society is crucial for them and their children, not only from the point of view of their children, but also of society. The participant states: "It is important for us that our child is nothing special in society. We want and try to be a part of society, we don't need people to look at us in a strange way. We are people, all of us, our children have something to offer society. They have their disadvantage, but something extra has been given to them. Our children know how to give society more humanity. Through them, we see what is really important." Another participant joined the discussion as follows: "Our children are a source of humanity, they know how to present it very appropriately and put it into practice in society. They don't care if they hug a stranger or even a homeless person on the street. They do not distinguish between people. This is their advantage, and we, healthy people, have a lot to learn from our children".

All participants (parents) agreed that a kind of "protected space", a self-help group, where they can meet freely and thus gain mutual support is important for them. They are happy when they have a systematic framework available to support them as parents as well as children, where the specifics of their handicap and the specifics of stressful situations associated with the given disability are taken into account. The parent states: "It is important for us that we can all meet as we are. Our surroundings, apart from our family, don't understand us, but this is a place where we don't have to fake anything. We complain to each other, we tell each other what's new, what progress our children are making, or what problems are bothering us at the moment." Another parent adds: "It's very important to know each other, to share the same experiences, to be able to support each other. It is such an oasis of humanity where we can confide in other parents. Because the parents of healthy children do not understand us." Here, there is a pronounced need for the systematic creation of support self-help groups for parents who have children with disabilities.

Several parents highlighted the use of daily outpatient care in the environment of day care centers. Those who have the opportunity use the day care center as a place where several times a week their children can spend their time effectively, in a group where they are taken care of and where they can use their talents. In this way, parents are offered time to fulfill their needs. A participant in the group states: "My daughter looks forward to going to the hospital, they make bracelets there, and she happily gives them away afterwards. It is a space for their self-

realization, while we, the parents, can go shopping, can go to the office, and some, who are allowed by their child's condition, also go to work. We put .... (child's name).... in the hospital three times a week for 4 hours, so I can't work. However, I use this time differently and it is efficient for both parties." "I am very thankful that this service is available to us. That way, I can also do my own things, and my daughter is happy in the hospital," adds another participant. Here, the need for self-realization on the part of children and parents is highlighted, which the regular use of the day care center enables them to do.

Analysis of the second research question: Absence of specific support services in the care of a child with a medical handicap.
The aim of this part of the research was to find out which support services are missing or insufficient, and why these services are unavailable or inadequate for families. This includes identifying gaps in the current support system.

Special schools are an important aspect of support for children with disabilities. They provide customized education that takes into account the individual needs of each child. However, parents face challenges associated with these schools, such as large numbers of students and insufficient capacity. Parents often emphasized the need for the availability of special schools and related educational programs that address the specific needs of their children. The main emphasis was on the principle that the pedagogical approach and teaching methods should participate with the interests and possibilities of the children, so that the educational results would be achieved as efficiently as possible. For example, one of the parents stated: "special schools are suitable for our children, later lower secondary education, practical school, but then they stay at home because they have nowhere to go. After graduating from these types of schools, there are no educational programs that would continue to develop our children". Another parent added: "although our children attend compulsory schooling in special education, where they develop. After graduation, however, they remain at home, without further development, which they still need. They can't just sit and watch TV, there is no progress there. They are capable of further development, but for that they need an educational institution, an organization that would develop them comprehensively even after finishing a special school." Another parent states "these children have potential, but it is difficult to find a suitable school. We don't want them to be integrated into mainstream education, they need special education methods, which they get in special education. The problem is that we don't know how to develop this potential after they leave school. It is difficult for them to find their place in the world.'

According to parents, the education system for children with disabilities has serious gaps. There is a need for more practical programs and better specialized teaching that takes into account the individual needs of children. An important insight was provided by a participant who states: "We were not satisfied with the content of studies at a special elementary school. They taught them the alphabet all around, to read, which our son was not able to master. It seemed more beneficial to us to teach him practical skills that would prepare him for life. These skills could be the main content of further educational programs after completing compulsory schooling" This statement points to the problems with the availability and financing of specialized educational programs and the need for effective methods of education.

