

**Dorota Otapowicz**

Uniwersytet w Białymstoku

ORCID: 0000-0002-8036-1273

Child raising: the perspective of mothers of children with autism spectrum disorders

Parenting a child affected by a disorder with vast consequences for functioning such as autism undoubtedly modifies the family's situation and broadens the scope and essence of parents' responsibility. Daily experiences connected with facing new, previously unknown, problems are not an easy challenge. On the other hand, they constantly enrich mothers' awareness related to parenting. The aim of the research was to learn the significant problems, feelings, opinions and reflections arising from the experiences of mothers of children with autism spectrum disorders. The research material was collected through free-form interviews with 20 mothers raising autistic children. The analysis of the collected empirical material shows that mothers construct various concepts of parenting, including their own roles and everyday relations with the children. Their early reactions reveal the collapse of the previous vision of parenting and the loss of the real perspective concerning the perception of the child and their own role in child raising. Everyday parenting experiences – full of unique difficulties with building relationships with the children – allow the mothers to constructively seek individual solutions and patterns of coexistence.

Keywords: motherhood, autism, child raising

Wychowywanie dziecka: perspektywa matek dzieci z zaburzeniami ze spektrum autyzmu

Wychowanie dziecka dotkniętego zaburzeniem o ogromnych konsekwencjach dla funkcjonowania, jakim jest autyzm, niewątpliwie modyfikuje sytuację rodziny oraz poszerza zakres i istotę odpowiedzialności rodziców. Codzienne doświadczenia związane z przewyciężaniem nowych, nieznanych wcześniej problemów nie są łatwym wyzwaniem. Z drugiej strony stale wzbogacają świadomość matek związaną z rodzicielstwem. Celem badań było poznanie istotnych problemów, odczuć, opinii i refleksji wynikających z doświadczeń matek dzieci

z zaburzeniami ze spektrum autyzmu. Materiał badawczy został zebrany poprzez swobodne wywiady z 20 matkami wychowującymi dzieci z autyzmem. Analiza zebranego materiału empirycznego pokazuje, że matki konstruują różne koncepcje rodzicielstwa, w tym własne role i codzienne relacje z dziećmi. Ich wczesne reakcje ujawniają załamanie dotychczasowej wizji rodzicielstwa i utratę rzeczywistej perspektywy postrzegania dziecka i jego własnej roli w wychowaniu dziecka. Codzienne doświadczenia rodzicielskie – pełne wyjątkowych trudności w budowaniu relacji z dziećmi – pozwalają matkom na konstruktywne poszukiwanie indywidualnych rozwiązań i wzorców współżycia.

Słowa kluczowe: macierzyństwo, autyzm, wychowanie dzieci

Introduction

Parenting a child affected by a disorder with vast consequences for functioning such as autism undoubtedly modifies the family's situation and broadens the scope and essence of parents' responsibility. As pointed out by Ewa Pisula (2012, p. 8), abnormalities in development of an autistic child are the source of great emotional (and often also physical) burden for the parents, connected with the need to face many responsibilities unknown to caregivers of children who develop normally.

Parents are naturally responsible for raising the child, for their development, satisfying their needs and preparing them to living independently. Usually, the main burden of raising the child is on the mother.

Parents' distress resulting from raising an autistic child

Parents, especially mothers, caring for autistic children suffer considerable stress, which is much greater than that experienced by parents of children with other developmental disorders (Pisula & Noińska, 2011, p. 53).

In the concept by Antonina Gurycka, parents' distress resulting from child raising occurs when the planned goals cannot be achieved. The author defines such a situation as the parents' internal sense of having to deal with educational difficulties (Gurycka, 1990). They can approach these difficulties in different ways. Even the statement that the child is problematic reveals the unsatisfactory relationship between the parent and the child, as well as the impossibility to modify the child's behaviors (Szymańska & Aranowska, 2016, p. 21). Clinical descriptions of autism promote the image of a child whose atypical behaviors and reactions are a serious educational and therapeutic problem. In the situation of the

lack of sufficient knowledge of the causes and possible treatments of the disorder the very diagnosis of autism definitely causes anxiety and expectation of educational difficulties. Autism is also socially perceived as a particularly troublesome and incomprehensible disorder, causing fear and the sense of being incompetent to help people who suffer from it. In some parents, it results in negative thinking about the child's future and the possibility to carry out parenting responsibilities, as well as the feelings of helplessness and confusion (Pawluk-Skrzypek & Olszewska, 2015, p. 156). In this concept, even the beliefs concerning autism may pose a problem based on the assumptions that parents' interventions as part of their parenting process will be ineffective.

