



Danuta Szeligiewicz-Urban*
Małgorzata Kolisko-Nagły**

FUNCTIONING OF FAMILIES WITH CHILDREN WITH AUTISM AND THE ROLE OF NON-PROFIT INSTITUTIONS

*The child is the source of hope.
It tells parents about the purpose of their lives,
represents the fruit of their love.
It also lets them think about the future.*
Pope John Paul II

INTRODUCTION

We talk about autism today, about the causes and its consequences in the functioning of children affected by this disorder. It is a general social problem that affects a growing population of children. It is important to not forget throughout the entire process about the parents who similarly experience a collision with the fact that their child is burdened with autism.

Diagnosis of autism is a challenge, especially difficult for parents. It is worth considering how to act in such situations, who can help them. The foremost is the whole team of specialists who help, but among them there unfortunately also is a group of people interested only in the financial profit, or simply cheaters who point to impossible solutions. Thus, there is a clear need for a public benefit organization in the immediate environment, such as foundations or non-profit associations that really help families in their difficult situations and are often created by the parents themselves.

Experience and the literature show that the stages of functioning related to obtaining a diagnosis of autism experienced by parents are very similar and proceed in a systematic way. Therefore, families should look for specific tips on how to cope in each of the stages of the collision with the actual diagnosis and its consequences. Yet, a few of such parents decide to do something more. An interesting question is there-

* Humanitas University in Sosnowiec.

** Humanitas University in Sosnowiec.



fore how do these stages progress for the parents who decide to create institutional forms of support for themselves and other parents in a similar situation.

THE CHALLENGE OF DIAGNOSING AUTISM

Autism is currently recognized primarily by symptoms, mainly on the basis of a list of symptoms contained in two classification systems of diseases, functional disorders and health problems. This is the ICD-10 from 1993 (International Statistical Classification of Diseases and Health Problems) and the DSM-IV-TR from 2000 (Diagnosis System of the American Psychiatric Association). Both of these classifications similarly capture the issue of autism, although the number and the type of developmental disorders included overall is slightly different in each of them (Markiewicz, 2007, pp. 70-72).

There are often reservations about whether the diagnosis is accurate. These classifications were not created for therapeutic purposes, but for the needs of psychiatrists and neurologists and there are many doubts about the terms used there. Therefore, a “delayed” diagnosis is often made, while in principle the development is disturbed and therefore early therapeutic intervention should be undertaken. J. Cieszyńska indicates that at a later stage it is difficult to say whether the actions taken helped the child to compensate for the delay or whether they were not needed at all. However, the immediate consequence of the improper exclusion of autism in the diagnostic process leads to the expectation of spontaneous improvement and as such may lead to the consolidation and deepening of the disorder (Cieszyńska, 2011, pp. 15-17).

Assuming that the diagnosis has been made and the child can receive help, the diagnosis can be deepened, for example, one can check the child’s functioning in various areas, such as: level of psychomotor development, level of intelligence – Psycho-educational Profile by E Schopler, one can study the Brunet-Lezine Scale, or examine social maturity with the Social Progress Assessment (PAC), or use the HC Gunzburg scale, or also developed for sensory integration disorders – the Sensory Integration Test (SCSIT) of J. Ayres (Bobkiewicz-Lewartowska, 2014, p. 125). Establishing an early, accurate diagnosis is a difficult challenge, but allows for proper intervention, and thus better therapeutic effects (Błeszyński, 2010, p. 13).

All actions aiming at proper early diagnosis allow to draw a specific way of supporting the child, not only through a team of specialists, but also through the family and the immediate environment of the child. This allows for the direction and proper behavior of the environment that supports not only the child, but the whole process that is sometimes a lifelong path. It is important to realize that autism does not end with childhood, but it is a life-long disease. Autism is not a uniform disease entity, and the latest version of diagnostic criteria determines a number of disorders. In the DSM-IV classification, the following Pervasive Developmental Disorders are mentioned:

1. Autistic disorder (otherwise known as early childhood autism, Canner's autism or autistic syndrome).
2. Rett syndrome.
3. Childhood disintegrative disorder (CDD), also known as Heller's syndrome and disintegrative psychosis.
4. Asperger's syndrome.
5. A deep development disorder that is not otherwise specified (including atypical autism).

J. Kruk-Lasocka characterizing children's autism draws attention to the existence of a triad of symptoms of disorders:

- disorder of social relations manifested by a very low awareness of the existence and feelings of other people, as well as difficulty in following, entering into relationships with other people and understanding the habits and principles in social interactions;
- communication and fantasy disorder manifested in the lack of non-verbal and verbal communication, inability or difficulty in playing any fictitious-illusionary roles and games, difficulties in making and maintaining a conversation;
- the use of movement stereotypes, limited repertoire of activities and interests, as well as anxiety with even slight changes in the environment (Kruk-Lasocka, 1997, pp. 246-247).

