

ADAM MICKIEWICZ UNIVERSITY IN POZNAN

**INTERDISCIPLINARY
CONTEXTS
OF SPECIAL PEDAGOGY**



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MAGDALENA OLEMPSKA-WYSOCKA

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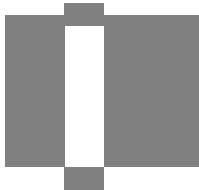
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Preface

This next volume of *Interdisciplinary Contexts of Special Education* is a collection of articles addressing child issues in early care and education systems, child's distinctness arising from its disability, stress and parental crisis, as well as the issues of children with autism spectrum disorder and Asperger syndrome. This publication is a response to already initiated legal and organisational actions. Discussed issues can serve as an inspiration for planning and implementing activities supporting optimal development of a child and providing support for its family.

The paper opens with the article by Katarzyna Ćwirynkał and Urszula Bartnikowska on how adoptive and foster parents discover distinctness of the child caused by its disability. As the authors point out, the confrontation with the distinctness of the child can affect both biological parents, as well as adoptive and foster parents. Many common elements can be found between them, as it can be assumed that in their majority they share similar parental experiences. The empirical part of the text is an interesting analysis of the results of qualitative research conducted with parents from 20 adoptive and foster families who raise a child with a disability. The analysis of the interviews shows the ways of discovering the distinctness of the child, accepting this distinctness, and the meaning assigned to it.

There are many interesting solutions that can be found in the Polish care system for impaired children. However, due to the lack

of consistency in the management of individual types of childcare facilities for young children, some of these solutions cannot be fully implemented. This problem is related to the system of nurseries and early child development support, as noted by Anna Mikler-Chwasztek. The author emphasizes that in the case of any diagnosis or suspicion of any developmental disorder in the child, it is worthwhile to undertake, as soon as possible, multifaceted actions in order to support this child's development. This will not only improve the existing condition, but may also contribute to reduction or even elimination of problems that may have consequences in the future. Many disorders have a tendency to worsen with age, so the sooner the child is treated, the greater the chance is for it to avoid many difficulties.

The issue of the crisis affecting parents of children with disabilities in the perspective of new standardisation tools is addressed in the article by Joanna Doroszuk. The author points out that social and cultural changes determine the functioning of families of children with disabilities. Internet, support groups or associations are the new normalisation tools that parents can use. They can influence both the construction of their parenting and their capability to deal with difficult situations. The author analyses the social and emotional situation of parents of children with disabilities based on her research. She also indicates significant categories and areas relevant for further scientific exploration.

Another article by Barbara Winczura focuses on the very important issue of the development of social relations in children with autism spectrum disorder in contacts with their relatives. The author presents the development profile of social relations of young children with autism in contacts with their close ones and analyses the conditions of the attachment in the child-parent relationship in this group of disorders. As pointed out by B. Winczura, almost half of all people with autism participate in various forms of social life, although their profiles of social-emotional deficits remain highly varied. Impairment of the social sphere in this population includes limited capability and ability to recognise, understand and engage in contact with other people and in interpersonal communication.

Parents / guardians become the first observers of disturbing behaviours of the child, but also the first initiators of establishing close relationships with their offspring.

The article by Aneta Wojciechowska and Anna Gulczyńska presents the results of a pilot study on sexual behaviour of children and adolescents with autism spectrum disorder in their mothers' opinions. In the first place, the authors presented the theoretical background, based on which the research methodology was designed. Then they described in detail the results, the discussion and the conclusions possible at this stage of the research. The respondents were 38 mothers who completed questionnaire surveys indicating both the type and frequency of sexual behaviours observed in their children or adolescents.

An extremely important issue concerning the stress of mothers of children with autism was presented in the article by Anna Banasiak. The purpose of this study was to determine the level of parental stress experienced by mothers of children with autism. The study involved 39 mothers of children with autism, 40 mothers of children with Down syndrome and as many mothers of children developing properly. The results indicate higher level of parental stress in mothers of children with autism than in mothers with Down syndrome and mothers of well developing children. Potential sources of strength for coping with stress in mothers of autistic children are related, as emphasised by the author of the text, to relatively low stress resulting from family disharmony, personal burdens, child health and financial problems. The research presented in the article by Mieczysław Dudek, dealing with the stress of parents of autistic children, complements this issue. As the author points out, the appearance of a disabled child in the family is always a source of tremendous stress. This problem is particularly evident in case of a child with autism because of its unpredictable and non-typical development. The subject of this study was to investigate ways to cope with stress among 130 parents of children with autism.

The specifics of verbal and nonverbal communication of a child with Asperger syndrome in the context of his role as a student and

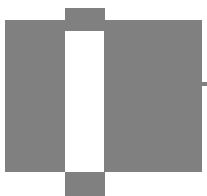
colleague was discussed by Ewa Gacka. The author emphasises that communication is one of the most important elements of human existence, since human as a social being strives to communicate with others. Communication skills affect, amongst others, the level of acceptance of the person by the rest of the community, they contribute to succeeding in various aspects of life and fulfilling social roles. The article focuses on the analysis of communication skills, both verbal and nonverbal, of a child with Asperger syndrome (AS) as well as on showing the specific ways of communication of a person with Asperger syndrome, that hinder finding themselves in school community.

In the next article, Małgorzata Moszyńska presented conclusions of the study on school environment in narratives of students with Asperger syndrome. This article deals with the social functioning of a student with diagnosed Asperger Syndrome in a mainstream school environment, in his subjective assessment. The article is embedded in the framework of qualitative research, and the purpose of the research was to reach the subjective meanings that students with Asperger's assign to this institution and to understand what school is for them.

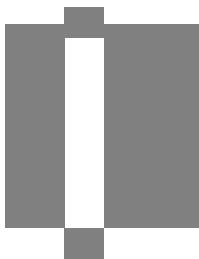
Interesting analyses are presented in Rita Khoury's research on the mothers of children with Tourette syndrome. The purpose of the study was to collect data from mothers of children with Tourette syndrome (TS) to determine to what extent the existence of a TS child in a family influenced the quality of its mother's life. The study involved 50 mothers of TS children. The results show that the lack of reliable and comprehensive diagnosis and information can lead mothers to high levels of stress, discomfort and lack of balance.

The paper concludes with reports from conferences (19th National Scientific and Educational Conference 'Speech Therapy. Practices in Speech Disorders', 30 June - 2 July 2017, Lublin, Poland and 3rd International Scientific Conference 'Child and Teacher in the World of Media) and a review of a scientific publication.

*Editor
Magdalena Olempska-Wysocka*



ARTICLES



Interdisciplinary Contexts of Special Pedagogy
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KATARZYNA ĆWIRYNKAŁO,
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A child's otherness resulting from disability. A phenomenographic study of adoptive and foster parents

ABSTRACT: Katarzyna Ćwirynkało, Urszula Bartnikowska, *A child's otherness resulting from disability. A phenomenographic study of adoptive and foster parents.* Interdisciplinary Contexts of Special Pedagogy, No. 19, Poznań 2017. Pp. 11–33. Adam Mickiewicz University Press. ISSN 2300-391X

A certain percentage of disabled children are not raised in their biological families. It happens more and more often that the place of residence of such a child is not an institution but the adoptive or foster family. Increased prevalence of this type of families makes the study of this area of functioning of children with disabilities more and more important. The paper covers the issue of dealing with a child's difference by their adoptive/foster parents. The difference has its source e. g. in a disability. The empirical part of the article is the result of qualitative research conducted with parents from 20 adoptive/foster families that raise a child with a disability (this is a part of a broader research project conducted by the authors with these families). The analysis of the interviews shows the ways to discover the otherness, the difference of the child, the ways to accept this otherness, and the importance they ascribe to the otherness of the child.

KEY WORDS: adoptive / foster family, disabled child, difference, otherness

Facing the otherness of one's child can be a task both of biological, as well as of adoptive and foster parents. In this regard, one can find between them many common components, indeed, it can be assumed that most parents are party to certain experiences and events from the realm of parenting. In both cases, situations in which the financial situation (or the general living conditions) worsens, can arise, as every child within a family requires additional financial resources, and a disabled child even more so, in particular due to its special needs¹. The emergence of a disabled child in the family can lead not only to the reduction of its financial resources, but it can also impact its psychological resources and bring about social isolation². This situation is further exacerbated by the effects of the political transformation related to the feeling of loss of security, financial stabilisation, and the abandonment of institutional forms of social support³. As a result, families have to cope with various types of problems, e. g. financial, educational, changes to the power balance between the various members, negative attitudes of the environment, and others⁴.