Parents also perceive shortcomings in day care for children with disabilities. **Day care centers** and **inpatients** are often not available, or they do not have sufficient capacity to cover the demand. In various parts of the discussion, parents repeatedly emphasized the lack of ambulatory social services. These services are necessary so that parents can either work, take care of routine duties, and at the same time ensure that the child spends time effectively. The participant states: "I am lucky that my daughter is placed in a day care center several times a week. This stay helps her and me, she is always happy there. However, I know that there are 7 more applicants on the waiting list for the hospital, but they cannot accept them, as they do not have the

financial means to cover the care of other clients. Also, when we were still looking for day care options for our daughter, I was told at the office that I could put her in a nursing home. They would put her, a 24-year-old lady, in the seniors' home. It would be unimaginable for me or her. We are not interested in this kind of care." Another participant adds: "Our child also attends a day care center. He has a program there. However, I know an adult girl in our village who graduated from practical school and has been at home with her mother ever since. She does nothing but walks on the streets. She has no interest activity. Nothing, only she and her mother, who takes care of her, are surviving." "There is a hole in the system, after they graduate from school we have nowhere to put these children to further develop their potential." The participant concludes the discussion. On the basis of these reported experiences, it is possible to state the lack of outpatient social services (day care centers), which clients with a disadvantage could visit and continue to develop their potential here, and their parents could thus have time for work and hobbies.

Sports and recreational activities (leisure interest activity)
Sports activities provide children with the opportunity for physical activity and socialization, which is important for their overall development. Parents would appreciate that leisure and sports clubs are more accessible for their children with special needs. They agreed that until now they had not encountered optimally created opportunities for the development of their children's talent among intact children in leisure centers or sports fields. The participant states: "It is not possible for our son to attend a football or other sports club, because he needs special guidance methods." Another parent adds: "our son always just started attending some club, he never finished the school year, because there was no staff to was able to attend to him. They only had one lecturer and that was not enough. It's a shame, because he was interested in the club he had chosen, but due to insufficient staffing in the leisure center, it was not possible to keep him there." Here are identified shortcomings in the area of adapting the activities of leisure centers also for applicants with a disadvantage.

Acceptance of a disabled child in society
Parents declare the importance of integration and acceptance of their children in society, with the recommendation that they should have the possibility of social interaction and be accepted in the community. One parent expressed: "It is important that our children are accepted, integrated, which can also be very beneficial for other people." Parents expressed the need for better integration into the community and better support from social services. One of the parents mentioned: "You need to have your own community where you can feel free, but you also need to go out a little so that people can have that experience, after the experience with our children they will perceive our situation differently. They get to know them" Another parent claims: "The way people look at my son when we walk down the street is not always just nice. I would like to change that. He is a human after all. But I also understand those people. It also always freaked me out when I saw a person on the wheelchair on the street. But our son shattered my ideas about disability and changed me completely. I thank him.' Another participant opens a new topic in this area, regarding the unprofessional approach to their children at the labor, social affairs and family offices or other institutions. Social workers often do not know how to communicate with this type of client: "...they lack both expertise and humanity. Social workers often meet similarly disabled people only in the practice of their profession, not during their studies, which is very much felt and seen. And how can society accept us when even the social workers themselves don't know us?" Similar statements point to the need for inclusive social activities and services, the need for acceptance and tolerance by the entire society.

Support groups and counseling
Support groups and counseling for parents are essential for coping with stress and sharing experiences. Parents also appreciated the services of social workers: "We have good experience with social workers who work with us in the civic

association, we have space for regular support group activity there." "We cannot praise the civic association enough, it would be good if there were more of these organizations so that they would be available to all parents with children like ours. We can get a lot out of these informal meetings." Another parent adds that both parents and children need counselling: "they also need further development on several levels and this is where there is room for professionals to attend to them in the field of occupational therapy to learn more practical skills." This type of service and guidance is sorely lacking here." These support services represent the basic infrastructure that enables families with children with disabilities to meet their needs and support their development. At the same time, their parents marked them as insufficiently covered.

These areas represent key challenges faced by families with children with disabilities. Parents emphasized that improving and expanding these services would significantly improve the quality of life for their children and entire families.

Analysis of the third research question: Specific proposals for support services for families with children with disabilities.
During the focus group, parents of children with disabilities discussed specific proposals that could improve the quality of life of their children and families. These proposals include improving existing services, expanding educational programs, introducing new therapy and support services, and strengthening community support. A more detailed summary and specification of these proposals follows.

Parents emphasized the need to **improve and expand existing services such as day care centers and special schools**. For example, they suggested increasing the capacity of day care centers and improving the quality of care: "The fact that I can place my daughter three times a week for 4 hours in a day care center, I am thankful for that. However, we could imagine that she would be there for more hours every day of the week." Another participant states: "In the day care center, even if she is there, not all the therapists work with them in the same way. Only when a specific person is on duty he does work with them, the others don't do so much..." Several participants expressed the opinion that not all professionals they meet in social services are able to respond in the right way to the demands of children/clients and their approach is also not always at a professional level.

Parents pointed to the need to introduce practical educational programs that would enable children to learn practical skills and be better prepared for life: "but it must be said that our child does not need to be taught to read, write, count, he simply will not use it in life. In school and aftercare, they should focus on the development of practical life skills from the first grade."

