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Motherhood on the spectrum

Macierzyństwo w spektrum

Abstract

The author has attempted to present a very specific aspect of parenting an autistic child, namely being an autistic mother raising an autistic child. Starting with a personal narrative about her experiences, including how her son's autism led her to discover her own, she analyses positive aspects of being a mother on the spectrum such as a specific way of communication, a unique relationship between a mother and a son or understanding sensory needs. Among the challenges she points out possible overwhelm, problems of communication with neurotypical representatives of various institutions or lack of specific instructions. Since autism is genetic, it would be a good idea for the professionals to take into consideration the possibility that one of the parents (or both) may be on the spectrum.
Keywords: autism, mother, motherhood, genetics, positives, challenges

Streszczenie

Celem autorki było przedstawienie bardzo specyficznego aspektu bycia rodzicem autystycznego dziecka, a mianowicie przypadek, kiedy autystyczna matka wychowuje autystycznego syna. Swoje rozważania rozpoczyna opowiadaniem o swoich osobistych doświadczeniach, a w szczególności o tym, jak diagnoza jej syna doprowadziła ją do jej własnej. Autorka analizuje takie pozytywne aspekty bycia matką w spektrum, jak specyficzny sposób komunikowania się, wyjątkowa relacja między matką a synem czy rozumienie potrzeb sensorycznych. Wśród wyzwań wskazuje na możliwe przytłoczenie sytuacją, problemy z komunikacją z neurotypowymi przedstawicielami różnych instytucji czy brak konkretnych i szczegółowych instrukcji postępowania z ich strony. Skoro autyzm jest uwarunkowany genetycznie, byłoby dobrym pomysłem, gdyby osoby pracujące z autystycznymi dziećmi wzięły pod uwagę to, że jedno (lub oboje) z rodziców również jest w spektrum.
Słowa kluczowe: autyzm., matka, macierzyństwo, genetyka, pozytywne aspekty, wyzwania

Introduction

The issue of parenting autistic children has been in the centre of researchers' attention for some time. It is crucial to note their hard work, their struggle, their need for support. There are books on general parenting e.g., how to raise a happy

child etc. However, there are no publications on how to raise an autistic child that would be a contributing member of society and a content, even happy adult. It seems like a mission impossible to some. And it is admirable to find ways to support those parents made to embark on this mission by fate rather than by their own choice.

However, it does not go without notice that the problem of parents who are autistic themselves and who raise their autistic children has not been addressed yet. More and more studies confirm the hypothesis that autism spectrum disorder (the author of this article does not approve of the term 'disorder;' it is rather a different way of existing and functioning in which being a part of society is not always easy or even possible) is genetically based. Thus, it is not at all uncommon to meet a mother or a father of an autistic child who is not entirely quite easy to talk to, who seems to be extremely resistant to, for example, accepting the diagnosis, or who knows the subject matter of autism inside out during the second session with a specialist. Parents do pass their genes to their children, including the genes of autism. Studies point out that the occurrence of ASD is caused by a combination of genes rather than just one.[1]

Therefore, it would be interesting and beneficial to consider whether autistic parents' style of upbringing differs from that of neurotypical ones. Is it more difficult for them to raise such a child, since they know painfully well what it is like to be the odd one in society? Or perhaps they naturally and subconsciously choose the right way of communication which is more efficient even in case of non-verbal autistic children? And what about the sensory make-up of both the parent and the child? Do they contradict making it difficult to co-exist or do they contribute to mutual understanding and respect?

There are many issues to be studied in case of autistic parents raising autistic children. However, research into this area would not be very easy since the parents are too often undiagnosed. When they themselves were children, the set of criteria was different and they would often get away with their little weird behaviours due to the overall intelligence, being able to somehow deal with social demands well hiding at what cost it happens.

It is not uncommon to see hidden undiagnosed autistic parents to be so fixated on fulfilling social demands that it becomes hard for them to accept that their children are autistics, not to mention accepting the signs from their own behaviours. It often happens that changing the parents' way of thinking and, what follows, acting may be the key to their child's progress.

Researching this aspect of autism could result in profound conclusions concerning communication, level of understanding, tolerance etc. And these may contribute to creating a platform for co-existence of autistics and neurotypicals within society on the appropriate level of dignity and respect for both parties.

[1] R. Muhle, S.V. Trentacoste, I. Rapin, *The Genetics of Autism*, "Pediatrics" 2004, No. 113, e476.