¹ E. Muszyńska, *Ogólne problemy wychowania w rodzinie dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, ed. by I. Obuchowska, WSiP, Warszawa 1999, pp. 101–164; G. Kwaśniewska, *Rodzina dziecka z przepukliną oponowo-rdzeniową*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2005; A. Sakowicz-Boboryko, *Rodzina jako realizator potrzeb rehabilitacyjnych dzieci niepełnosprawnych*, Trans Humana, Białystok 2005.

² M. Parchomiuk, *Rodzice dzieci z mózgowym porażeniem dziecięcym wobec sytuacji trudnych*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2007; B. Górnicka, „Rodzicielski świat” matek i ojców wychowujących dziecko z niepełnosprawnością, [in:] *Rodzicielstwo w kontekście wychowania i edukacji*, ed. by J. Brągiel, P.E. Kaniok, A. Kurcz, Wydawnictwo UP, Opole 2013; J. Lipińska-Lokś, B. Skwarek, *Rodzice w obliczu niepełnosprawności dziecka*, [in:] *Rodzicielstwo w kontekście wychowania i edukacji*, ed. by J. Brągiel, P.E. Kaniok, A. Kurcz, Wydawnictwo UP, Opole 2013.

³ Conf. A. Krause, *Człowiek niepełnosprawny wobec przeobrażeń społecznych*, Oficyna Wydawnicza „Impuls”, Kraków 2005.

⁴ Conf. Z. Kazanowski, *Przemiany pokoleniowe postaw wobec osób upośledzonych umysłowo*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2011.

Edyta Chajda⁵ indicates that despite the public opinion being aware of the difficulties encountered by families raising disabled children, in the opinion of the decisive majority of Poles (94%), the care for and the support of disabled people is primarily the duty of the family. Commonly, the rehabilitation of the disabled child is assigned to the role of the parents. The mother is perceived as the animator of life of the disabled child. Beata Antoszewska⁶ notes that the mother becomes the direct animator, when she takes care for the child basing herself on her innate intuition and the need to help, and the indirect animator, when she seeks specialist help and makes use of it. The mother also becomes the entity implementing the recommendations of specialists. The child spends most of its time in the area of the family, and it is in most instances that this is where it is expected that the recommendations of therapists/ rehabilitation specialists are implemented by the next of kin, which might multiply the probability of an ultimate therapeutic success. The uptake by an even larger fraction of the population of the new, partnership-based model of the family, assuming a more balanced distribution of power and obligations between the individual members of the family causes fathers to be party to ever more tasks related to the raising of the child, caring for them and rehabilitating them⁷. Irrespective, however, of whether we are considering the situation of biological, adoptive or foster mothers or fathers raising disabled children, it can be assumed that they have to cope with an higher number of difficult situations than the parents of children without disabilities. Difficulties related to the differences in the

⁵ E. Chajda, *Postawy wobec osób niepełnosprawnych*, Komunikat z badań. CBOS, Warszawa 2007, p. 8.

⁶ B. Antoszewska, *Matka jako animator w życiu dziecka niepełnosprawnego*, [in:] *Współczesne problemy pedagogiki specjalnej*, ed. by U. Bartrikowska, Cz. Kosakowski, A. Krause, Olsztyn 2008, pp. 186–191.

⁷ K. Ćwirynkalo, *Ojciec w wychowaniu i rehabilitacji dziecka z niepełnosprawnością*, [in:] *Edukacja i socjalizacja w życiu osoby niepełnosprawnej*, ed. by A. Klinik, D. Prysak, Oficyna Wydawnicza Humanitas. Wyższa Szkoła Humanitas, Sosnowiec 2011, pp. 133–147.

functioning of a child, and social expectations, make the parents' stress greater⁸.

Beside the similarities in the situation of biological as well as adoptive and foster families of a disabled child, noticed should be also their special characteristics, for a few reasons at least. First of all, noticeable is the high frequency of prevalence of various kinds of disorders within foster or adoptive care⁹. This phenomenon is also noticed in Polish literature¹⁰. For instance, Jacek Błeszyński¹¹, having analysed 97 adoptive families, indicates that among 41 children adopted by these, no symptoms of various diseases and/ or developmental disorders were registered. The report of the Polish Central Statistical Office in turn, 'Social assistance and care for the

⁸ Conf. E. Pisula, *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwa Uniwersytetu Warszawskiego, Warszawa 1998; Pisula E., *Rodzice i rodzeństwo dzieci z zaburzeniami rozwoju*, Wydawnictwa Uniwersytetu Warszawskiego, Warszawa 2007; K. McGlone, L. Santos, L. Kazama, R. Fong, Ch. Mueller, *Psychological Stress in Adoptive Parents of Special-Needs Children*, "Child Welfare" 2002, LXXXI, 2, pp. 151-171; A. Borowicz, *Stres rodziców wychowujących dzieci z niepełnosprawnością słuchową*, "Niepełnosprawność – zagadnienia, problemy, rozwiązania" 2012, 2, pp. 55-80.

⁹ J.A. Rosenthal, V. Groze, A.G. Aguilar, *Adoption Outcomes for Children with Handicaps*, "Child Welfare" 1991, LXX, 6, pp. 623-636; H. Minnis, K. Everett, A.J. Pelosi, J. Dunn, M. Knapp, *Children in Foster Care: Mental Health, Service Use and Costs*, "European Child & Adolescent Psychiatry" 2006, 15, 2, pp. 63-70.

¹⁰ U. Bartnikowska, K. Ćwirynkało, *Rodziny adopcyjne i zastępcze dziecka z niepełnosprawnością*, Oficyna Wydawnicza "Impuls", Kraków, 2013; Bartnikowska U., Ćwirynkało K., *Dziecko z niepełnosprawnością w rodzinie adopcyjnej i zastępcej. Część I – zetknięcie się z niepełnosprawnością dziecka, analiza decyzji*, Kwartalnik „Szkice Humanistyczne” 2012a, XII, 2(28), pp. 197-216; Bartnikowska U., Ćwirynkało K., *Dziecko z niepełnosprawnością w rodzinie adopcyjnej i zastępcej. Część II – jakość funkcjonowania rodzin*, Kwartalnik „Szkice Humanistyczne” 2012b, XII, 4(30), pp. 199-216; U. Bartnikowska, *Dziecko z uszkodzonym słuchem w rodzinie zastępcej – studium przypadku*, „Wychowanie na co Dzień” 2013, 1-2, pp. 3-8; K. Ćwirynkało, *Rodzina zastępca z dziećmi z niepełnosprawnością intelektualną. Studium przypadku*, „Wychowanie na co Dzień” 2013, 1-2, pp. 9-16.

¹¹ J.J. Błeszyński, *Kluczowe zagadnienia przysposobienia i funkcjonowania rodzin adopcyjnych*, Oficyna Wydawnicza „Impuls”, Kraków 2010.

child and family in the year 2015' ("Pomoc społeczna i opieka nad dzieckiem i rodziną w 2015 roku")¹² indicates that for the end of the year 2015, in the realm of family foster care in Poland, 10.5% of all those under care had a statement of disability. However, information about how many of the other children would have other, 'minor' dysfunctions, such as difficulties in learning, emotional disorders and behavioural disorders. It can be speculated, based on studies from the United States and Great Britain¹³ that these are more numerous than children with statements of disability.

A further issue concerns the character of relations between the adoptive/ foster parent and the child. On the one hand, it can be speculated that the lack of a biological bond between the parents and children can strip parents of a major source of mobilisation to provide the child with the best possible care. On the other hand, however, these parents are very often very determined and have at their disposal various methods thanks to which they are able to provide the child with optimum conditions for development. Available research suggests that e. g. adoptive and foster mothers raising intellectually-disabled children suffer from depressions comparatively to a lesser extent than biological mothers of such children¹⁴, and the level of satisfaction of adoptive and foster parents from raising a disabled child can be judged as high¹⁵. Not insignificant is also the issue of the ability to receive additional financial support as

¹² Pomoc społeczna i opieka nad dzieckiem i rodziną w 2015 roku (2016), Warszawa: Polish Central Statistical Office, pomoc_spoleczna_i_opieka_nad_dzieckiem_i_rodzina_w_2015.pdf [access: 8.07.2017].

¹³ J.A. Rosenthal, V. Groze, G.D. Aguilar, *Adoption Outcomes for Children with Handicaps*, "Child Welfare" 1991, LXX, 6, pp. 623-636;

¹⁴ L.M. Glidden, V.L. Valliere, S.L. Herbert, *Adopted Children With Mental Retardation: Positive Family Impact*, "Mental Retardation" 1998, 26, 3, pp. 119-125.