Parents expressed the need for better support and **acceptance from the community and the church**. They would suggest more inclusive activities and the creation of a space where they could meet and share their experiences without prejudice: "I would be happy if they accepted our children in the church, at least a little bit... because not everyone accepts that my child sometimes disturbs during St. mass. He sings loudly or simply dances at the holy mass and the eyes of the people around... they don't understand, they ask if he does it on purpose and why he does not prefer to sit at home". Non-acceptance of a child's disability is crucial for parents and is not often present in the community.

These proposals represent concrete measures that could significantly improve the quality of life of children with disabilities and their families, ensure better integration into society and support their overall development.

2.3 Discussion and recommendations for practice

The discussion of the results clearly indicates that families with children with disabilities face several challenges that affect not only education, but also social integration and access to support

services. Based on these findings, it is possible to formulate recommendations for practice that could improve the quality of life of these families and make the provision of necessary services more efficient.

In the field of education, according to the respondents, it is clear that the current model of inclusive education does not suit all children with disabilities, especially those who carry mental or combined disabilities. Parents clearly point to the need for smaller classes, adapted learning aids and environments that would reflect their specific needs. Therefore, it is important for the current education system to rethink its approach and focus on improving the availability of special schools with individual adapted educational programs. The concepts of "inclusion for all" and "inclusion for some" are also analyzed by the authors Leien, Arcidiancono and Bauca (2021), who summarized various aspects of the school integration of disadvantaged children as well as the reality when it is more effective for a child to be educated in special education. At the same time, it is necessary to expand practical educational programs in schools that would enable children to acquire skills that can be used in everyday life. Such programs should mainly focus on the development of manual, communication and social skills (Hvalby, Guldbrandsen, Fandrem, 2024).

Another critical point is increasing the capacity of day care centers and other social outpatient services. Day care centers provide clients (including respondents' children) with disabilities not only a space for socialization and self-realization, but also a relief for parents who, thanks to these services, can devote time to work or personal activities. Therefore, it is necessary to expand the network of these facilities throughout Slovakia and ensure their sufficient funding so they can receive a larger number of recipients. In addition, it is necessary to improve the quality of care in these facilities, which could be achieved by regularly evaluating the quality of the services provided and emphasizing an individual approach to the needs of clients (Neda, Angel, 2023).

Another key issue is the support of parents through self-help groups. Parents of children with disabilities they often experience social isolation and emotional exhaustion. Self-help groups for parents of children with disabilities provide important emotional and practical support to help them cope with everyday challenges. These groups create a space for sharing experiences between parents facing similar situations, reducing feelings of isolation and stress. Research shows that parents who are members of such groups often experience an improvement in their emotional well-being, an increase in their sense of self-confidence and competence in caring for their child. These groups can be expert-led or function as peer-to-peer support where more experienced parents share their experiences with new members (Jackson, et all, 2018). It is therefore necessary to establish several regional support groups that would provide space for regular meetings of parents. These groups should be organized in cooperation with social workers and experts who could also provide professional advice and psychological support. At the same time, it is important to support civil associations that deal with this issue so that they can expand their activities and provide even more effective help to families (Dew et all, 2019).

In the field of social integration, it is important to ensure that children with disabilities have equal opportunities to participate in sports and leisure activities. Such activities not only contribute to their physical and social development, but also to their better integration into the wider society (Geidne, Jerlinder, 2016). To improve this area, it would be appropriate to create inclusive sports and interest clubs that would be adapted to the needs of children with disabilities. At the same time, it is important to improve public awareness of the challenges faced by families with children with disabilities. Better information and education of the public could reduce the level of stigmatization and misunderstanding, which would contribute to greater acceptance of these children in society (Hepperlen et all, 2021).

Social workers play a key role in supporting families with children with disabilities. However, it is clear from the results that not everyone is sufficiently prepared to work with these families. Therefore, it is necessary to strengthen the education and professional training of social workers, especially with a focus on the specifics of caring for children with disabilities and effective communication with their families. The introduction of mandatory training for social service workers could help develop empathy, communication skills and the ability to provide psychological support to families (Bennett, Harvey, 2019).

3 Conclusion

By implementing these recommendations, significant progress can be made in improving the quality of life of families with children with disabilities. Emphasis on specialized education, expanding the capacity of support services and supporting parents are key steps that should be a priority of current social policy.

The basis of this study is a better understanding of the problems faced by these families and the search for solutions that could improve their quality of life. By expanding the understanding of these problems and their context, we can not only identify current shortcomings in support services, but also propose concrete steps that could lead to their improvement. This approach is particularly important in social policy and practice, where it is necessary to constantly adapt to the changing needs and circumstances of families with disabled children.

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