Since there are obvious obstacles to conducting proper scientific research into these problems, the author proposes observation and conclusions based on her own experience. Of course, it may be a starting point for further, scientifically proper investigations. A personal narrative will be used to show the way to diagnosis of both the son and the mother. That will be followed by possibly the most objective analysis leading to conclusions. Autistic brains love to analyse everything and they love the truth. That is why the method applied here could be considered close to participant observation, although the subjects observed have been the son and the author – his mother. Hopefully, the considerations in this article will be beneficial to better understanding the functioning of at least certain autistic people. Perhaps thanks to this autistic people will be less invisible, they will not be called 'it' as has been very emotionally pointed out by one of female participants of the show entitled *Autentyczni*,[2] or denied their feelings.

Our journey

My son, Alex, was born in 2008. We had some problems with the labour due to pre-eclampsia resulting from metabolic issues I had. The pregnancy was a huge change for me. My body was out of my control. I had no idea then that autism may be in fact my own reality. Now I know that I was trying to deal with change by overeating ad reaching for my favourite comforting food. Tha was my stimming, but my family perceived it as a way of taking care of the baby ('eating for two'). Unfortunately, that led to the metabolic syndrome – probably pregnancy diabetes developed in the end of the third trimester along hypertension. Alex was born with signs indicating that he was oxygen deprived and four weeks before the term but because of his size (60 cm long and weighing 4.6 kg) he was assumed a mature baby despite his low Apgar score in the first minute (5, then 7 in the 3rd minute after administering oxygen). Now I could argue that size does not equal maturity of the nervous system but unfortunately, we do not yet have tools to measure that. So, he was not placed in the incubator and soon he was brought to my room. That was my great joy.

I had always wanted to have children apart from the times of teenage depression caused by bullying at school. Later on, despite problems in relations with men and generally with other people I was quite determined to become a mother. When that finally happened, I was on cloud nine. I had a baby and I wanted all that was best for him.

When he was two or three months old, our paediatrician noticed that his muscle tension was rather weak. So, he was referred to OWI (Eng. CEI – Centre of Early Intervention) where he was evaluated by the doctor first, then by a psychologist and rehabilitated to improve his muscles. The psychologist saw him every few months to

[2] Episode with Agnieszka Chylińska broadcasted on 25 December 2025 in TVN channel.

check his development. It was then when the suggestion was made that Alex might be autistic. Unfortunately, this suggestion was made in a very unpleasant manner – the psychologist said something like 'if his autism is confirmed, that will be very bad'. I believe that my own undiagnosed autism rebelled against the statement said in this way. I could not understand why my son's autism should be treated as the end of the world, especially by me. That was one among many things I found really hard to understand when facing the institutions of diagnosis and therapy.

I was in two minds about continuing with the CEI, especially that his physical rehabilitation was over. He started sitting correctly at the right time and then the same was with crawling and finally with walking. I did listen to my family who said that he should be given time to develop in his own time. I would like to say that it was a mistake but as I later found out about autistic people, we would not cooperate with people whose attitude we do not like. Observing my son throughout his life I know that he does not like people whom I do not like either. Perhaps he picks my micro-expressions of disapproval, but I choose to think that he has his own mind and it just happens that we dislike similar vibes.

When he was one year old and started walking, there was what I call a brain reset. He stopped reacting to his name and seemed to be focused on his newly acquired skill of walking and especially running. It was difficult for me to pay a lot of attention to that since I had a newborn in my arms. On the day of Alex's first birthday his younger brother was born. And I was a single mother. Although we were married, my husband was not much around, so I was dealing with everything on my own with the help of my parents (especially my mother taking over decision-making process when I was weak after the second pregnancy and childbirth, so my executive functions were not in top shape). And no speech developed. When Alex was a baby and then a toddler, my husband would come to visit first quite often, then the frequency was steadily decreasing. So, we used quite a lot of English at home, and I researched that bilingual children tend to have their speech development delayed. After all I did not have any idea how to get proper help in that matter. No one gave me instructions, and I could not develop the right procedures. I waited until he went to kindergarten. Then even more signs were noted and another suggestion about him being autistic was made. This time I was instructed clearly enough so I pursued the process of diagnosis. When Alex was four, it became official that he was autistic.