¹⁵ N. Gallant, *What works in special needs adoption*, [in:] *What works in child welfare*, Child Welfare League of America, ed. by M. Kluger, G. Alexander, P. Curtis, Child Weldare League of America, Washington, DC, 2000, pp. 227-234; A. Gath, *Mentally Retarded Children in Substitute and Natural Families*, "Adoption and Fostering" 1983, 7, pp. 35-40; J.A. Rosenthal, *Outcomes of adoptions of children with special needs*, "The Future of Children" 1993, 3, 1, pp. 77-88.

well as with respect to specialist aid by foster families (both related as well as professional), in particular these having the status of specialised foster families that by definition are there to provide care to children with developmental disorders.

Utilised methodological procedure

The subject of the undertaken studies was the experience of adoptive/ foster parenthood over a disabled child, with specific focus on the parental reception of the otherness of the child. It was the purpose of the research to show the methods of comprehension of the otherness of a disabled child by its adoptive/ foster parents. The research problems were formulated as follows: In what categories do the adoptive/ foster parents describe the otherness of the disabled child accepted into the family? What does the otherness of the child mean in their view? What is the meaning ascribed by those under research to their experience of the otherness of the child?

In order to respond to the specified questions, a qualitative research strategy was chosen within the interpretative paradigm. The assumption of this research route stems from the specifics of the analysed group, the uniqueness and difficult accessibility of the analysed group. The selected paradigm permitted the assumption of the presence of intersubjectivity. According to Edmund Husserl¹⁶ it yields the basis to state that subjectively experienced worlds have a common intersubjective part that may, through science, gain the name of an objectively existing reality.

Phenomenography was chosen as the method utilised to find the answers to the questions posted above; it “deals with qualitatively varied methods utilised by people to experience phenomena and consider them, and to think of the mutual relations between

¹⁶ E. Husserl, *Nastawienie nauk przyrodniczych i humanistycznych. Naturalizm, dualizm i psychologia psychofizyczna* (translated by Z. Krasnodębski) [in:] *Fenomenologia i socjologia*, ed. by Z. Krasnodębski, Wydawnictwo PWN, Warszawa 1989, pp. 54–74.

people and the world"¹⁷. For data collection, deep interviews were utilised that, after transcriptions, were encoded based on the inductive approach¹⁸ and components of grounded theory of Katy Charmaz¹⁹.

The presented results constitute a fragment of a broader research project concerning the situation of disabled children in adoptive and foster families conducted in the years 2010–2012²⁰. The research group was composed of 20 families (in each case one or both of the parents took part in the study), who had adopted or taken in to a foster family a disabled child. There were eleven adoptive families in the study, and nine foster families, of which three were related and six were unrelated foster families (in this group only one family had the status of a specialised foster family). The age of the children varied between two and 27 years, and the disabilities they suffered were e. g. damage to hearing, intellectual disability, grave chronic illness, FAS, cerebral palsy and autism. The studied used an original proprietary questionnaire used to conduct the interview. The study was executed using the qualitative procedure. Interviews were conducted that were later transcribed and subjected to qualitative analyses.

Results of own research

Descriptions of parents pertaining to their first experienced related to the child's otherness divide all the analysed parents into

¹⁷ R.G. Paulston, *Pedagogika porównawcza jako pole nakreślania konceptualnych map teorii paradygmatów*, [in:] *Spory o edukację. Dylematy i kontrowersje we współczesnych pedagogiach*, ed. by Z. Kwieciński, L. Witkowski, IBE, Edytor, Warszawa – Toruń 1993, p. 41.

¹⁸ M. Hammersley, P. Atkinson, *Metody badań terenowych*, Poznań 2000.

¹⁹ K. Charmaz, *Teoria ugruntowana. Praktyczny przewodnik po analizie jakościowej*, Warszawa 2009, pp. 59–124.

²⁰ U. Bartnikowska, K. Ćwirynkało, *Rodziny adopcyjne i zastępcze dziecka z niepełnosprawnością*, Oficyna Wydawnicza „Impuls”, Kraków 2013.

two main groups: 1. those who discovered the developmental disorders in their children only after accepting them into the families, 2. those who from the beginning knew that the child has developmental problems.

Parents unaware of the child's otherness

The discovery of disorders – as it seems – should rest in the competences of specialists deciding on the transfer of a child to a specific family. The parents should fully consciously, knowing their abilities and skills, decide to take a child with certain limitations into their care. In actuality, in several cases, the matters were different.

The unawareness of the parents concerning the presence of disorders in children was caused by two factors. In some of these cases, it was the age of the child that prevented the statement of a broad diagnosis concerning further e. g. mental or motor development. In younger children (in particular newborns, but toddlers as well), it is difficult to describe an ultimate diagnosis concerning developmental abilities due to the large variations in individual development, and also due to the difficulty in differentiating symptoms of negative influences of external factors from the arising of a child's actual (limited) potential, as well as due to the flexibility of the child and its abilities to its abilities to surmount developmental difficulties under favourable conditions. In other cases, the lack of knowledge of the parents was caused by the employees not disclosing to them the known diagnoses of the children.

The first cause (the child's age at the time of acceptance into the family) resulted in the disability being discovered with a delay of several years. The following example statements prove such experiences of some of those questioned:

"Frania's problems became apparent only in grade zero of primary school. I was made aware of the emergence of difficulties in terms of her

acquiring knowledge and skills. Many contraindications against commencing primary school were indicated [...] We did not want to accept the fact that our only child has problems in school, that she has limited cognitive abilities. We did, after all, care for her, and had not noticed anything worrying earlier [...] We thought that once she would start school, these difficulties would disappear by themselves and that everything would be all right, so we sent her as normal to the first grade of primary school. That's when the problems started..." (Felicia, adoptive mother of an eleven-year-old girl with an intellectual disability)

"Kamil developed normally, until the age of three it was normal, a cheerful child, running around... When he was a year and three months old – we did away with nappies. [...] There were only problems with speaking, because he spoke very little, and then he ceased to altogether. He went to preschool only for a month, because the teachers already noticed that Kamil behaves differently when among children [...] started those visits at psychologists, various doctors, where we found out more and more that he was autistic" (Krystyna, related foster mother of a fourteen-year-old girl with autism).

In both cases, the diagnosis of the disability was a surprising discovery for the interviewees. In the narrations, there appears a gradation of experiences in life, and the moment of the diagnosis is placed among those most difficult. This is not a phase of shock as seen in parents, to whom a disabled child is born, but it is an experience that can be compared to the experiences of biological parents, the children of whom are diagnosed later than just after birth. The children of the interviewed people already have behind themselves several hears of history at the family, hence both statements include the diagnosed problems set against the children's prior successes (quick adaptation to using the potty for physiological needs, observing an emotional balance and a lack of tendency towards aggression in a child). They form the context for the changing family situation. Both of the interviewees relate stories about the child venturing outside of the family circle, going to preschool, and, accordingly,

the possibility of confrontation of the child's functioning with the functioning of their peers. The statements also exhibit a category of waiting for an improvement, which, however, does not come about in the extent expected by the parents.

The force of experiences of the interviewees is noticeable through those parts of the narrations that apply to the defence mechanisms used against them²¹: denial ("We did not want to accept the fact"), the illusion of the temporary nature of the problems ("once she would start school, these difficulties would disappear by themselves") and undertaking not necessarily rational activities that were to remove them ("we sent her as normal to the first grade"), seeking out the guilty and self-accusation ("We did not send the child to preschool [...] perhaps this was a mistake"), the need to confirm the diagnosis, maybe even seeking a different, more advantageous one ("those visits at psychologists, various doctors, where we found out more and more that he was autistic"). The information about the defence mechanisms utilised by the parents, included in the stories of the emergence of disability diagnoses in the child confirm that these were difficult emotional experiences.