If the child's undesirable behaviors do not change as a result of the interventions, parents tend to attribute their educational failures to external factors, often to the child themselves, considering them to be the person with the dominant influence on the relationship. Consequently, the sense of lower parenting influence leads to increased aggression toward the child and lower sense of parental competence, and thus, to the negative image of the child. Being unable to achieve the educational objective, parents experience distress, which may result in the formation of a negative representation of the child (Szymańska & Aranowska, 2016, p. 156). Even early symptoms of autism in the form of preference for solitude, ignoring and lack of interest in physical contact with the mother or ostentatiously pushing her away are hard to accept for mothers (Winczura, 2019, p. 219). Parents especially worry about problems with establishing communication with the child, which are connected with disorders in the sphere of verbal and non-verbal communication. The messages sent by the child are unclear and hard to understand, and the messages sent by the mother are ignored and ineffective. Establishing a relationship with the child is difficult both due to the significant delay in speech development and to considerable problems with understanding what is expected of them (Pisula, 2005, p. 132). In addition, due to repeated behaviors and the need of routine, they are highly attached to rituals and observing a fixed schedule and ways of doing things. Schematic functioning is also reflected in atypical interests. Their range is very restricted and they are extremely intense and absorbing (Pisula, 2010, p. 54).

The above-mentioned characteristics of children with autism mean that parents need to accept a great challenge to establish contact with the child, participate in their socialization, development of basic skills, and overcoming behaviors that make their everyday functioning difficult. Negative experiences and parents' stress are combined with positive experiences connected with care for the child. One important fact is the very perception of parenting experiences, because positive attitudes may serve as a coping strategy and contribute to reducing distress connected with the child's developmental disorders (Pisula & Noińska, 2011, p. 78).

As pointed out by Pisula (2005, p. 132), it is also important for parents to be good observers of their children. Then, they can see the significant symptoms of autism but they do not perceive their children as the source of problems, trying to interpret and explain them and making a distinction between the disorder and the child. This way, it is not the child that is considered the cause of parents' failures but the disorders resulting from autism, with which they are not always able to deal effectively.

Still another way of explaining educational difficulties experienced by parents assumes that the difficulty results from parents' expectations concerning the course of educational interaction. A parent who expects difficulties behaves in a way that actually evokes the child's reactions which confirm those expectations. This pattern repeats until the parent develops the representation of a problematic child (Szymańska & Aranowska, 2016, p. 22). Undoubtedly, mothers of children with autism, not having any ready patterns of behavior regarding their children, try various methods and ways of communicating with them, resorting to more or less constructive educational interventions. However, the effects of educational interventions are not immediate, and in the case of autistic children, they may even seem beyond reach.

In accordance with the theory of parents' emotional adaptation to the child's disease, the achievement of emotional stabilization and constructive adaptation to the child's disability is preceded by the phase of shock followed by emotional crisis and superficial adaptation. This process may be more or less turbulent. The intensity of parents' feelings may also vary. However, the achievement of the ability to cope with problems in mental and practical terms is significant both for the parents' and the child's benefit (Szafrńska, 2015, p. 38).

Traditional and contemporary approaches to disability and child raising

The traditional model of parenting was based on carrying out the plan determined by the caregiver, who openly showed the child what to do and expected them to imitate their actions and meet their requirements. Their task was to introduce the child into the world of culture, ensure the conditions for learning necessary models of behavior, some social roles and functions, and develop in them the proper traits and moral beliefs (Smetański, 2011, p. 179). Therefore, expectations of the mothers of autistic children included the kind of parenting that would make the children learn the patterns of behavior displayed by neurotypical children. If the child failed to meet the expectations typical of their age, the mother was blamed for that, because she was fully responsible for the child's

life, development, health, intelligence, behavior etc. (Titkow, Duch-Krzystoszek & Budrowska, 2004, p. 26).

This attitude corresponds to the medical model of disability and approach to supporting the child's development, focused on their deficits and disorders. The child was attributed the role of the patient, and the mother had to accept the fact that the child would never get better "on their own" and needed professional assistance. The aim of assistance activities should be the desired changes in their individual characteristics (Twardowski, 2018, pp. 99–101). Parents were the continuers of the therapy introduced by specialists (Twardowski, 2012, p. 9).

Currently, the essence of education as a factor of personality development is perceived differently: the main task is not to direct the process of its formation but to promote and help develop it. The first task of the caregiver is to establish contact with the child based on mutual respect, trust and love. Then, they should get into the child's internal world, determine their needs and abilities, find out their capabilities, understand the current interests and motivations, and learn what life problems worry the child (Smetański, 2011, p. 181).