The surprising thing was that I never pulled my hair out and asked dramatically, 'why me?'. That was never the issue for me. I was focused on what I could do to make things better. Of course, as many parents, I had the period of 'there must be a way of curing autism,' I even made a few appointments with a homeopath specialising in autistic children. Luckily, the doctor (yes, she was a doctor, but I am not sure if she still is one) was also a psychologist and a good one. She taught me one very important thing – that I should approach Alex on an instinctive

level. If I wanted him to do what I did – speak, behave well socially etc., I had to become the 'alpha' of my family herd. For example, the fact, very characteristic in our culture, that we serve food to children first, is confusing as it puts a child in a position they are not equipped to. When relying on instinct who should eat first? The hunter because they must have strength to hunt for more. Children are too weak to hunt. They do not have the skills necessary to bring food to the table. So, they should not be served first. I must say I was convinced by the logic of this argument and although reluctantly at first, I started following this rule. I know now that my autism helped me here to overcome years of cultural conditioning in the upbringing of girls in our country. I believe that there are still quite a significant number of women, especially older ones, who would never agree with the rule that they should put the oxygen mask on their own face first and then on their child's.

The changes were subtle, but they happened. Over time Alex started noticing me more. There were still meltdowns, especially when things did not go his way. I reacted intensely to them and once I looked at a situation from a distance. Alex was screaming and hitting the TV. And he liked the TV. I was trying to get to him by shouting. I was trying to be louder than him so that he could hear me. It hit me how pointless and ridiculous it was. As I was getting louder, he was getting louder. Afterwards I thought the whole situation through. I decided to change my own behaviour, to become calm. It was the more difficult that I knew that I could not pretend to be calm. Alex would know the difference right away. I had to BE calm, find a place where I could find a little bit of peace and let it overtake my mind completely. I was successful only after a few attempts because during his meltdowns automatically my emotions kicked in and I would forget about the plan (thanks to my ADHD). That was a game changer. Now at the age of 17 Alex practically does not have meltdowns. Of course, he might get frustrated when things do not go his way (just like anybody), but he learned to deal with it by running or jumping. He murmurs, sometimes, quite loudly and angrily but it is easier and easier to explain things to him.

Another game changer for us was when he learned to write. He did it from TV. First things that he learned to write were TV programmes titles. He learned it on his own. I did not treat it as anything wrong, just provided paper (a lot) and colourful pens to write (even more). Later on, when I lost hope that he would learn to speak, I invested into another game changer – a tablet with the Mówik software. He had had experience with using a tablet before and he had liked it a lot (especially the aspect of being able to have control over watching the things that he liked on YouTube, for example, and even playing them over and over again). Another tablet was not anything new to him and he got used to the beauty of communication very quickly. I took care of the settings so that he wouldn't use it for different purposes.

Now he freely communicates his needs, although I must confess he was spoiled by me quite significantly in this respect. I always knew what he was all about. I was the first to figure out what change led to his meltdown. I knew what he wanted.

I observed him and drew conclusions. For me his every move communicated something. Maybe this has not really contributed to his speech development, but it has built his trust in me. He is able to go to the doctor with me, he allows for the examination, he was even able to put up with cutting out a suspicious pigment nevus from his back, he allowed me to restrain him so that the surgeon could act and then he allowed me to remove his stitches (I was trained by the surgeon!). I know that when he has a problem, he will come to me and show it to me hoping I would solve it. Of course, first he will try to solve it on his own.

Alex cannot make his own decisions about the legal and financial matters, does not always know right from wrong (e.g. it took us a long time to understand the notion of somebody's personal property) but right now he can make a sandwich for himself, heat food in the microwave, have a shower, get dressed. He is fairly easy to live with, he is not a threat to anybody in the family (although he is 1.95m tall and weighs about 120kg), he follows instructions and helps around the house. He is very happy and knows how to be affectionate. I am very curious what he will be like in the future.

When Alex was diagnosed, I started reading everything I could about autism. I read both in Polish and in English. As I was doing this research, I noticed that more and more things were not only about Alex but also about me. He was doing something and I remembered the sensation just from watching him. He was putting something into his mouth (when he was a few years old) and I could easily recall the taste. I started thinking that we were more similar that one would guess from the first glance.

Then I decided to face the facts and did some tests online. At first, they indicated that I was at the threshold, but I felt that there was something wrong with my answers. It took me some time to go beyond my own 'fit-at-any-cost' mask and be totally honest with myself. When I managed to do that, I got results that I should seek specialist's counselling and professional diagnosis. So, I did it because, as a real autistic, I needed confirmation of my suspicions. I got it. In 2024 I was diagnosed with atypical autism and in 2025 with ADHD. I know where Alex's autism comes from. And my life makes a lot more sense now. I understand myself better, my close friend understands me better and I do not doubt that I really understand Alex, his way of communication and his reactions.

