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Parenting a child with special educational needs - challenges, barriers, problems

**Być rodzicem dziecka ze specjalnymi potrzebami edukacyjnymi
– wyzwania, bariery, problemy**

Abstract: This work addresses the psychosocial situation of persons raising children with special educational needs. The study it describes involved thirty parents or legal guardians of children with the Down's syndrome, Asperger's syndrome, autism spectrum disorder, and after traumatic events. Learning the narrative of a deliberately selected group of respondents was made possible by the adopted strategy of qualitative interviews. A partially guided individual interview was chosen as the method of data collection. The analysis of conversations with parents indicated difficult and highly challenging social relationships, lack of sufficient support from the environment, and severe stress resulting from burdens related to duties. The conversations presented in this manuscript show many difficulties stemming from social isolation and high costs of children's therapy. Difficulties with adaptation in the group and fears of misunderstanding were identified as the main reasons of inactivity in certain areas of life. The stress experienced by the parents raises a sense of anxiety or frustration.

Keywords: parents of children with special educational needs, social relations, difficulties in functioning, support.

Introduction

A significant part of the human existence entails the support of another human being. A sense of community experienced by every person is inherent to having a specific support group from family, friends, and acquaintances (Kawula, 2002). Social support includes emotional support (support by listening and providing comfort and safety), belonging to a social community, being valued, informational support (practical help as well as information and guidance), and financial assistance (Drageset, 2021).

The sense of community rooting, the bonds with other members of our families or friends protect against the sense of alienation, thereby reinforcing mental immunity. Interactions and relationships with other people make the support, or rather the conversation itself, an autotelic (intrinsic) value (Kawula, 2002).

Unfortunately, although we declare ourselves an open society, ready and willing to help, there are groups of persons who feel lonely, frustrated, and grappling with multiple crises resulting from functioning in a difficult reality. Many social groups are stuck in uncomfortable situations stemming from, e.g., reasons completely beyond of their control. One of the reasons behind this problem can be seen in the phenomenon of the disadvantage, which

can be understood in many respects. It is not necessarily tantamount to concepts such as social exclusion, social marginalization or discrimination, because people may be disadvantaged by the very fact that they come from these environments. In the psychological and pedagogical context, social disadvantage refers to persons who have found themselves in disadvantageous circumstances, which can be understood in many respects. On the one hand, these circumstances may result from the functioning of a particular family and its origin; but on the other hand, they may be linked to a broader range of socio-cultural transformations. For this reason, the socially disadvantaged environments are very often understood as, among others, families at risk of marginalization or social exclusion as well as socially excluded families, including those facing difficulties with the upbringing of their children, namely the miseducational ones (Kasprzak, 2017, p. 185).

This work addresses the psychosocial situation of persons raising children with special educational needs.

Being the caregiver of such a child requires providing continuous care, concentration, sometimes a lot of patience and, above all, great mental

resilience. Fatigue due to the repeatability of certain behaviors often underlies impotence, helplessness and loss of faith in the possibility of finding any solution. What, then, gives strength to those social groups that experience a series of many harms and difficulties in coping with everyday challenges?

“An attempt to explain the phenomenon of good functioning of the individual, despite unfavorable life conditions or traumatic events” is analyzed by Anna Borucka (2011, p.11).

According to Magdalena Boczkowska – “in a broad sense, the concept of resilience concerns the adaptive capabilities of individuals, families or entire communities in the face of experienced adversity” (Boczkowska, 2019, p. 125).

The resilience of an individual depends on the resilience of interconnected systems. Today, resilience can be broadly defined as “the ability of a system to successfully adapt to disturbances.” This definition may refer to the key integration of concepts and knowledge about human resilience in different disciplines and levels of analysis. Typical protective factors include effective care and other supportive relationships, problem-solving and self-regulation skills, self-efficacy, optimism, and the belief that life makes sense (Masten, 2019, pp. 101-102).