The optimum educational environment promotes the development of the child's faith in their power and the sense of subjectivity, i.e., the feeling that they have an influence on what happens around them and the conviction that others take their opinions into consideration. This kind of education can be called subjective, open to the child's needs, at the same time preparing them to independently satisfy their personal needs and respect the social norms and regulations (Brzezińska, 2009, pp. 40–43).

Nowadays, the approach to disability issues has also changed. The idea of normalization is a kind of guide setting the proper humanistic direction for all who are present in the life of a person with disability (Głodkowska, 2014, p. 101). First of all, it stresses the need to unconditionally respect the dignity of all humans, including children with disabilities, display respect and ensure the proper conditions for maximally normal life. We no longer want to concentrate on limitations in the child's development; instead, we want to reinforce their strong points and ensure support for their personal development. A lot of importance is attached to the child's relations with their family members as the foundation of the bond conditioning the course of the child's later social relations. Subjective treatment of the child is regarded as both the objective and a way of specialist intervention. In the subjective situation, the child in a way is expected to engage in self-rehabilitation as much as possible. People present in their environment observe, listen and react to important signals sent by the child that reveal their needs, expectations, worries or anxieties. This allows the child to experience their own agency, independence and autonomy (Głodkowska, 2017, p. 46).

The challenges accepted by the mother of an autistic child are analogous to the challenges faced by a young child, because just like the child, the woman is learning something completely new, even if she has prepared to the role of a mother before. First, the mother learns to accept her role and establishes a close relationship with the child. Success in these two tasks allows her further growth, until the woman becomes a mature mother (Mađry, 2012, p. 10). Carrying out the role of a mother of an autistic child is a difficult task. The woman's life changes dramatically and the parenting activities do not always provide sufficient satisfaction. However, different studies show that many mothers can see some positive changes in themselves: the child teaches them empathy, tolerance, understanding and patience, increasing their resources of love and humility (Park, 2003, p. 47).

Research assumptions

The object of research prepared on the basis of the qualitative strategy was the experiences of women as persons finding themselves in the situation of facing unexpected, difficult challenges connected with raising autistic children. The goal of the research was to learn the difficulties connected with raising autistic children from the perspective of their mothers' experiences and subjective feelings and reflections. The following study questions were formulated:

How does the oddity of the autistic child's development change the perspective of raising the child?

How do mothers construct their own vision of raising children with autism?

The research material was collected through free-form interviews with 20 mothers raising autistic children. Each mother had many years of experience, because their children were 8 to 22 years old and were diagnosed with autism spectrum disorders. The interviewed mothers were between 31 and 51 years old.

Perceiving the child in the light of their autism and the tragedy of parenting

When confronted with their children being diagnosed with autism, mothers usually do not have the reliable knowledge or experience connected with the developmental disorder they are facing. Actually, most interviewed mothers did not have any knowledge or experiences related to with autism. Autism was only an obscure term, a label given to their children. Those who had some ideas of autism admitted that they were very general and unclear. Even the women who had previous experiences connected with the presence of autistic children in their fam-

ilies or some knowledge acquires as part of pedagogical studies felt completely unprepared to this kind of motherhood in practical terms. The child's behaviors were incomprehensible, seemed to be beyond control, causing fear and the sense of helplessness. Not knowing the nature of the child's disorders and the methods of raising the child, just like anything that is unknown and considered a threat, causes a lot of distress.

In the community there is a widespread perception of disability arising from the individual (medical) paradigm, concentrated on the biological / medical dimension. From such a perspective, disability is considered as an individual (psychosomatic) problem, understood merely as individual limitation of physical, sensory or mental abilities (Barnes & Mecer, 2008). Therefore, limitations resulting from the diagnosis of autism come to the fore, and as a result, the child is treated as unable to do things healthy children do. All this is important, because the socially shared ideas of autism significantly influence the children's behaviors and differences in development that mothers notice after their children are diagnosed with autism spectrum disorders.

The interviewed mothers' utterances reveal that as a result of the diagnosis, all their ideas concerning the upbringing of their children are related to developmental disorders and typical symptoms of autism and a permanent, unchangeable condition.