Parents to whom the fact of a disability already persisting in a child include, among others, Regina and Ryszard. This is their dialogue showing the unawareness of the difficulties of the intellectually-disabled children accepted into the foster family:

"We knew nothing. We were told he wets the bed at night [...] It is a fact that the children's home did not notify about any disturbances at all" (Regina)

"We received all the documents only when the case in court was officially closed [...] Among them was the medical statement of the disability" (Ryszard)

"Yes, but even this statement in reality told us nothing [...] when Rafał came, then my husband told him already on the second day: "You

²¹ Conf. E. Pisula, *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwa Uniwersytetu Warszawskiego, Warszawa 1998.

know, son, when I was your age I was already reading «The Deluge» and we gave Rafał a thick book [...] on the next day, we asked: "Sweet Rafał, did you already read something in the evening?" He replied, not really [...] Then we said – we need to visit the eye doctor [...] We only realised later that it's not the eyesight that's causing the problems [...] nobody warned us about it" (Regina)

"We have met people as people, you know, not as their problems, but people as people. Had we not met people as people, but just knew the documents, the decision might have been different" (Ryszard)

The discovery of the disability, of which the parents were not informed, happens quite quickly. The statements of interviewees representing this kind of family show several characteristic components. The first one is getting to know the child as they are, but – as the interviewees stress – getting to know them through the lens of humanity and not developmental shortcomings. The description of the parents usually spans the meeting of one person with another, and the force of the "first impression" without the burden of negative information. The second component is lack of information on the development of children. They do not come to families labelled and marked with their limitations. The parents can personally discover their potentials (including the specifics of their functioning along with certain limitations). Parents stress as well that the decision to accept a child due to lack of access to diagnoses was based upon getting to know the child(ren) and not their flaws. The third component is the process of discovering the children's shortcomings itself. This discovery covers two paths: documents and own observations. Documents are a natural path of getting to know children that should precede accepting them into the family, and for the interviewees, it was "disclosed" quite late. The interviewees, however, ascribe a particular significance to having discovered the diagnosis later, as an important fact contributing to the reaching of a positive decision concerning the commencement of care of the children. They ascribe the cause of emergence of negative attitudes

towards children and their rejection to the early information of the diagnoses and the training materials.

With this element, interwoven is the process of entering parent roles, the formation of the identity of the parent and the identity of the child (expressed by the words "*You know, son, when I was your age...*"). Identical means "the same". Ryszard shows identification of the child's abilities with his own abilities presented at a given age, ascribes to him similar interests. This leads to the discovery of (unidentified as of yet) differences in a child, and initiates the process of looking for causes. The parents accept two possibilities: sight problems and neglect. Intellectual disability is more difficult to accept. Defective sight can be corrected, neglect was halted by the child being accepted into the family, and may be compensated. However, intellectual disability is disability that – as shown by the research of Antonina Ostrowska²² – gives in most cases in the environment rise to an attitude not only of rejection, but distance. It can be speculated that for this reason, the interviewees had it easier thinking of limited abilities of children as being the result of neglect or eye damage. In addition, the interviewees confess that in their case intellectual disability is something not seen earlier. Both state that earlier they had no contact with people below the intellectual norm, quite the opposite – they revolved around educated people.

The ultimate element distinguished in the process of discovering the children's disability is the fear of one's competences as a parent. The parents are intuitively aware that specific needs of disabled children also require specialist knowledge and skills.

Parents aware of the child's disability from the very beginning

Two subgroups may be differentiated between among the interviewees: Persons fully aware, and those partially aware. Persons

²² A. Ostrowska, *Niepełnosprawni w społeczeństwie 1993–2013*, IFiS PAN, Warszawa 2015.

partially aware, which include the foster mother quoted below, had received the information that the children they plan to accept into the foster family have certain limitations or health problems. However, as they went about getting to know the child, other developmental limitations came to light.

"I knew she went to a special school, but I was told that this disability borders on the norm, later it emerged that the disability is moderate, despite mine and Celinka's enormous work" (Czesława, unrelated foster mother of an eleven-year-old girl with an intellectual disability).

The other interviewees were from the very beginning aware of the child's disability, which does not mean that all were fully at home with it. Some of the interviewees had formerly contact with people with such disabilities as the child accepted by them (e. g. Monika with deaf children, and Wanda with her own child fed parenterally).

"The illness is unforeseeable. [...] For seven years we had [a parenterally fed daughter – author's note] before Witek made his way to us, we learned to live with it" (Wanda, unrelated foster mother of a five-year-old boy with a grave chronic disease).

Wanda focuses first of all on the otherness related to the necessity of parenteral feeding for Witek. This is a disease that she could already "live with", because here biological daughter is fighting the same disability. She thus knows that it cannot be foreseen, that it requires frequent medical consultations and this knowledge allows their family to calmly accept the boy's otherness. The interviewee, after her daughter was diagnosed with the disability, most probably went through all phases of adaptation: shock, emotional crisis, apparent adaptation and constructive adaptation²³. The acceptance of

²³ A. Twardowski, *Sytuacja rodzin dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, ed. by I. Obuchowska, WSiP, Warszawa 1999, pp. 18–54.

the daughter's otherness let her naturally accept such a disease in others. The interviewee, when speaking of the first period of the presence of Witek in their family, completely omits his other difficulties: hearing difficulties, hospitalism, intellectual difficulties. It is possible that even opening up to otherness of a single type caused also openness to the differences of others in general.

Monika is in a similar situation – she knows other children with deficient hearing that go to the same school as the girl she had taken in.

"Marysia was already nine years old, and she went to a school for the deaf for two years already, she was stuck in zero grade, she couldn't budge from there [...] she did not know how to eat. She was so thin and little. But when I took her in, it was one of the most frightening things" (Monika, former unrelated foster mother of a currently 27-year-old deaf daughter).

Monika is also at ease with Marysia's main disability – the hearing deficiency. Work at a school for the deaf caused her to become, using the terms of Erving Goffman²⁴, "oriented" or "informed" in the specifics of the functioning of the people with such a trait. She thus had no trouble with accepting her and welcoming even as normal and obvious. Moreover, she had met Marysia with her personal limitations, she knew her position in the school and in the class (the fact that other children have contempt for her due to the death of her mum), she knew about the other problems (related for instance to her mental development), she knew her past at least fragmentarily (stay at the children's home). The skills and basic limitations of Marysia are thus known and accepted. However, it comes to light that a certain difference of the girl causes much disconcert to her mother – eating problems. Monika discovers not only her disability, but a certain difference in behaviour. She describes this in quite a lot of detail, because she ascribes to this a great signif-

²⁴ E. Goffman, *Piętno. Rozważania o zranionej tożsamości*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2007.

icance. The ability and the will to eat is one of the basic activities supporting life. The inability and dislike by Marysia to eat is like "defending herself against life" or life with her needs minimised. This is behaviour that is completely unknown and strange in her mother's view, who undertakes various efforts to understand them, uncover the causes and change them. So, in Monika, there arises the additional question of getting to know THAT particular person, her specific mode of functioning different from other deaf children.

The troubles of other people began with getting to know the specific child, its abilities and limitations, and the specifics of the disability. If we would consider signs related to a child's otherness that was included by the interviewees in their statements, then it emerges that not all of these were related to the disability itself. Some of them applied to the appearance and form of the body of the child, the (not always proper) medical diagnoses, others indicated otherness stemming from the experiences of the child with the biological family or care facility.

"FAS was suspected, and that disease – hepatitis C, as it turned out, it wasn't there [...]. It turned out later that there are still other flaws" (Lidia, adoptive mother of a six-year-old girl).

"She was frighteningly small [...] born in the 33rd week of pregnancy, she weighed 1300 grams, she should weigh over 2 kg, she had microcephaly, she did not have the bodily proportions of a newborn" (Judyta, adoptive mother of a seven-year-old girl).

The statements quoted above show a part of the diagnoses quoted by the interviewed parents. These span mainly medical statements. Others pertained to the behaviour of children. This was described in detail in the narrations of Anna and Antoni, who had adopted three-year-old Agnieszka:

"There were various suspicions, that she was sexually abused, she feared men. She was very withdrawn, scared. When she was told to stand, she could stand motionless all day. She was not trusting, par-

ticularly of men [...] Whatever one gave her, she hid it under her pillow [...] The beginnings were very difficult, she was a very inaccessible child. She always wanted things her way. She did things to spite me. [...] She was negative towards everything" (Anna).

"She was very scared. She was frighteningly distrustful, distanced" (Antoni).

Anna and Antoni describe specific behaviour of their daughter. Their statements clearly show the meeting of people from two different worlds: friendly-minded adults and a child that has a lot of negative experiences behind her. Beside symptoms of disability, a child accepted as an older one bears in itself the stigma of experiences from the former period of life. This might be some form of sexual abuse, physical or psychological violence. It is the cause of behaviour that in the described case (in the subjective view of the interviewees) manifested itself with negativism, timidness, withdrawing, motionlessness, "spitefulness", persistence, the child's "deceitfulness". The interaction of the parent with the child in such a case is a grand challenge, as seen in the memory of the mother's own powerlessness. The meeting between these two worlds (of the parents and the child who was hurt) causes an incongruence in their cooperation to emerge. Both sides try to "survive" and impose their "rules of the game", whereby both parties use strategies they had known up to that point. The parents use their knowledge on raising children, the child uses old mechanisms aiding survival (e. g. resists or shuts down, which enabled it to survive difficult situations until then).