Resilience refers to the ability of a dynamic system to effectively adapt to disturbances that threaten the viability, functioning, or development of that system. This kind of definition makes it easier to think and collaborate with people who are trying to prepare populations to deal with disasters. We want to build this kind of adaptability (Southwick, Bonanno, Masten, Panten-Brick and Yehuda, 2014).

The research was diagnostic in nature. Their aim was to describe the experiences of parents raising children with special educational needs¹(Participants included children with Asperger’s Syndrome, Down’s Syndrome, on the autism spectrum and traumatic injuries). All parents and two legal guardians of the children involved in the project were invited to participate in the interviews.²The majority of the interviewees were not economically active (in the case of women), between 30 and 60 years of age, residing in

¹ The research sample was made up of parents of children who had been qualified for the project by school principals on the basis of an opinion from a psychological-educational counselling centre (disability symbol consistent with the disability certificate, demonstrated dysfunction, health difficulty in the child consistent with the disability symbol).

² The participants were 30 children and their parents, two of whom were legal guardians. Mostly women (mothers) were willing to participate in the interview, with the exception of two men (fathers) who volunteered to be interviewed together.

the Warmińsko-Mazurskie Voivodeship.³The interviewees had higher and secondary education. The results of the research in the form of interviews with parents were conducted at the turn of January and March 2024. The duration of the interviews ranged from 30 to 130 minutes depending on the interviewee.

The research problem statement took the form of the following questions:

1. What is the nature of social relationships?
2. What kind of support do parents expect?
3. What kind of social difficulties do the respondents experience?

The adopted interview strategy enabled gathering stories and experiences of a deliberately selected group of parents. A partially guided individual interview was chosen as the method of data collection. During the interview, parents were allowed to speak freely and were listened carefully, making sure to obtain answers to the topic of interest to the researcher. The qualitative interview enables getting to know the world seen through the prism of the experiences of the surveyed, describing his/hers actions or views (Kvale, 2010).

“Statements are not a simple representation of the world. They are part of the world they describe” (Hammersley and Atkinson 2000). The need to understand reality becomes essential (Silvermann, 2009). Conversations with parents make us become a kind of traveler looking for new knowledge that can lead to new ways of understanding the world (Kvale, 2010), which is particularly important for parents of children with special educational needs.

The questions asked by the researcher were the same, also focusing on specific issues so that cognition could identify the problem.

The material collected during the interviews was transcribed and then subjected to thematic coding.

³ Research carried out as part of the project “Development and implementation of R&D works and innovative service in the Spectrum Possibilities Center consisting in providing comprehensive support and mental well-being for children with disabilities and dysfunctions in the area of inland waters of the Wulpińskie Lake”, financed from Norwegian funds.

Nature of social relations

Fossilized social norms still valid in our society and a lack of certain flexibility in the perception of reality can significantly impede the functioning of some social groups, including parents of children with special educational needs.

The surveyed group appeared to encounter multiple challenges in their social relations, including social isolation, relations with family and teachers, and finally stigmatization.

Based on the experience of parents, it may be concluded that most children were severely blocked during contacts with others. Sometimes this could be affected by the way peers treated them at school (during interviews, the parents recalled situations when children were offended because of their disability, appearance or behavior). The pursuit of strengthening the interpersonal relations of children with others was one of the main initiatives that parents declared when participating in the project (as mentioned above).

Some conversations also emphasized that children would like to have their friends, someone close among their peers, with whom they could feel liked and accepted.

He was in a few schools and he always had a problem with this adaptation, I didn't really know why. What's going on? (...) His dream is to have such a friend, and there has been no such person so far. (Antek's Parent).

According to their parents, the children who participated in the study loved spending time with their closest family members, usually the parents of the child's mother. Animals played an important role in the lives of children as well. They loved to spend time with cats, horses, chickens and, above all, dogs (even though they caused some kind of fear or anxiety in some children).