Autism is the starting point for evaluating the possibility of raising the child (*Autism is a barrier in raising the kid*). Generalizations, by definition arising from the symptoms attributed to autism, also include a generalized image of ideas with a wide spectrum of educational difficulties (*Autism means avoiding social contacts, withdrawal from the social life, and the lack of establishing satisfactory emotional relationships. All this causes huge problems with raising the child*). This perspective clearly contributes to anxiety, fear of the future, and first of all, causes the sense of self-doubt and lack of faith in one's motherly intuition and disinterested love (*Autism is distorted general development, lack of speech, lack of love and attachment to me as the mother. The child wants to love me but cannot, and I'm not sure if I'm able to raise the child*).

The mother develops the image of the child as devoid of feelings, affection and the ability to express them, and unable to establish a relationship with their mother. All that each mother desires the most, i.e., the expression of love and affection, seems to be completely beyond reach. The child's attachment is important for the mother because it is a bilateral relationship from which both the child and the adult derive the sense of security and greater self-confidence as a result of the closeness and accessibility of the person they are attached to. Hence, the belief in inability to establish close relationships with the child creates the image

of an inaccessible child, which deprives them of self-confidence related to the possibility of performing her parenting tasks.

Mothers' despair is strengthened by perceiving autism as an incurable disease involving the child's lifelong suffering (*I was devastated, I cried a lot. I was afraid my child was ill and would never get well*).

Thus, the task of raising a child with autism means continuous struggle with their disorders. Mothers' descriptions of problems with raising the child are full of remarks about the disorder's symptoms (*I'm often distressed by his lack of emotional attachment to me. I feel he doesn't love me, because he doesn't express any positive feelings toward me. He also has difficulty speaking, so I don't understand what he wants from me*).

The mothers suffer from the sense of incompetence, confusion, anxiety and helplessness, or even doubt the natural bond between a mother and a child. It is so because they can see a number of problems they need to cope with although they lack the necessary preparation, knowledge and experience (*I often don't know what my daughter means. Her eyes are full of tears, and yet I can't help her. This helplessness is horrible*).

Mothers' belief in unavoidable difficulties connected with raising the child mostly results from their own ideas on autism. The analysis of the collected material shows that autism is perceived as a disorder that determines the child's development, omnipresent, permeating all spheres of their development. What is especially important is the fact they develop conviction of their own incompetence to deal with the child, and any models of education they have had so far seem to be inadequate and useless. The dominant belief is that raising an autistic child means educational difficulties they will not be able to cope with.

Stereotypes functioning in the community and parents' insufficient knowledge on how to deal to the child may lead to their reduced self-esteem and prevent them from effective coping with difficult circumstances, emotions and stress (Twardowski, 2018, p. 101).

They feel guilty because they cannot change the child's behavior, do not know how to help them, and simply because they have children with autism. The multi-factor etiology of autism allows to seek the alleged factors which might have led to its development (*I analyzed whether my diet was proper during the pregnancy, whether I didn't take any dangerous drugs, whether there was no oxygen deficiency during the delivery and whether similar disorders had not been found in the family before*).

They think about the period of pregnancy, trying to decide what they did, what they neglected, and what they did wrong (*I thought I didn't care about myself properly, I went to a wrong doctor, I didn't take the necessary supplements. / I was in my fourth year of university course when my daughter was born. I didn't take*

enough care when I was pregnant, I would attend all classes and go to the swimming pool, so I strained myself).

The perspective of raising an autistic child appears as a punishment they deserve, a tragic event affecting the entire family. *(I thought it was the worst that could have happened. My world collapsed. I felt a huge sense of injustice; I wondered why it happened to my family).*

It was hard to accept the fact that the child would develop differently. *(Before I accepted the thought that my child was ill, I experienced a number of extreme emotions, from grief, the sense of being harmed, fear and anxiety, through a kind of internal peace, up to complete fading of negative emotions. I'm still angry with my lot, but I no longer feel that generalized anger).*

In face of autism disorders, the traditional concept of parenting based on exerting influence on the child and forming their character and mind appears an impossible and infeasible task. The child's behaviors seem particularly difficult, beyond the mother's control, regardless of what she tries to do and how she reacts to them. *(I was devastated with my child's behavior and helpless, because I couldn't control and help him. It was especially difficult for me, because I didn't have any experience with raising children. He is my first child).* Therefore, they have the sense of incompetence and lack of parenting experience. *(I couldn't do anything. He didn't understand what I was telling him and wasn't listening to me. I could only protect him so that he would not harm himself).*

Thus, mothers face the infeasibility of tasks connected with changing the child's traits and the burden of social expectations attributed to mothers. This situation causes parents' serious stress as a result of impossibility to plan and achieve educational goals due to the child's characteristics dominated by a wide spectrum of limitations resulting from autism. The tragedy of parenting is that all previous assumptions, ideas or models that mothers have in mind cannot be used with reference to the child. Not having any concept of how to raise their children, mothers feel helpless, powerless and lost. Many of them, as their utterances prove, are in deep despair combined with the sense of failure to fulfil their role regarding the children.