As we can see from the above classification, it is difficult to diagnose autism as a disease entity. Psychologists and doctors sometimes give a binding diagnosis too late. Parents have no choice. Many of them are looking for their own way to help their child, which is not necessarily compatible with their needs and abilities. Sometimes, they just wait for the right diagnosis, fearing not to harm their own child, and the time inexorably runs to the detriment of an undiagnosed child.

Parents are distraught and confused by the multiplicity of contradictory signals coming to them from different environments that surround their child. An interesting example of how to find the right path and dilemmas that affect parents is the following story of a marriage that understood what action to take to help themselves and their child... but also the other children with autism and their parents. Let us trace from what experiences and needs a non-profit institution can develop.

THE STAGNATED SOCIAL PERCEPTION AND US

Family. It is an unimaginable good. It is a thing in life, without which a person cannot live. When a child comes into the world, you only want two things. You want happiness. You want health. After all, nothing bad can touch you now. Nothing can

happen. It comes to the world and then you know that nothing more beautiful will ever happen to you because this child will give you this a hundred percent delight in life. You will always be with them, behind them, in front of them, next to them. It does not matter what is happening in the outside world. Everything that is bad and attributed to the misfortunes of this world will not touch you.

Are you sure? You watch how your child grows and grows. Everything is fine. According to you. There is nothing that you cannot deal with in certain situations – you think, it is probably my parental inexperience. It means nothing that your child behaves differently than the other children, after all, all children are different. Yours is unique. It means nothing that your child at the age of 2 communicates with you only by single words. This is often the case with boys and they grow out of it – you hear. Then you find out what echolalia is. It means nothing, that your son stumbles, falls over and is so clumsy. It means nothing that you are constantly walking along the paths chosen by him, while the way to the destination takes more and more time. It means nothing that you suddenly notice that you cannot play together. It means nothing that no one understands you. Everything is fine (according to you).

Your first workshops in the kindergarten start as pure happiness. A lot of children are there, their grandparents and other parents. Christmas mood and fun, a sunny happy day. And suddenly the moment that destroys happiness comes. Why are the headmaster and teacher heading towards you? They have strangely worried faces. Such without a smile. Numb facial expressions. No... they just confused me with someone else. We do not know really know each other. We only swing our children here. Maybe he did not want to eat his lunch. What autism? What autistic features? What disorder? What are they talking about? You receive flowing words with calmness, and at the same time you feel that everything you saw and heard a minute ago, starts disappearing. You are in the desert, and in the ears, in the sea of words, you remember only this word. Autism.

THE FIRST STAGE – DISBELIEF

The grandparents feel what is happening. They take their grandchildren for a walk and to their home. We sit down to the treasury of modern knowledge – the Internet. We read, watch, make various tests. Our apartment turns into the scenery of the cheapest movies. We cry out, we cry. We do not agree. They are not right. Our son is not like that. Unless he is like that? Specialist diagnoses leave no illusions. “Your son suffers from autism.” There is no us. We do not exist. It is just a computer game. A matrix. Only without a way out.

We operate mechanically like programmed robots. What will be his future? How can we handle it? What shall we do? A year passes. Two years. We go to therapies. State and private, just more and just faster. We pay for a miracle, for the result. We

take another mortgage loan – everything for him. The price does not matter. We feel lonely, abandoned and misunderstood. Aggressive in relation to the world. It is only later that we start to think soberly. It is only later that we start to understand. It is only later that we start to change. Change with him.

SECOND STAGE – SELF-ORGANIZATION

We meet new people – other parents who have been faced with the same problem. Therapists who are starting to explain everything to us. They are our advisers. It is thanks to them that we think to find a support group. Or better – start a group. Association. Foundation. Anything that gives us strength and a community of thinking. We will talk about it loudly. They will not point fingers at us. They will not laugh and mock our children. They will reflect on words and behavior when we come to the playground again. We will show them what they can do. We will tell them... well, what? What will we tell them? What will we show them? What can they do? Then we realize that it does not work like that. We do not care about our rebellion. Everyone has their own matters and lives. This does not work.

STAGE THREE – THE CHANGE OF TACTICS

We will help everyone, we will inform. After all, we once wanted to be led by others. Where to go and seek help, where to find proven specialists and centers. Katowice, Kraków, Warsaw, Będzin, Tarnowskie Góry. We advise: “Here you have this, and there that. Here is this method, and there it that one.” Again, a miss. This also does not work. Everyone has different needs. Like the same disorder, but different. Children speaking and not, pre-school and school. Poor and affluent families, single and large families, broken and full.