One of the significant elements of conversations with children's caregivers was also their behavior in the family and home environment. Through the organization of various activities and daily natural integration with the child, the parents were able to notice a range of diverse behaviors, which often became an element of anxiety. The women surveyed (mothers of the children) recalled attacks of self-aggression, attacks of unjustified anger or other unpredictable behaviors. The statements presented below appear to be symptomatic:

At school he is quiet, cool as a cucumber, small-talking, while at home he is so active, he simply relaxes at home. He shows his emotions, he is more aggressive, he is nervous; even though there is peace and quiet in the house, he is nervous. (...) some attacks of self-aggression do happen. (Max's Parent).

Aggression not toward himself but toward us, toward our family. Fortunately, he is not aggressive towards colleagues, but only towards me and his grandmother, to mother and grandmother immediately when he returns from school, so probably to his closest people. (Karol's Parent).

The parents repeatedly emphasized the high degree of vulnerability of their children. The atmosphere at home and at school was of particular importance for the children's later behavior.

He is like a sponge and I will always emphasize this - my son is like a sponge, he absorbs as much negative emotions as positive ones, if something negative happens at school, we will immediately feel it (Tobiasz's Parent).

He is such a barometer of affection, if it is loud in a positive sense, he reacts to it in the same way, but if I start from, for example, I don't know? Or if I'm experiencing something more loudly? Or when I start to doubt in a negative sense, well, then he is already walking around and I feel that he is nervous then, but in general he is a cheerful child. He also doesn't like being closed and now he's a bit annoyed at the moment (Janek's Parent).

There were many factors that promoted aggressive behaviors. The most often indicated ones included having a different opinion on a given issue, performing a task that was not always to the child's liking, a new environment, losing an unimportant object, and a change in the daily rhythm.

At home, when he does not know something or loses something, he says that he is stupid (...) and sometimes he hit himself in the head (Michał's Parent).

He has all sorts of schematic behaviors, something that must be done as it should be, when it does not come that way - he may be irritated, he may be anxious, but there will be no aggression on his part. There must be a specific scheme, (...), sometimes it is enough to explain something well to him and he will not have a problem with it (Krzyś's Parent).

It is worth adding that there were single voices among parents indicating the element of the desire to isolate the child after returning, for example, from school. The respondents would like to show support, participate fully in the process of growing up, provide advice and guidance, and this is sometimes very difficult due to the attitude of their offspring.

He would rather lock himself in a room and just lay there. After returning from school, he does not want to talk to anyone, he is tired and closed, he does not talk about it at all and the worst thing is that he does not talk about anything (Olek's Parent).

It is worth paying attention to one more topic that was emphasized during the interviews. Several of the surveyed parents mentioned a negative approach from the educational institution that the children attended.

The statement presented below seems noteworthy in this respect:

For having bitten the teacher, we had trials in court and the judge simply said he would give us a curator. We are in the process of appealing all this in court because we disagree with all that, because the child has Asperger's syndrome. This teacher has been working with us since the second grade, so he knows the child, he knows what the behaviors are, and he is supposed to be a supportive teacher yes? (...) he complained to me that my child does not want to talk, does not want help from a supportive teacher, but, I am not surprised of this fact because my child received punishment from this teacher instead of help (Janek's Parent).

The lack of the expected response from the school, the parent's unawareness of certain aspects of the child's existence at school caused grief, contributing to deeper frustration and sometimes anger.

The teachers did not react as they should, because if I had known about it, about this situation – I would strengthen him at home, (...) they tried to deal with it at school and it is not always possible, (...) he just walked so sad, and did not want to go there, I learned from one of his classmates that such situations do happen. (...) I felt sorry that he didn't tell me about it, because if I had known, I would have just strengthened him at home (Tobiasz's Parent).

Social stigma resulting from the disability of children affected their relationships with others. Building an image of a given individual based on appearance or behavior caused a sense of injustice among the respondents.