Therapy in raising children with autism

The first direction of activity, also of the mothers who did not react in such an emotional way, was to ensure the child the proper assistance in the form of specialist therapy *(I knew I had to be strong so as to help my child. Immediately I started to act and looked for the best institution to help mu son).* The basic impulse activating the mothers' energy resources is the faith in the therapy improving the

child's functioning thanks to specialist assistance they need to provide them. The hope that arises in relation to therapeutic opportunities is the first and fundamental turn from despair to action. They are even happy that they can start acting for the good of their own children (*In the beginning, I was resentful, but then I believed the situation could improve. I felt the desire to act. I accepted the challenge, and smiled*).

Driven by the pursuit of helping their children improve, they accept many sacrifices and changes in the lives of the whole families. Ensuring the child the opportunity of treatment is the highest priority, the most important need they can see (*We've had to prioritize our needs with regard to the need to treat our child. We have to settle the fees on time at the expense of buying our clothes, replacing the car or other, more mundane things. In other words, we need to reduce the expenses as much as possible, to basic needs only, and pleasures, such going to the movies or the theater, are something we can't afford at all*).

If the institutions were not located in the parents' neighborhood and daily commuting was difficult and tiresome, some of them even decided to move to another place.

Finally, mothers are engrossed in everyday tasks, the most important of which are ones connected with ensuring the child the opportunity to take part in the therapy. (*Driving my son to the center and back, participation in sessions, home therapy, and housework: all that is my job*).

However, above all, they count on changing the child's behavior and improving communication with them (*I could even sell the house, I would give away anything, only to ensure my son starts speaking and behave like a normal child*).

In the initial period of child's development, therapy is a specific fight against autism, the most important part of which is the pursuit of the expected changes in the child's behavior, development, and following normally developing peers. It definitely creates the opportunity to help the child in a constructive way, giving the sense of fulfilling the parental role properly, and first of all, hope for some effects.

Therapy and mothers' engagement in it allows to gradually change the previous tragic approach to the disorder and the vision of hopelessness of the situation, get rid of the burden of guilt and concentration on their own powerlessness (*I felt guilty that I went to work when my son was one year old. I blamed myself with being a bad mother. When I learnt what autism is, I stopped blaming myself and I focused on helping the kid. At the same time, as I saw his progress, I helped myself*). Noticing the opportunity to support the child's development leads to creating energy resources, giving the mothers the strength and energy to act as well as strong faith in the possibility to ensure the child the opportunity to grow and gradually overcome the existing limitations (*In the beginning, I was resentful, but*

then I believed the situation could improve. I felt the desire to act. I accepted the challenge, and smiled).

Therapy seems to be the only way to help the child. The mother's role is reduced to ensuring the opportunity to take part in therapy, continuing it at home, and applying therapists' recommendations in daily activities regarding the child. The directive approach, still dominant in therapy offered to children with autism, naturally penetrates everyday relationships, in which the child is the object of interventions, manipulations, and fulfilling others' expectations and instructions. It is no wonder, then, that directiveness and failure to take into consideration the child's expectations are present in this parenting style.

The mothers' utterances reveal that the period of the child's early development is burdensome in physical and mental terms (*When the problems with the child stabilized, life became easier. The situation was the most difficult in the first four years of his life*). As a result of considerable burden with responsibilities and difficult behaviors of the child, emotional tension is constantly present and has a negative impact on relationships with the child. In some cases, there is a real danger of development of incorrect relationships between the mother and the child, even mutual hostility or hatred. One mother even describes her own behavior regarding the child in a drastic way (*When my daughter was younger, I was fighting with her, venting my frustrations on her. Six a.m., I go to work, 4 p.m., I go back. As I collect my daughter from the kindergarten, I hear again what she did wrong, on the way she jerks, runs away, bites me. At home, I have to do everything and she goes on, although I beg her, cry or yell. She was very intelligent, and she used her intelligence against us. I was completely exhausted, depressed, I hated my child. She was expelled from one kindergarten after another, I couldn't go anywhere with her. She evoked my aggression, I often couldn't compose my emotions. I would jerk and slap my daughter*).