Autistic mother – positives

The author's experience shows that the parent's autism (mother in this case – perhaps it would be advisable to take into account the specificity and disparity of female autism[3]) may positively influence the quality of relations between her and the child and in consequence also the relations between the child and other members of society.

[3] E. Furgał, *Autentyczna w spektrum*, Warszawa 2023, p. 19.

The first and the most obvious observation is the quality of communication between the autistic parent and child. On the one hand, it may foster even longer delay in speech development, but on the other hand, it may add to building trust. It is the author's conviction that autistic people need in their lives somebody who helps them make sense of the world, of all the confusing, chaotic sensations that attack them from all directions and all the time. A high-functioning adult can do that for their child and that leads to decreasing the level of anxiety. The world may become a little friendlier place.

This is, of course, closely connected with the sensory imbalances in both the mother and the child. As it has been mentioned in Introduction these may be contradictory or complementary. For instance, the mother may be visually oversensitive and the child – visually undersensitive. What consequences may it have in their life? The child may try to fill their room (if they have one) with various LED lights, often blinking, bright and in sharp colours. The mother may have problems with staying in the child's room as the lights give her headache and nausea. The child may focus better with the lights on. The mother must work on the child's skills when they are really focused. The situation seems to be impossible to solve.

However, this kind of situation may be treated as a perfect opportunity to teach mutual respect. It is always a good idea to talk about all those sensations and come up with solutions which would be beneficial for both parties. The child may limit the lights to one mobile blinking thing that they may place out of their mother's sight (e.g. under the desk). In time it may evolve to the situation that just the presence of this object will be enough for them.

Let us not be deceived by this apparent imbalance that only child gives way. The mother must do it as well. She has to disregard those glimpses of light that may appear under the desk. And for autistic people ignoring something that is frustrating is not an easy task. Especially that there is always a danger of anxious fixation on the area where it occurred and may occur again.

The crucial thing here is that the mother understands that the light is important for the child just as, for example, loud music or certain perfume would be for her. She understands how certain sensory input may increase or decrease focus, may bring pleasant and relaxing or unpleasant and stressful sensations. They may relate their oversensitivity or undersensitivity within different senses to each other.

It is possible to explain those things even to non-verbal autistic children, as the author managed to do with her son. He respects her oversensitivity to sound (wearing headphones and releasing his loud expressions of pleasure from watching favourite adverts on his tablet in the bathroom, where they do not seem so loud), and she respects his oversensitivity to touch (hugs only for a second or two, always releasing at his very first attempt to move away).

This sensory awareness makes it possible for the parent to pick the child's oversensitivities earlier and, thus, act in a way that can prevent possible meltdowns

due to sensory overload. Also, the autistic adult may more easily notice when the child is getting close to the meltdown point and ease the situation with the child's favourite stims, for example.

Self-stimming activities are also the area of mutual understanding. The parent may use here their experience of what is acceptable in the world and direct the child's stimming into such activities which are both acceptable and in accordance with the child's sensory profile. An autistic adult who manages to go beyond their own camouflaging will not discourage the child's self-stimming as they are well-aware of the benefits the specific nervous system of autistic individuals gets from such activities.

An autistic parent would subconsciously understand that their autistic child needs clear and unambiguous boundaries. Youngsters need very distinct lines between right and wrong. They need honest feedback about their behaviour. If something they do, is bad, they need to hear it and then hear what they should do instead to make it good. For neurotypical people this behaviour may seem a bit harsh as they do everything in their power (especially women) not to seem mean or angry. This is the cultural conditioning in our society. The autistic people, however, do not perceive it as being mean or angry. It is just giving honest information. And the instruction what to do better is a necessary condition to restore the sense of security.

What is more, when difficult behaviours occur, the parent on the spectrum is less likely to seek escape. They would rather view such behaviours as problems to solve. And when one has a problem to solve, one needs to find the cause for the behaviour. In many cases once the cause is found, the behaviour disappears. This adds to the total non-judgemental acceptance an autistic parent may offer their child.