They watched my child, everywhere - in the shop, in the playground, at celebrations and whispered. They whispered so that I could feel their look at me. Whether the fact that he was shouting, looked different, was different a little bit perhaps... must make him rejected, make us not accepted. Are our kids the only ones that drop the goods off the shelves? Or are they the only ones who lie down on the ground? "I asked why, then, you do not know but you judge? (Michał's Parent).

An important topic of the conversations in terms of physiological factors was the reactions of the children related to their behavior. The surveyed parents were asked about compulsive behaviors, slowed reactions or hyperactivity. The everyday experiences of parents indicated that the most common type of this form of behavior was hyperactivity, including both motor hyperactivity and excessive impulsivity. Interviewees actively involved in the process of education most often pointed to difficulties with staying

in one place, pointless hiding of objects (car keys, phones, etc.), increased impatience, unintentional breaking of given objects or waving hands.

Support

Parents, struggling with many problems on a daily basis, often left to deal with everything on their own, strongly look for various forms of help and support. The interviews revealed two groups of respondents; the first one benefiting from a number of sources of specialist assistance in both the public and private sectors, and the second one benefiting from the support provided by the school. In addition to the help of psychologists and psychiatrists, the parents emphasized a meaningful role of neurologists, although - at the same time - they pointed to a high level of indifference and lack of involvement shown by the latter group. The conversations also emphasized frequent consultations with specialists outside the voivodeship.

In addition to individual occupational therapies, extra-paid classes included hippotherapy, dog therapy and other forms of classes focused mainly on motor skills.

Thus, the analysis of conversations with parents revealed a strong need for help and support.

No influence on the course of the disease and the lack of sufficient knowledge on how to deal with the child increased the sense of uncertainty among parents.

Sometimes I reach the limit of my endurance because I don't know how to talk to her sometimes? How to approach her, and then this form of screaming appears, and I must admit that then I am able to raise my voice at her and shout at her. I say, child, calm down, I'm already fed up with this, I can't cope this. I don't intend to hide it, because at the moment I have a problem with understanding not only myself, but also Nina in all this, because my whole life, I mean maybe not my entire life but most of our life is focused around Nina and supporting her in education, in emotional development (Nina's Parent).

Leaving with children having special educational needs and various degrees of disability poses a challenge for many parents. Although the so-called "giving up" attitude was sometimes noticed in their conversations, their desire to fight, seek help and believe in a better life for their children was prevailing.

In their statements, parents often emphasized the need for help not only for children, but above all for themselves.

I would probably be most interested in such techniques, although of course everything has been discussed before, but I believe that such techniques for dealing with specific situations are never enough (Michał's Parent).

well, definitely such support in terms of everyday behavior, coping and so on (Amelia's Parent).

We need support and tools to deal with his emotions, because for many years we treated Olgierd as a child with a disability, so we demanded less from him. We demanded a lot from the older son (Janek) and we came to such a wall where we have a lot of duties, Janek has a lot of duties and Olgierd has no duties at all (Olgierd's Parent).

First, a mother must learn how to deal with a child and then try how much will the child allow to implement? So, it's hard to expect a great "wow" effect, that someone will tell me something, I'll use it, and it will be great (Olek's Parent).

I would expect, for example, more communication with the child, yes, and in general, but for example, for him to talk more to other people, be more open. This is what I would expect, respect for others, for us, for others - especially for older people (Max's Parent).

Difficulties in functioning

The basic everyday experiences of children, depending on the type of disability, including the degree of damage to a selected organ, as well as depending on age and gender, cause various difficulties and even impairments in many areas of life. According to the parents, the list of disturbing symptoms related to mental factors in children is long. In the conversations, the main emphasis was put on fears resulting from fear of the dark, separation from parents (even a short separation was a symptom of severe anxiety), fear of strange people, changing the rhythm of the day, and introducing something new.