And then a revelation comes. Let us do it here. In our place. How many of these children do we already know personally? Well, eight. And about how many have we heard? Well, about the next six. How many of them can be there? Let us check. Many. Too many. Where will we organize this? We do not have the money. Who will do the therapy for these children? We call everyone who could help us: teachers, specialists, volunteers. Thanks to contacts, we get available kindergarten rooms free of charge. There are 20 children coming to the first meeting that we organize. At different ages, the oldest is 6 years old. It turns out that the city cares for these children. They can support us with space and rooms.

Later, in accordance with the guidelines of the specialists, we create subgroups of children more disturbed and higher functioning children. We organize four age groups. Every two weeks. We are working on a coherent plan for several months

ahead. We managed. This worked. This works. There are currently over 80 of us. Every week. And now on Tuesday, Wednesday, Thursday and Friday. Every day. For a few years now.

THE NEW EVERYDAY

An organization is a dimension of a special bond. Family? Not completely. Community? Definitely. If people who have a common goal appear in life, then enemies who have a different purpose grow next to them. Since you are fighting and running a wide-ranging social campaign that primarily serves to promote what a disorder is, you cannot turn your eyes away from injustice. To the harm of children. And adults. You must act. You want to do something measurable. You cannot pretend that this does not interest you. You must help, listen, talk and intervene. Otherwise, *pro publico bono* loses its meaning, and the mission and message of the Foundation look beautiful, but only on the website.

You fight for every penny to keep this costly train on its track. You pay for rent, utilities, therapists. You are looking for the possibility of financing the renovation of a large venue and therapy. These which are really valuable. Because you know the needs and expectations of people affected by this disorder. At the same time, you are subject to social, often hard and unjust evaluation – it hurts and undercuts your wings, but you have no power over this. This will continue until your data disappears from the National Court Register.

You work professionally, you have three children, you deal with all this. Bureaucracy is your daily bread. You cannot forget about anything, you sit at night. You devote every free second, engaging not only yourself but also your closest family. Whether they want it or not. You do not earn a cent on this activity. Some people do not believe it, they look at you and smile ironically patting you on the back in the proof of understanding, and the smell of contempt is in the air – this is the hardest thing. Despite this, nothing can interfere with what you do, because there are people who work in the Foundation. Great people of good will, who always support you in volunteering, donations, whether financial or in kind, allow the organization to exist and develop.

The first assumption was to create a place where entire families affected by the disorder could find help and support in various forms: children – therapies and families – happiness. Was this successful? We do not know. We will see. We are working on it.

CONCLUSION

Research on the aetiology of autism is conducted very intensively. The brain of a person with autism functions differently because it receives the surrounding world differently and processes information differently. Children affected by autism do not differ physically from their peers. People with the spectrum of autistic disorders are a very diverse group in terms of social, communication and intellectual functioning. Autism can, therefore, have different forms. Some autistic children will not be able to control speech and will present different levels of intellectual disability and large deficits in social development, and still others will be quite communicative, may show signs of attachment to significant people (parents), while having difficulties in establishing correct relationships with peers and numerous stereotypes and schemas in behavior (Kręgiel, 2017). But autism is always accompanied by a difficulty in understanding the surrounding world.

Analyzing the current results of various studies, it can be concluded that the cause of autism disorders is unlikely to be the same for all people. The complexity of etiological processes and their diverse course are reflected in the previously described material. This is precisely the reason why so important is the role, in the life of both a child with autism and his parent, played by all kinds of institutions of people of good will, foundations, associations and societies, so needed in the life of every lost parent and his child. Foundations help to dispel a number of doubts that parents have because that is where people meet with very similar problems and dilemmas. The case study presented in the article, however, shows that helping others can be a special case of self-help and a form of therapy for a family that is struggling with the challenge of autism in their child.

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Keywords: autism, non-profit institution, autotherapy

Abstract: The article discusses the issue of the diagnosis of autism and how it affects the family's emotional and intellectual survival. Referring to the essential function of a public benefit institution and based on a case study, the article presents the process of accepting the diagnosis of autism in a child by parents and how the process of autotherapy takes place through the creation, conduct and total involvement in the functioning of a foundation for helping children with autism and their families.

ZNACZENIE ORGANIZACJI SAMORZĄDOWYCH W FUNKCJONOWANIU RODZINY DZIECKA Z AUTYZMEM

Słowa kluczowe: autyzm, instytucja non profit, autoterapia

Streszczenie: Artykuł omawia zagadnienie diagnozy autyzmu oraz jego wpływ na przeżycia emocjonalne i intelektualne rodziny. Odnosząc się do istotnej funkcji instytucji pożytku publicznego, na przykładzie studium przypadku, w artykule przedstawiono, jak przebiega proces akceptacji diagnozy autyzmu u dziecka przez rodziców oraz jak w trakcie takiego procesu dochodzi do autoterapii poprzez utworzenie, prowadzenie i całkowite zaangażowanie się w funkcjonowanie fundacji na rzecz pomocy dzieciom z autyzmem i ich rodzinom.