She considered her child as the main cause of her problems and problems at the kindergarten. As she currently admits, she was fighting with her own child, failing to notice the child's perspective, not even trying to understand what was going on with her. The child was also fighting for herself as much as she was able to, which consequently led to constant aggression, violence, creating the perspective of mutual hostility and hatred. Both the mother and the child cried for help, not being able to solve the situation. Currently, the mother blames her family for not reacting when she was harming her own child, for letting her do so (*I feel regret that my husband and friends didn't prevent me from reacting this way*).

In mothers' perspectives connected with parenting autistic children there are memories referring to particularly difficult and burdensome responsibilities in the children's early development period. Most descriptions include negative emotional experiences, overburden with responsibilities, and pursuits of ensur-

ing the children therapeutic assistance. Education seems to be absent, replaced by mothers' struggle with the critical situation, in which the therapy is an important element of constructive coping with the sense of parenting helplessness, or even complete failure of the previous education concept. Undoubtedly, this is a critical situation and we can identify some stages of mothers' coping with the situation. Mothers' utterances mostly include descriptions focused on their own emotions and experienced difficulties combined with joy resulting from the possibility to act, i.e., engaging in therapy.

Mothers engage in a specific fight with autism, as well as with the child, which is still present, though more or less conscious. Full and absolute acceptance of autism and distinguishing it from the child seems unrealistic, and in reality, there is still objection and disagreement to the fact that the child is functioning differently and hope that autism will be overcome one day (*I will never accept it that my daughter will always suffer from autism. I will always want to help my daughter. I hope, maybe not for full recovery, but for a new drug or method that will allow my daughter to progress*). Despite the passing time and a number of changes in the child's life and functioning, hope and readiness to start treatment is still there. Although it is impossible now, faith in the advancement of medicine motivates constant readiness to look for modern therapeutic possibilities.

It also seems that it is mothers' fight for their own lives, for their previous plans, ambitions and hopes, which are not only shaken but often need to change dramatically, as sometimes previous pursuits and personal accomplishments are cancelled. Thus, no wonder adopting the role of a mother of an autistic child does not come naturally but requires time and turbulent emotions so that one can mature to the new reality and the role, and emotional instability may even occur in further stages (*So sometimes I'm angry and fearful, and sometimes I'm happy that I succeeded in doing something. An emotional swing. I guess most mothers feel the same*).

Maturing to the role of a mother of an autistic child and a change in the approach to parenting

All mothers point out that while parenting autistic children an important change takes place in their approach to the child, to their own lives, values and pursuits. Before they accept challenges connected with raising children whose development is marked with autism, mothers need to mature to it. Growing to the role they are attributed is a slow process, but in the initial phase, it does not always go smoothly. Sometimes it is preceded by a period of disagreement, rejection, panic, and sometimes even fight for oneself. Emotions are articulated more or

less openly and cannot be ignored. As proved by the mothers' utterances, the maturing process is slow, but finally they calm down and accept what they get, their test in motherhood. It is important that the tasks they carry out, though different from ones done by all mothers, are considered as necessary, significant and valuable, and as a result, the mothers may feel the satisfaction from doing them well. (*My emotions evolved as I did. First I was angry, furious with the tragic lot, then I slowly matured to the role of the mother of an autistic child, and finally, I decided there was no point despairing, that I needed to approach anything that befalls us as a life test, a challenge to accept, and then I felt the joy of doing a task well*). It boosts optimism and the desire to carry them out, and thus, to assume the new role and feel the satisfaction from succeeding in it. The fundamental issue in fulfilling the role of the mothers is the emotional bond between the mother and the child. It is the basis of the unique role and its importance in the family micro system. As pointed out by Lucyna Bakiera and Żaneta Stelter (2010, p. 135), a woman becomes a mother not by having a child but by establishing close emotional and physical relationships with them.

The basic condition is the turning towards the child and understanding their perspective of the experienced situation. As mentioned by one mother, the fundamental turning point was becoming aware of the need to stop fighting with the child and noticing the need to fight for the child (*My friends made me aware that I should fight for my daughter, not against her, when she told me how cruel the kids at the kindergarten were and how they treated her. I learnt to cope with my aggression, I matured to calm reactions. I stopped working. All my time was for my daughter, I began to understand her and have a good relationship with her. When she was in elementary school, I was already completely on her side, and if someone doesn't know how to deal with her, now I tell them to go and educate themselves*). So they become reflective and critically evaluate their own role and behavior, which is the basis for adopting a different perspective of perceiving the child's needs.