When it comes to dogs, he was terribly afraid of dogs, while he had never been afraid of anything in his life, maybe it's not because he was left somewhere alone with a dog, it's rather a result of these integration disorders, because he said that he didn't want to be with the dog. He will lick me (...), I see that he doesn't like it very much, but over the past year or so he has warmed up to dogs. There is no problem again, no problem at all now, but there were phobias, fears in fact in the past. When there is a toilet with a light switched on/off by the sensor, he is terrified that it will go off, and to this day it is the case that the door must be open. At home, he locks himself from the inside, but somewhere outside, at someone's place, the door must be left open. I have to stand in the

doorway and make sure the light doesn't go off. These are fears that have still remained (Karol's Parent).

There are, for example, situations when he is afraid to ask something and, for example, he is asked why? I say, this is normal to ask. You could have asked. But then he says: no, because I was afraid. But he could not provide the reason why he had been afraid (Michał's Parent).

We have noticed that he is more afraid of the dark. We don't have any idea where it came from yet? Perhaps there is such a stage, in general, I have the impression that it is a bit about separation anxiety, that it is there somewhere. He spends a lot of time with his parents, and this causes him to be afraid when his parents are not there. When he's at school, there's no problem, but at home, when he doesn't see us, when he doesn't hear mom or dad, the fear appears. (...) we have a two-story house, so when he is downstairs and I am upstairs, he will still call mom! (Kacper's Parent).

During the talks, there were also issues related to the fear of death or leaving the child.

He's afraid of death, and he's been talking about it openly for some time, (...) first it was the fear of death, then it was that we wanted to die

He has a phobia of me coming on time, and he's also afraid that I won't pick him up, that he'll go to the orphanage (Maks's Parent).

The surveyed parents emphasized many times the fear of their children triggered by high intensity of sound - it could be the crying of a child, the flight, loud music, screams, etc.

In the parents' narratives, the way their children functioned was highly influenced by the problems related to concentration of attention.

Parents' statements were overloaded with this issue. Parents participating in the survey indicated a particular lack of concentration when doing homework, no response to messages, the ability to focus on one activity only, and losing many things.

Two mothers also mentioned the lack of concentration caused by the scent of the therapist's perfume, too intense lighting and the presence of other typical distractions.

Perfumes bother him, for example when the therapists use perfumes, or I don't know, he is bothered with fluorescent lights, dogs or something that might distract him (Olgierd's Parent).

It is worth emphasizing that, according to my interlocutors, children were able to concentrate on activities that gave them joy or aroused any interest. Most often, these were the media, mainly mobile phones, the Internet and television. Technology, paradoxically, gives children enormous

opportunities for concentration and comfort. Submerging in the Internet space allowed children to fully focus and concentrate.

Parents also noticed a significant element facilitating concentration related to their favorite form of play. These could be activities related to motoring, animals, old clocks or even Lego bricks.

(...) he loves motoring. He has been a fan of excavators and tractors since he was a child and he has remained the fan to this day. (...) He loves watching because his favorite thing, if someone asked him what he likes to do the most? is scrolling the tablet, as he would say. For him, scrolling the tablet means watching videos on YouTube, his favorites, including feeding swans, ducks, motoring in every respect. (...) races, not races, that type of thing (Olek's Parent).

She can set up an entire old stable, yes, her horses, various compartments, and she can sit there for half a day and play with it. She spends a lot of time arranging, she also has her collection of beads, which she also arranges. She gets distracted during doing homework, she basically has to have a clean desk, a pen and nothing else. All the distractions are hidden and then she does her homework well (Nina's Parent).

One of the key issues during conversations with the parents was the question whether they felt discriminated in any way. (however; the question - are you experiencing any unpleasant situations? - was deliberately used here to avoid words with a strong emotional message).