The experience of a child's otherness brings about with itself correcting certain own and others' views of the child and its future, as told by one of the adoptive mothers – Judyta:

"But as I sat there in intensive care, my sister called, asking: how are things? Any progress? I told her: it's just that – no. And then my sister said: listen, when Justynka will already have your last name, I will get her an account and every month I will transfer a little something

for her. And when she'll be 18-19 years old, going to university, she will have some money of her own [...] ... And I got terrified, I said to my sister: listen, but I don't even know if she'll even be able to graduate from primary school. Nobody knows that, and the probability is high... maybe she'll just be able to grow a field of carrots. And my sister said: then she'll get a field of carrots (laughs)" (Judyta).

This statement includes the characteristic component of assigning Justynka a place in the family. Belonging to the family, being part of its system, means using its support, including financial support. Both sisters ponder the future of the little girl, and both would want the best for her, so they think about securing her future. In the discussion, however, a clash appears between the knowledge of Judyta on her daughter's difficulties, and the visions of her sister. In this briefly described dialogue, articulated is the possibility of emergence of intellectual difficulties of the child, with a simultaneous declaration of their acceptance and the reorganisation of the future "planned" for the child.

A further category placed by the parents in their statements were the causes for the observed signs of otherness in children. As it turns out, they seek the reasons for a part of these not only in the disability, but also in the environment, from which the child originates. This is partly even medically justifiable (as was in the case of Lidia and Judyta – their daughters suffered from FAS, being a result of the mother consuming alcohol during pregnancy), partly the parents may barely speculate that certain disorders are due to negative emotional, social, psychological experiences that the children had suffered in their biological families or at institutions. The environment of origin is not only held for the cause of disability, but of the different behaviour of the child as well:

"This was her way. It's not that she's bad, but she must have taken a lot from the environment she was raised in. She was in a group of children who would constantly argue and shout, and it was not possible that she would be positive towards you from the very beginning,

react to your questions or orders [...] In general, she did not want to go anywhere. She was afraid of everyone around her, because she was not certain of her footing, whether she's with us to stay [...] What ever did she have to go through as a child... When you raise one from a very young age, it's completely different" (Anna).

The interviewee is referring to (un)known history of a child, and she speculates that some of her behaviour is the result of past experiences. She's experiencing the otherness of behaviour of her adopted daughter even comparing her to children adopted just after birth. Fears, withdrawing or negativism are assigned to the feeling of uncertainty. The mother - what's important - is convinced that the child isn't "bad". She's not looking for sources in flawed genes, tendencies inherited from biological parents, but in experiences. Her 'speculations' were confirmed in the last decade in the thoughts of Alan Schore analysing the research of other scientists on the influence of neglect and violence aged up to the second year of age²⁵.

A further category of descriptions that is used by the parents in relating their first parenting steps in coping with the child's otherness are methods of dealing with emerging difficulties.

When it comes to the effects of unfavourable experiences in life, there regrettably are parents who only mention "home" coping methods. Here, professional support is missing. When in turn speaking of the effects of disabilities, some of the interviewees (in particular those who had little children) describe quite precisely the therapeutic and rehabilitation schemes. Lidia and Judyta describe a very intense period of rehabilitation right after taking the children in. They both met their adopted daughters soon after birth, and - as Judyta recalls - "*it was about getting as much from her as possible*". Lidia also stresses the purpose of the work: "*this was work to get her to develop faster, for certain things to subside faster, so that she could start*

²⁵ A. Schore, *The Effects of Early Relational Trauma on Right Brain Development, Affect Regulation, and Infant Mental Health*, "Infant Mental Health Journal" 2001, 22, pp. 201–269.

talking faster, so that she could start turning over faster, so that she could start walking faster [...] I wanted to do everything not to lose these first moments, because I knew they are very important to improve her functioning".

At this stage, what matters most is the intensity of effort, contact with many specialists that are able to guide the rehabilitation process, orientation towards specific minor goals, engagement of other members of the family. In both cases, the roles of the parent and the rehabilitation specialist intertwine. It's an intense, yet not stormy time – as opposed to families, in which disabled children are born. The interviewees accept the child, are joyous with it, are focused on it and not on their own feelings that also differ from those presented in the first stage by biological parents. Emotions are usually positive here, related to the initial euphoria of having "found" a child, and not to the shock related to the diagnosis of disability. Disability is an important component of the first interaction between mother and child, but it does not burden it negatively. The child does not lose its value if it has certain limitations.

The final category in descriptions that emerges in narrations concerning the first struggles with a child's disability/ otherness are the observed effects.

"I remember that the psychologist told me (laughs) to let go of these fears of the child's development already, because she was really already developing well" (Lidia).

"Justynka was really developing then. Then she turned cute, some people were appalled that a single person can get a child to raise, and such a cute one at that" (Judyta).

Successes (a veritable metamorphosis of the child) are confirmed by the environment. In both cases, from the very beginning, the child with their limitations is accepted in full, and this acceptance is not tied with passivity. In both families there is mobilisation, the faith in the possibility of improvement, and a crowning of efforts with success.

Summary

The beginnings of handling a child's disability were described by the interviewees in the following categories: discovering otherness based on experiencing daily life with the child, getting to know the symptoms present in children (medical, psychological and other diagnoses, reaching existing documents or obtaining the results of specialist tests), familiarising oneself with this particular case of difference, attempts at describing the reasons and initial methods of handling the difficulties, and obtaining and using specialist aid.

The research suggests some closing thoughts. A prior diagnosis of the child is important, because the improved awareness of the parents allows them to reach a responsible decision that will be free of negative emotions related to the uncovering of impediments. Such actions shall also permit the determination of the direction of the parents' actions, saving the parents "running around in circles" and destroying the chances for a child's better development – allowing the usage of all abilities and the entire potential of the child, the resources within it, and the resources of the parents and of the environment.

Examples of interviewees who had known the child earlier show just how this permission of mutual, spontaneous learning about one another of orphaned disabled children and people who may not necessarily be planning on being foster/ adoptive parents can be important and how it can open up the way for disabled children to adoptive/ foster families. The parents get to know the child as it is, and knowing its difficulties, may undertake the role of parents for it.

"A civilised world of people and values makes attempts at discovering various dimensions of humanity. It is keen to accept the unique that every one carries in them"²⁶. In case of the described

²⁶ Frąckowiak T., *Tożsamość człowieka upośledzonego umysłowo: niezrozumiałą odmienność, kryzys indentyfikacyjny i edukacyjny dylemat*, [in:] *Społeczeństwo wobec autonomii osób niepełnosprawnych*, ed. by W. Dykcik, Eruditus, Poznań 1996, p. 76.

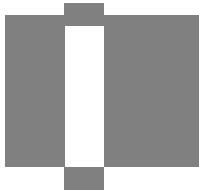
families, this is an attempt at discovering uniqueness that is carried within by the doubly-burdened children: by abandonment and disability, and also an attempt at making them valuable, needed, loved... The interviewees undertake the effort to handle the child's otherness, spanning on the one hand a specific disability, and on the other hand - abandonment, neglect or violence.

References

- Antoszewska B., *Matka jako animator w życiu dziecka niepełnosprawnego*, [w:] Współczesne problemy pedagogiki specjalnej, red. U. Bartnikowska, Cz. Kosakowski, A. Krause, Olsztyn 2008, s. 186–191.
- Bartnikowska U., Ćwirynkał K., *Dziecko z niepełnosprawnością w rodzinie adopcyjnej i zastępczej. Część I – zetknięcie się z niepełnosprawnością dziecka, analiza decyzji*, Kwartalnik „Szkice Humanistyczne” 2012a, XII, 2(28), s. 197–216.
- Bartnikowska U., Ćwirynkał K., *Dziecko z niepełnosprawnością w rodzinie adopcyjnej i zastępczej. Część II – jakość funkcjonowania rodzin*, Kwartalnik „Szkice Humanistyczne” 2012b, XII, 4(30), s. 199–216.
- Bartnikowska U., Ćwirynkał K., Rodziny adopcyjne i zastępcze dziecka z niepełnosprawnością, Oficyna Wydawnicza „Impuls”, Kraków 2013.
- Bartnikowska U., Ćwirynkał K., *Rodziny adopcyjne i zastępcze dziecka z niepełnosprawnością*, Oficyna Wydawnicza „Impuls”, Kraków 2013.
- Bartnikowska U., *Dziecko z uszkodzonym słuchem w rodzinie zastępczej – studium przypadku*, „Wychowanie na co Dzień” 2013, 1–2, s. 3–8.
- Bleszyński J.J., *Kluczowe zagadnienia przysposobienia i funkcjonowania rodzin adopcyjnych*, Oficyna Wydawnicza „Impuls”, Kraków 2010.
- Borowicz A., *Stres rodziców wychowujących dzieci z niepełnosprawnością słuchową, „Niepełnosprawność – zagadnienia, problemy, rozwiązania”* 2012, 2, s. 55–80.
- Chajda E., *Postawy wobec osób niepełnosprawnych*, Komunikat z badań. CBOS, Warszawa 2007, s. 8.
- Charmaz K., *Teoria ugruntowana. Praktyczny przewodnik po analizie jakościowej*, Warszawa 2009, s. 59–124.
- Ćwirynkał K., *Ojciec w wychowaniu i rehabilitacji dziecka z niepełnosprawnością*, [w:] *Edukacja i socjalizacja w życiu osoby niepełnosprawnej*, red. A. Klinik, D. Prysak, Oficyna Wydawnicza Humanitas. Wyższa Szkoła Humanitas, Sosnowiec 2011, s. 133–147.
- Ćwirynkał K., *Rodzina zastępcza z dziećmi z niepełnosprawnością intelektualną. Studium przypadku*, „Wychowanie na co Dzień” 2013, 1–2, s. 9–16.