In the adopted educational approach to the child, the key thing is the value of the child as a person who has their own needs, preferences, as well as weaknesses and limitations. Then, the fundamental direction of mothers' pursuits is care for ensuring the child the sense of security and the opportunity to grow in a friendly and understanding environment. An important element of such an educational role is protecting the child from any threats, improper actions that may threaten their development, and first of all, harm the child. The mother also becomes the child's spokesman and protector of their rights. She expects specialists to display professionalism based on understanding the child's needs and ability to communicate with them.

Another important element is their attitude to autism as a quality that does not need to be changed and removed. Instead, we need to learn how to establish

everyday educational relationships with the child, how to understand them and how to teach them to understand others, finally, how to establish the rules of living together, how to make their life together meaningful and valuable. As one mother points out, they need to learn how to live with autism (*Now I know autism is not the end of life. You need to learn how to live with it*). Thus, the thing is not to superficially accept the fact that autism exists and we will not remove it; the thing is to find a way to tame it and skilfully respect it in daily life. The crucial thing in the adopted vision of raising an autistic child the pursuit of personal development of the child with moderate and real expectations concerning their autonomous functioning and preparation to adulthood (*I would like to raise by child so that he would be a good and relatively independent person*).

Another educational direction is the functional approach, the most important in which is care for the development of the child's autonomy (*I'd like my child to be as autonomous as possible. Although I know it can't be fully achieved, I try to work on all I'm able to do*). This is connected with the need to accept the fact that the child functions differently, the existing limitations, a realistic change (often limiting or reducing) of the requirements and expectations in favor of developing whatever is possible and feasible. As the mothers indicate, accepting the occurrence of disorders in the child's development is necessary to stop fighting with autism and focus on what is significant and needed in raising the child (*I quickly came to terms with the diagnosis. The sooner you accept the situation, the easier it is to mobilize and ensure the child whatever they need. / I accepted it; it's pointless to fight with what is unchangeable anyway*).

The situation presented by one mother is a good example of noticing the value and importance of the personal vision in raising the child in daily work on the development of functional skills (*One day, I asked my daughter to make a decision, to choose one of two things. She was looking at me bluntly and I pushed her to tell me. At the time, she didn't speak yet. Suddenly, I unconsciously held her head and repeated: 'Tell me what you want.' I only understood what was going on when I saw tears in her eyes*). With reference to time, mothers' reflections are often reduced to the fact that excessive determination to work on the development of the child's skills may easily lead to force and objectivization.

In raising autistic children we can identify various experiences of mothers, being individual ways of learning motherhood. Undoubtedly, for mothers raising children with autism the children are considered as an unusual challenge, which transforms the women, teaching them humility, patience, understanding and love (*I regard autism as something that teaches me humility, patience, understanding and love. I think this disorder is a unique challenge given for a purpose*).

Specificity of raising an autistic child from mothers' perspective

The specificity of raising a child with autism is related to individual preferences of the child, and the child reacts strongly if they are not respected.

Therefore, mothers must take part in their children's daily rituals so as not to provoke them to undesirable behaviors which consequently occur in response to disturbing the constant routine expected by the children (*My daughter stuffs her mouth with food, because she wants to be the first or she doesn't eat if she can see that someone else has already finished eating. When persuaded and requested, she continues eating, but she cries and gets irritated*). Mothers try to persuade or force a change in the children's behavior, but unfortunately, they have to give in (*We try to fight with her refusal to eat. We tell her that if she doesn't eat what we give her, she will not get anything else, but as a result, she can go on an empty stomach for many hours*).

Finally, the mothers do not grumble or do any radical actions but simply accept the children's requirements as their own way of daily coexistence.

Sadly, there are also situations that cannot be predicted or avoided. Then, it is the mothers who must accept negative emotions, in a way becoming their addressees (*A guy came to exchange radiator knobs. All the situation, a stranger coming, commotion and change, made my son unhappy. As long as the worker was present, he tried to keep calm and composed, but once he left, he vented his anger*). In fact, any circumstance that may take place and disturb the expected harmony may be the reason to demonstrate the child's irritation (*When the computer breaks down and we cannot start it, which means that my son's order and sense of security are disturbed, he throws a tantrum: he falls on the floor, screams, stamps his feet and bites himself*). Children with autism often resort to behaviors that are hard trials for the mothers as regards restraining their own emotions, patience and understanding (*Sometimes words can harm more than actions. Sometimes I hear my son throwing insults at me that he wouldn't tell anyone else*). As the closest person, the mother becomes the target of anger, working as the comforter.

The oversensitivity to stimuli displayed by some children means that their presence causes negative reactions and fear. Ordinary activities, such as brushing hair or cutting nails, may become a nightmare. The kid cries, runs away, tears loose.