Only a few parents indicated the absence of such situations and even recalled help from their immediate surroundings. Most of the narratives, however, were based on the statement that they experienced such situations repeatedly, not only from strangers, but also from among their closest relatives.

it was very difficult, there was no support - as I would expect. Some of the family seemed to be supportive, but unfortunately some of the family was not. My husband's family, so to speak, was not supportive. As if my family was always supporting me, but today, having already been in therapy for two years for a different reason, it was as if I came to therapy not for this reason, but it also gave me support in this sphere, so I think that since I have also been participating in the workshops conducted by Mateusz and Ania at school, simply (...no problem, there are probably still a lot of emotions associated with it, but today I can talk about it, I know what it is all about and I can also deal with it (Kuba's Parent).

For me, for example, I have a lot of difficulty talking about it, because that's how I feel. Sometimes people ask, well, how is it when my older son goes here and there, and even though he is 13 he still goes to the fifth grade,

there is an immediate question (...), so I try not to say that I have a child, because in the past I was saying I had a disabled child, then they said you cannot call it disabled anymore, but a child with disability. So, I started to say I had a child with disability. (...), today I say I have a child with special educational needs.

At the beginning, when I was going to the children's hospital, I was somehow irritated, even by people who stood and looked at us, that's all (Tobiasz's Parent).

The interviews also revealed parents who, despite comments from people around them (in a store, on a train, on the playground), tried to ignore these comments, respond with a smile to the commenters, or reply in a way that made the person feel embarrassed.

I'm a person who doesn't really care about what others think, and I had to work on that too, but I don't care. Well, I'm so lucky that the kid doesn't die, because we just watched these children die in hospitals, so I'm happy that it's just autism. You can live with that. I once had a situation when I was about to pick up balloons at the store and there was a lady with a small child, I understand her too, because she had a small child sleeping, and of course I went to pick up the balloons, they had been ordered. And Mikołaj was crying there, he was screaming so loudly, and that was the only time she reprimanded me (Krzyś's Parent).

The respondents often emphasized that even though they frequently felt sorry and offended by the behavior of certain social groups and lack of understanding, meetings with others also provided them with positive elements of emotional support.

Although, as they admitted during the conversations, they felt the greatest comfort in the circle of friends who had experienced similar circumstances.

Conclusions

The psychosocial situation of parents of children with special educational needs is influenced by various aspects determined by individual parameters. These were social relationships, difficulties in functioning, and support factors.

The analysis of interviews with the parents indicated difficult social relationships and many challenges.

The conversations presented in the manuscript show many difficulties that parents struggle with in social functioning. The social isolation becomes an overriding element in addition to the stress associated with care, burdens

related to responsibilities, lack of support, and high costs associated with children's attendance in therapies. Difficulties with adaptation in the group and fears of misunderstanding were identified as the main reasons of inactivity in certain areas of life. The stress experienced by the parents raises a sense of anxiety or frustration.

They also see some incompetence expressed by the lack of support from formal institutions (educational, health care) as well as from family, friends and sometimes even spouses.

Indifference to sadness or pain, perhaps fear of the unknown (lack of knowledge about a given disease) makes people react inappropriately. Not all of us are equally empathetic and compassionate, which may not be in line with the expectations of parents of sick children. Reminding (reprimanding) someone makes us feel better, perhaps it increases our self-esteem while hurting others. The respondents, left in a situation resulting from the lack of prospects for the future, with financial burdens, difficulties in understanding the diagnoses made and huge emotional burdens, continue to fight for a better future for their children.

Unconditional love and patience allow parents to face many challenges. A change in the circle of friends, lack of understanding from others, difficult relationships with teachers or stigmatization, although often overwhelming for parents, cannot destroy their mental resilience, which is often put to the test. The resurgent concept of resilience may prompt future research projects aimed at finding answers to the question - what methods can be deployed to make future social groups struggling with similar problems resilient?

Due to the qualitative nature of the research and the deliberate selection of the sample, which does not allow for generalization of the research results, they present the unique experiences of the parent invited to the research. The threads taken up in the article deserve further exploration, in the course which it is also worth developing elements of the psychological well-being of the surveyed parents and the search for forms of support.

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