- Frąckowiak T., *Tożsamość człowieka upośledzonego umysłowo: niezrozumiała odmiennosć, kryzys indentyfikacyjny i edukacyjny dylemat*, [w:] *Społeczeństwo wobec autonomii osób niepełnosprawnych*, red. W. Dykciek, Eruditus, Poznań 1996, s. 76.
- Gallant N., *What works in special needs adoption*, [w:] *What works in child welfare*, Child Welfare League of America, red. M. Kluger, G. Alexander, P. Curtis, Child Welfare League of America, Washington, DC, 2000, s. 227–234.
- Gath A., *Mentally Retarded Children in Substitute and Natural Families*, "Adoption and Fostering" 1983, 7, s. 35–40;
- Glidden L.M., Valliere V.L., Herbert S.L., *Adopted Children With Mental Retardation: Positive Family Impact*, "Mental Retardation" 1998, 26, 3, s. 119–125.
- Goffman E., *Piętno. Rozważania o zranionej tożsamości*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2007.
- Górnicka B., „Rodzicielski świat” matek i ojców wychowujących dziecko z niepełnosprawnością, [w:] *Rodzicielstwo w kontekście wychowania i edukacji*, red. J. Brągiel, P.E. Kaniok, A. Kurcz, Wydawnictwo UP, Opole, 2013.
- Hammersley M., Atkinson P., *Metody badań terenowych*, Poznań 2000.
- Husserl E., *Nastawienie nauk przyrodniczych i humanistycznych. Naturalizm, dualizm i psychologia psychofizyczna* (przełożył Z. Krasnodębski) [w:] *Fenomenologia i socjologia*, red. Z. Krasnodębski, Wydawnictwo PWN, Warszawa, 1989, s. 54–74.
- Kazanowski Z., *Przemiany pokoleniowe postaw wobec osób upośledzonych umysłowo*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2011.
- Krause A., *Człowiek niepełnosprawny wobec przeobrażeń społecznych*, Oficyna Wydawnicza „Impuls”, Kraków 2005.
- Kwaśniewska G., *Rodzina dziecka z przepukliną oponowo-rdzeniową*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2005.
- Lipińska-Lokś J., Skwarek B., *Rodzice w obliczu niepełnosprawności dziecka*, [w:] *Rodzicielstwo w kontekście wychowania i edukacji*, red. J. Brągiel, P.E. Kaniok, A. Kurcz, Wydawnictwo UP, Opole 2013.
- McGlone K., Santos L., Kazama L., Fong R., Mueller Ch., *Psychological Stress in Adoptive Parents of Special-Needs Children*, „Child Welfare” 2002, LXXXI, 2, s. 151–171.
- Minnis H., Everett K., Pelosi A.J., Dunn J., Knapp M., *Children in Foster Care: Mental Health, Service Use and Costs*, “European Child & Adolescent Psychiatry” 2006, 15, 2, s. 63–70.
- Muszyńska E., *Ogólne problemy wychowania w rodzinie dzieci niepełnosprawnych*, [w:] *Dziecko niepełnosprawne w rodzinie*, red. I. Obuchowska, WSiP, Warszawa 1999, s. 101–164.
- Ostrowska A., *Niepełnosprawni w społeczeństwie 1993–2013*, IFiS PAN, Warszawa 2015.
- Parchomiuk M., *Rodzice dzieci z mózgowym porażeniem dziecięcym wobec sytuacji trudnych*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin, 2007.
- Paulston R.G., *Pedagogika porównawcza jako pole nakreślania konceptualnych map teorii paradygmatów*, [w:] *Spory o edukację. Dylematy i kontrowersje we współczesnych pe-*

- dagogiąch*, red. Z. Kwieciński, L. Witkowski, IBE, Edytor, Warszawa – Toruń 1993, s. 41.
- Pisula E., *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwa Uniwersytetu Warszawskiego, Warszawa 1998.
- Pisula E., *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwa Uniwersytetu Warszawskiego, Warszawa 1998.
- Pisula E., *Rodzice i rodzeństwo dzieci z zaburzeniami rozwoju*, Wydawnictwa Uniwersytetu Warszawskiego, Warszawa 2007.
- Pomoc społeczna i opieka nad dzieckiem i rodziną w 2015 roku* (2016), Warszawa: Główny Urząd Statystyczny, pomoc_spoleczna_i_opieka_nad_dzieckiem_i_rodzina_w_2015.pdf [dostęp: 8.07.2017].
- Rosenthal J.A., Groze V., Aguilar A.G., *Adoption Outcomes for Children with Handicaps*, "Child Welfare" 1991, LXX, 6, s. 623–636.
- Rosenthal J.A., Groze V., Aguilar G.D., *Adoption Outcomes for Children with Handicaps*, "Child Welfare" 1991, LXX, 6, s. 623–636.
- Rosenthal J.A., *Outcomes of adoptions of children with special needs*, "The Future of Children" 1993, 3, 1, s. 77–88.
- Sakowicz-Boboryko A., *Rodzina jako realizator potrzeb rehabilitacyjnych dzieci niepełnosprawnych*, Trans Humana, Białystok 2005.
- Schore A., *The Effects of Early Relational Trauma on Right Brain Development, Affect Regulation, and Infant Mental Health*, "Infant Mental Health Journal" 2001, 22, s. 201–269.
- Twardowski A., *Sytuacja rodzin dzieci niepełnosprawnych*, [w:] *Dziecko niepełnosprawne w rodzinie*, red. I. Obuchowska, WSiP, Warszawa 1999, s. 18–54.



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The other in the early system of care and education

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Polish child care system for the disabled children offers some interesting solutions. However, lack of coherence in the management of individual groups of small-child outreach facilities makes it impossible for some solutions to be fully implemented. This problem concerns the system of nurseries and early support for the development of children.

KEY WORDS: young child, supporting the development, nursery

A young disabled child

Whenever any disability or other deficit is detected or only suspected in a child it is worth to take multiprofile actions aiming at supporting its development. It shall not only improve a current condition, but may also help to decrease or even reduce problems which might appear in future¹. Many disorders display a tendency to increase with age. Therefore the sooner a child receives treatment, the greater the probability that it will avoid many secondary difficulties.

¹ E. Reczek (1997), *Wczesna interwencja w Krakowie, „Światło i Cień”* No. 3/97.

We should also remember about the specific character of the development and growth of human nervous system. The younger a person is, the easier it is to compensate for many developmental deficits. It is closely connected with the so-called *brain plasticity*, consisting in ability of neurons to undergo permanent transformations². *Certain factors damaging central nervous system cells, such as: stress, some environmental factors, ischemia, anoxia, cerebral oedema and neurodegenerative diseases stimulate repair processes, resulting in creating new neurons. By repairing self-damage of certain areas, neurogenesis in pathological states, secures the ability of the brain to function properly. The developing nervous system displays the greatest ability to repair damage. The intensity of repair processes and compensating abilities weaken with age*³. Therefore young children make progress faster since their nervous system is more susceptible to stimuli than with adults⁴.

Since our knowledge of early stimulation is so vast, we may thus assume that omission of the treatment due to a limited access may result in irreversible changes in a child's nervous system. It may also prevent further developmental progress on such a level which would allow to e. g. implement a child in the peer environment⁵. Therefore, in order to effectively support the development of a young child with disability, the whole system of support for the child and its family shall be required.

² M. Borkowska (2001), *Uwarunkowania rozwoju ruchowego i jego zaburzenia w mózgowym porażeniu dziecięcym*, Warszawa, p. 32.

³ Quoted from J. Dorszewska (2008), Neurogeneza i plastyczność synaptyczna ośrodkowego układu nerwowego, in: Apoptoza w chorobach ośrodkowego układu nerwowego. ed. W. Kozubski, J. Dorszewska. Czelej, Lublin, pp. 45–64; K. Wójcik (2009–2011) Neurobiologia rozwojowa i inwolucyjna plastyczności mózgu, in: Neurokognitywistyka w patologii i zdrowiu, Pomorski Uniwersytet Medyczny, Szczecin, p. 165.