Therefore, the mothers try to prepare their children and gradually introduce them into new situations, slowly helping them get used to new stimuli. This is the basic condition for introducing the child into the community and ensuring he or she will function in it safely.

All this is just an outline of problems faced by the parents because of their children's specific preferences.

A difficult task is to encourage the child to broaden the repertoire of their activities, try new kinds of play, observe regulations or keep agreements. This is why many mothers use systems of reinforcement, not only in the case of little children but also in the case of older ones (*My daughters have a game: I give them pluses and minuses for keeping cleanliness and order in their rooms and behaving well. If they get a minus, I remove a plus*). Trying to change the children's undesirable behaviors, they refer to various negative reinforcements (isolation, ignoring the child, withholding something pleasant). Especially at the moments of tantrum or escalation of anger, the mothers do everything to isolate the child (in the case of little children, sometimes simply take them away) until he or she gets calmer.

At times, the mothers cannot control their own emotions and resort to slapping the child, which ultimately is a punishment for the mother herself (*I know this is wrong, later I apologize to my son. I feel guilty. He was crying, and I was too*).

However, first of all, the mothers try to talk to their children as much as possible, explain different situations, so as to avoid misunderstandings and misinterpretations (*I try to talk a lot to my kid. I know if someone talk to him first about something, he will absorb it and it will be impossible to change it*).

Although the children grow, many everyday activities must be supervised, controlled, and sometimes done together with the child (*If I just told her to take any item from the wardrobe and that thing were a jumper, she would put it on, even though it were summer*).

The mothers accompany their children in difficult moments, offer assistance, fulfil their expectations and follow the routines and individual preferences. Sometimes they feel dominated and devoid of their autonomy (*I can't talk on the phone longer than a moment, I can't have a friend visit me, it's good that I can breathe*). Determining and observing the boundaries of each person's autonomy is sometimes difficult but important and necessary.

Mothers cannot always see the reciprocity of feelings, affection and love on the part of their children. They doubt whether and to what extent the symptoms they see testify to feelings and to what extent they are only a learnt schematic activity (*My son tells me 'I love you, I like you', but I don't know if it means he really loves me or only says it because he know it's a nice thing to say, because he's seen it in a movie. When I cry, he comes to give me a kiss and dry my tears. I don't know if this is because he knows I suffer or because he feels there's something wrong*).

However, many mothers stress that their children are improving in noticing their mothers' emotions and responding to them (*I can see he has not only learnt to see my feelings but even empathize with me: he's worried when I cry, he cares when I'm angry, he protects me when he thinks someone is trying to harm me. But the child needs to learn how to express empathy. As for strangers, sometimes he misinterprets their emotions*).

Some mothers do not expect their children to display love or affection towards themselves. They don't need proofs in the form of traditional gestures or words. They can find them in each pleasant moment spent together (*The very fact my daughter is a joyful kid proves that she feels good with us and loves us. She doesn't need to do or say anything. We can see and sense that she loves us*). It seems this is the best way to derive satisfaction from doing the task well.

Conclusion

To assume the role of the mother of a child with diagnosed autism spectrum disorders, the woman needs to revise her ideas, beliefs and expectations connected with parenting. In the face of autism, mothers may feel all educational measures are ineffective and pointless. They are greatly determined to fight for their children in order to remove the disorders and regain the prospect of success in raising the child. Specialist measures and methods are the main instrument in fighting and overcoming the experienced difficulties and an element of the new vision of raising an autistic child they construct. They want to accept autism and the oddity of the child's behaviors, they introduce a new order into everyday relationships and customs, learning how to be understanding, patient, and sacrifice their own good for the benefit of others. However, while expecting changes in the children's behavior and evaluating their role and educational success from that perspective, they can only see insufficiencies, constant uncertainty and the lack of trust in the child and in themselves.

Adopting the child's perspective and noticing their needs independent of the disorders the child has offers the mothers a much more optimistic vision of parenting and their own role with regard to the child. They begin to see and understand the child's frustrations and anxieties, pursuits, determination and perseverance, the joy arising from being together, and they learn to interpret the signs of trust, affection and love. They develop sensitivity, acceptance for differences, satisfaction from the child's joy and properly fulfilled role as mothers. It is not autism but the child that becomes the basic point of reference and constructing a personal vision of bringing them up.

In the concept of supporting mothers in fulfilling their roles regarding children with autism it is important to construct the educational concept based on all children's needs, not on different, specific, "autistic" needs.

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