Many parents on the spectrum do all those things without even thinking about them. It seems to them that they and their child speak the same language. This cannot be overestimated as a factor contributing to the development of the child and perhaps even the parent. Knowing that a person is understood by somebody in the world makes life a lot easier and decreases the risk of depression as it often stems from the feeling of being alone and misunderstood in the world.

Autistic mother – challenges

It should be kept in mind that the decision of an autistic woman to have a child is not an easy one. The sensory side of the pregnancy, the labour, the care of the newborn may be a problem for an individual with various over- and undersensitivities. The mother may be so overwhelmed that it becomes impossible to stay with the child. This kind of situation was beautifully depicted in the film *The Hours*.[4] The

[4] *The Hours* (2002) directed by S. Daldry.

poet's mother, Laura, played by Julianne Moore who leaves her husband and her son to work as a librarian shows quite strong characteristics of an autistic woman. The family was too much for her, she had to get away to breathe.

What is more, supporting a new autistic mother may be a bit complicated. Part of autism is the need to maintain control. It is the basis for the sense of security. Making plans, doing research, making decisions is the proof that things go right and may indicate that there is nothing wrong with the child. However, new mothers are often exhausted, sleep deprived, full of hormones unpleasantly dropping after the birth. All these factors may lead to problems with executive functioning. The woman seems to be one thousand percent confident in how she is handling the baby (because she has read everything she could on the subject) and then there comes one drop that spills the spell, everything is too much, and she is unable to make any decision even whether to use the toilet. This imbalance in functioning is often frustrating and unclear to people surrounding the mother. Nevertheless, a person who can responsibly and in the right timing take over the executive functions is a real treasure.

Another huge issue may be the relations with the external world, with the neurotypical people, the taking care of official and institutional matters, talking on the phone, talking to people, trying to read between the lines. In the author's experience even qualified professionals in the field of psychology may disregard the fact the parent may be or is autistic. Parents are often given information about what would be 'good to do' without specific details. Vague messages like 'maybe it's this or maybe it's that' are useless for autistic individuals. And when they do not specifically know what to do, when, where and with whom, they will not do that. The author was told about her suspected ADHD and that the diagnosis had to be paid for. That was not detailed enough. The author needed to know where she should go and who she should talk to. When she got these details, she was able to act.

The autistic adults also have problems with literal understanding of especially legal regulations. That may contradict the neurotypical understanding. When they are not told that those requirements should be accompanied by additional e.g. documents, they will not provide them. When the author applied for the next disability certificate for her son, she submitted all the documents listed on the application form. Then, during the interview the psychologist told her off for not submitting all the required documents. It was unpleasantly surprising. When things are untrue or go in a dishonest way, autists often freeze as if they have huge difficulty with processing something wrong happening in the world or someone saying something very far from the truth. That is why they keep their silence and do not say anything as there is usually no time left to process the wrong information. The author of this article managed to speak up in her defence saying that the documents from school were not listed on the application form. In response she heard that all parents submit them and the legislators did not take them into consideration but hey should.

Autistic people are unable to figure something like that out on their own, but they learn from their mistakes. The author will never forget the school documents again.

It has been stated before that not all autistic parents will benefit from their own autism while parenting an autistic child. The biggest obstacle that may even be harmful to the well-being of the child, not to mention the mental health of the parent themself, is camouflaging of the adult. When its level reaches the point of being completely unrecognised by the adult, it may result in many negative consequences, such as low self-esteem in both the parent and the child, loss of identity, the parent could obsess about what other people think and, thus, reject the child as being different. There is also the danger of not accepting the diagnosis and not providing suitable therapy for the child.

Conclusions

Drawing from personal experience leading from the author's son's diagnosis to her own diagnosis, the author has attempted to analyse how being an autistic mother helped or challenger her in the upbringing of her son. She pays attention to the following positive aspects of motherhood on the spectrum:

a) better communication with the son;
b) absolute acceptance of the child;
c) problem-solving attitude towards difficult behaviours;
d) understanding sensory problems;
e) allowing for and directing self-stimming;
f) setting clear boundaries;
g) ability to change the parent's behaviour for the sake of the child.

In the following way motherhood on the spectrum may be challenging:

a) parenting may be overwhelming;
b) camouflaging and rejecting their own autism may be harmful to both the child and the parent;
c) communication with neurotypical world in their child interest – lack of specific instructions, not following legal regulations in a strict way.

It is hard to be a parent in today's world. It is even harder to be a parent of an autistic child. However, when the parent can find at least some genetic traces of autism in themself, it may have surprising results in the life of the whole family.

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