⁴ R. Stefańska (1997), Wczesna interwencja terapeutyczna – nadzieję i szansa na lepsze jutro dziecka, „Światło i Cień” No. 3/97.

⁵ Text compiled on the basis of A. Mikler-Chwastek (2011), *Dotykowe poznawanie otoczenia. Diagnoza i wspomaganie rozwoju małych dzieci*, Wydawnictwo APS, Warszawa, pp. 16–17.

Support system for parents of small disabled children

In Poland a parent whose child is struggling with developmental difficulties according to the law may expect various forms of support e. g. financial allowances and tax reliefs. These are the following:

- nursing aid
- nursing benefit;
- child benefit;
- supplement to the family allowance for education and rehabilitation of a disabled child;
- co-financing from PFRON (State Fund for the Rehabilitation of the Disabled) to rehabilitation holidays, rehabilitation equipment, orthopaedic items and aids;
- rehabilitation relief, while settling with Tax Office a parent is entitled to deduct the rehabilitation related expenses from his/her income;
- support from NFZ (National Healthcare Fund may partly finance the purchase of orthopaedic items and aids and long-term nursing care).

The aforementioned offers refer to financial aid, whereas parents may also receive psychological support. They participate in various support groups and self-help groups. However, such groups are established as a bottom-up initiative. Foundations and associations offering a variety of extensive help are often established thanks to the efforts of the parents of disabled children in reaction to lack of systemic solution. However, it should be remembered, that allowances and financial support are only a part of the whole range of needs. Organising professional help in the form of multi-profile support for the development of the child with detected disability is becoming equally essential.

In order to meet the needs of children and their families in 2013 a tool was created for providing additional support in the form of *Early developmental support*.

Early developmental support for a child inaccessible in a nursery

The Ordinance of the Minister of National Education of 11 October 2013 provides conditions for organising early support for the development of children, aiming at stimulation of psychomotor and social development of a child from the moment the disability is detected, until it begins its school education⁶. Thus the Ordinance covers young children with detected and documented disability. However, this is when the difficulty lies. Such early support may be organised in a kindergarten and a primary school, including special schools, and also in other forms of pre-school education and centres⁷, as well as in public and non-public psychological-educational counselling centres, including specialist clinics, if such units can realize the recommendations included in the opinion stating the necessity to provide early support of a child's development, have didactic aids and equipment indispensable for providing early support. Yet the Ordinance does not pertain to nurseries and children's clubs, which are not the responsibility of the Minister of National Education, but the Minister of Family, Labour and Social Policy. Thus children attending nurseries cannot participate in the procedure of early support of development in a unit where they spend a couple of hours daily. It means that units providing professional care to the youngest children cannot provide WWRD service (early support of development of children), despite the fact that their children fulfil all the requirements (e. g. have the opinion stating the need for an early support of the development).

⁶ It is Worth to differentiate between early therapeutic intervention (treatment and rehabilitation) and early support of development (psychological and educational impact). Early intervention is provided by healthcare system (National Healthcare Fund, rehabilitation centres), whereas early support of development is provided by education institutions. cf. <http://www.zespoldownia.info/roznica-wczesna-interwencja-a-wczesne-wspomaganie.html/23.05.2017>.

⁷ Article 2 point 5 Law of 7 September 1991 on the education system.

The Ordinance allows for the possibility to organise WWRD at home (*classes as a part of early support, in particular with children under the age of 3, may be conducted also in their own homes⁸*). However, one should remember, that the very possibility to spend time with a group of peers is a form of support for the child's development and may be additionally strengthened by therapeutic activities organised in the unit.

Thus a question arises, where we can find some help for a child who does not yet attend a nursery, and already suffers from disturbed development? Integration nurseries seem to be the solution here. Apart from everyday classes in the form of play, music classes, self-service activities, a child may be provided professional support tailored to its individual needs (e. g. Sensory Integration classes, rehabilitation according to Bobath concept). Such classes are offered by the integration nurseries.

Nursery – a place for an effective treatment of a young child

For every parent, and particularly for a parent of a disabled child, a transition of the child into a nursery is a difficult moment. We are dealing with a very small child (under 3 years of age), who has not collected much experience, especially with regard to peer relations. Besides, during this period difficulties with communications occur as a natural consequence of development and thus a considerable majority of children struggle with it, which causes adults to worry about the way the child will be able to communicate its needs and worries.

It should be remembered that recently a significant change has taken place with regard to management and organisation of nurseries in Poland. On 4 February 2011 Act on care for children under

⁸ The Ordinance of the Minister of National Education of 11 October 2013 on organising early support for the development of children, § 5.1.

the age of 3 (*Ustawa o opiece nad dziećmi w wieku do lat 3*) was adopted. Due to this legal act nurseries are no longer the responsibility of the Ministry of Health, but are taken over by the Ministry of Family, Labour and Social Policy. And consequently, the whole system of providing care, education and support of the development of such a young child has undergone changes.

Thanks to the involvement of the Comenius Foundation for Child Development (Fundacji Rozwoju Dzieci im. J.A. Komeńskiego) recommendations have been produced in the form of a document: Quality standards of the care and support of a development of a child under the age of 3 *Standardy jakości opieki i wspierania rozwoju dzieci do lat 3*⁹. A caretaker employed in such unit is currently required to provide safety for children, tender care, but also to be able to organize the whole system of support of development. In practice, the unit should ensure children considerable comfort in every aspect of their functioning. The recommendations are connected with the organisations of rooms and immediate environment:

- Theme corners furnished with real objects,
- Children have access to materials stimulating their senses,
- Children have access to materials for manipulation,
- All materials and toys should be directly accessible for children,
- equipment made mostly of natural materials,
- natural materials accessible for manipulative and constructive play,
- natural landscape is preserved, so that children can run, climb, dig, rake leaves, water flowers, etc.

Caretakers should provide optimal conditions for child development, therefore they have to:

- know the stages of a child development in all of its aspects,
- know the rules governing health prevention and protection, prevention of accidents,

⁹ M. Rościszewska-Woźniak (2012), *Standardy jakości opieki i wspierania rozwoju dzieci do lat 3*, Fundacja Rozwoju Dzieci im. J.A. Komeńskiego, Warszawa.

- know the rules of healthy nutrition,
- know the dynamics of a group process, development of an individual in a group, rules of establishing social relations in child groups,
- know conditions favourable for establishing bonds and positive social relations of young children,
- know the best way to arrange the area in order to facilitate the development of a young child,
- acquire the knowledge of the young child education,
- know the requirements to be met by the toys for young children,
- have the knowledge about the sexual development of a child,
- have the knowledge of certain legal aspects of the care of children and protection against abuse,
- have the knowledge of emergency medicine,
- know how to observe and interpret a child's behaviour in terms of its developmental needs,
- know how to recognise signals given by children related to e. g. its physiological needs, fatigue, etc.,
- be able to communicate with a child, ask questions, conduct a conversation, stimulate linguistic development,
- be able to cooperate with other adults, communicate with them, share tasks,
- have the skill of working with a group,
- be able to organise classes stimulating children's curiosity (arts, music, physical activity, cooking, natural science),
- be skilled at solving problems,
- be ready to conduct physical activities with children (caretakers with disabilities of locomotor system they work with the assistance of a person without disabilities),
- be able to detect problems faced by children and assess whether a given situation requires the assistance of a specialist,
- be able to provide first aid to a child,
- be able to plan and document their work with children.

Also some attention was drawn to personal traits of character of a caretaker who should:

- have readiness to a change, be curious of the world,
- be patient and able to control one's behaviour,
- be sensitive to the environment and other people,
- be ready to reflect and capable of critical consideration,
- display readiness to learn,
- be ready to accept, refrain from judgement or assessment,
- be ready to play,
- be flexible (can adapt its activity to dynamic changes of a situation),
- respect other people's individuality¹⁰.

Methods of supporting development of young children offered by nurseries

In order to meet the expectations of parents of the disabled children, directors and staff of nurseries try to organize a system of support. Although the system of early support of a child's development cannot formally function in nurseries, yet fortunately, employing effective forms and methods of support and hiring professional staff is possible.

Children with disorders related to chewing and gnawing, as well as those struggling with delayed speech development can count on the assistance of a **speech therapist**. Parents can learn proper stimulation to continue the speech therapist's work at home. Owing to this cooperation, a child's progress is more easily noticeable, whereas a therapeutic process may be continued regardless of the presence of the child in the facility (e. g. sickness or holidays).

Many institutions decide to hire a **psychologist**, whose task is often to make the first diagnosis of a child. In case of some children,

¹⁰ Recommendations prepared on the basis of M. Rościszewska-Woźniak (2012), *Standardy jakości opieki i wspierania rozwoju dzieci do lat 3*, Fundacja Rozwoju Dzieci im. J.A. Komeńskiego, Warszawa.

developmental disorders appear by the end of the first year of age or in the early childhood. Therefore, it is in the nursery that some deficits are detected. An experienced caretaker can assess which child requires additional support. A child psychologist has different tools at his/her disposal which he/she may use even with very young children. As an example, Psychomotor Development Assessment Cards are used (*Karty Oceny Rozwoju Psychoruchowego*) (KORP)¹¹.

A psychologist's task is also to provide care for parents who have to face developmental disorders of such a small child.

An interesting offer for children struggling with disorders of the motor development are **classes conducted by a physiotherapist**, often a NDT – Bobath therapist. In the medical community this method is considered highly effective, safe and useful in the therapy of the youngest children. It is the physiotherapist's task to properly influence muscular tension (reducing excessive tension and increasing the reduced one), reducing improper reflexes, inducing movements comparable to proper ones, consolidating the acquired motor skills in everyday activities.

The important thing is that the results achieved thanks to the application of Bobath method may be strengthened at home by parents themselves, who, to be honest, are not specialists, yet they ensure a proper care of the child, methods of feeding and playing¹². When properly prepared by a therapist, they will manage much better with the implementation of basic tasks, but also will be able to continue series of exercises at home¹³.

¹¹ It is a standardised tool, designer for initial assessment of a child's development. It helps to establish if a child under diagnosis displays harmonious development in accordance with the expectations determined for every age bracket.

¹² In Bobath method, which is often used with children with motor disability, e. g. suffering from cerebral palsy, a therapist teaches parents, how to provide proper care, how to carry them, feed and change them in order to strengthen therapeutic effects. Such organisation of a therapy helps to avoid consolidation of improper patterns.

¹³ M. Matyja, M. Domagalska (1998), *Podstawy usprawniania neurorozwojowego według Berty i Karla Bobathów*, Wydawnictwo Śląskiej Akademii Medycznej, Katowice

Other significant method of supporting development is a **music therapist**. In nurseries we find eurhythms classes and music classes, but many institutions introduce also elements of music therapy¹⁴. Mobile Music Recreation (Mobilna Rekreacja Muzyczna) is worth mentioning, in which sources of sounds related to our body are used (clapping, stamping, whistling etc.), and also strengthens the influence of music with all kinds of exercises: rhythmic, motor, breathing, imagination, relaxation, percussion, forms of art, literary and drama. The author of this method, M. Kierył, has determined its 5 basic stages, which can be narrowed down to five keywords: release, rhythm, awareness, recreation, stimulation in Polish establishing the acronym of OZURA:

Stage 1 - **O**, namely releasing (clapping, stamping, jumping, shouting) making a few simple spontaneously dynamic movements.

Stage 2 - **Z**, adding rhythm, namely strengthening the rhythm of music by movement or playing instruments.

Stage 3 - **U**, evoking awareness by integrating music with art, literature, may also consist in playing simple instruments.

Stage 4 - **R**, recreation, consists in learning various forms of rest with the use of music, breathing exercises while lying or sitting.

Stage 5 - **A**, means stimulation by rhythmic exercises, dancing, singing. Mild activation (easy exercises in the lying position, moving to a standing position through sitting position); dynamic activation (exercise done at a pace).

Sensory Integration Therapy is another interesting way to complete a therapy of a child with development disorders. Many

ce; Z. Szwiling, P. Zawitkowski (1998), *Podstawy pielęgnacji i opieki nad małym dzieckiem wg zasad NDT-Bobath* [in:] Warszawskie warsztaty neurologiczne. Materiały wybrane 1996–1997, Poradnia Diagnostyki i Terapii Neurologicznej POLEK, Wydawnictwo Polskiego Stowarzyszenia Terapeutów NDT-SI, Warszawa; http://www.ndt-bobath.pl/?page_id=65/29.05.2017.

¹⁴ Cf. M. Kierył, *Mobilna Rekreacja Muzyczna – MRM*, w: <http://www.zdrowamuzyka.pl/pdf/mrm.pdf/29.05.2017>. Cf. <http://www.zlobki.waw.pl/zlobki.php/poradnik.php?z=23&pid=14799>

institutions invest in special facilities for rooms¹⁵ and therapist training, since SI method may be used already with very young children.

Already the youngest children with difficulties within SI suffer from: excessive sensitivity to sensory stimuli, lack of or excess of sensitivity to sensory stimulation, display too low or too high level of physical activity, difficulties in concentration, have reduced motor skills, coordination problems, display delays in development of speech. Such behaviour is visible already in the early childhood, therefore it seems reasonable to make use of SI method in the nursery.

Summary

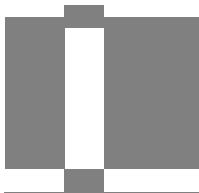
Although the Programme of Early Support of Development of a Child cannot be applied to nurseries (they are not managed by The Ministry of National Education (MEN), and thus are not subject to its legislation) yet, directors and caretakers try to organize support in such a way which would meet the expectations of children and their parents. Many institutions, both public and non-public, hire professional staff and invest in necessary equipment. Therefore parents may use the Programme of Early Support of Development of a Child at home (law provides for that) and take advantage of a valuable offer of nurseries, which will certainly have a positive impact on a child's development.

References

- Borkowska M. (2001), *Uwarunkowania rozwoju ruchowego i jego zaburzenia w mózgowym porażeniu dziecięcym*, Warszawa.
- Dorszewska J. (2008), *Neurogeneza i plastyczność synaptyczna ośrodkowego układu nerwowego*, in: *Apoptoza w chorobach ośrodkowego układu nerwowego*, W. Kozubski, J. Dorszewska. Czelej (ed.), Lublin.

¹⁵ Si therapy room is properly equipped, in terms of, e. g. swings, rolling pins, mattresses, springboards. Cf. <http://poradnia-ada.pl/sala-integracji-sensorycznej-si/>

- http://www.ndt-bobath.pl/?page_id=65 29.05.2017
- <http://www.zespoldowna.info/roznica-wczesna-interwencja-a-wczesne-wspomaganie.html> 23.05.2017
- <http://www.zlobek.duna.pl/23.05.2017>
- Matyja M., Domagalska M. (1998), *Podstawy usprawniania neurorozwojowego według Berty i Karla Bobathów*, Wydawnictwo Śląskiej Akademii Medycznej, Katowice.
- Mikler-Chwastek A. (2011), *Dotykowe poznawanie otoczenia. Diagnoza i wspomaganie rozwoju małych dzieci*, Wydawnictwo APS, Warszawa.
- Reczek E. (1997), *Wczesna interwencja w Krakowie, „Światło i Cień”* No. 3/97.
- Rościszewska-Woźniak M. (2012), *Standardy jakości opieki i wspierania rozwoju dzieci do lat 3*, Fundacja Rozwoju Dzieci im. J.A. Komeńskiego, Warszawa.
- Rozporządzenie Ministra Edukacji Narodowej z dnia 11 października 2013 r. w sprawie organizowania wczesnego wspomagania rozwoju dzieci.
- Stefajska R. (1997), *Wczesna interwencja terapeutyczna – nadzieja i szansa na lepsze jutro dziecka, „Światło i Cień”* No. 3/97.
- Szwiling Z., Zawitkowski P. (1998), *Podstawy pielęgnacji i opieki nad małym dzieckiem wg zasad NDT-Bobath*, [in:] *Warszawskie warsztaty neurologiczne. Materiały wybrane 1996–1997*, Poradnia Diagnostyki i Terapii Neurologicznej POLEK, Wydawnictwo Polskiego Stowarzyszenia Terapeutów NDT-SI, Warszawa.
- Ustawa z dnia 7 września 1991 r. o systemie oświaty.
- Wójcik K. (2009–2011) *Neurobiologia rozwojowa i inwolucyjna plastyczności mózgu*, in: *Neurokognitywistyka w patologii i zdrowiu*, Pomorski Uniwersytet Medyczny, Szczecin.



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The crisis of parents of a child with a disability in the perspective of new normalisation tools

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Social and cultural transformations determine the functioning of a disabled child's family. The Internet, support groups or associations are the new normalisation tools parents can use. They can affect both the structure of his or her parenting as well as the process of coping in difficult situations. The author analyses the social and emotional situation of parents of children with disabilities, based on her research. They describe the significant categories and areas important for further scientific exploration.

KEY WORDS: family system, child with disability

Introduction

Learning about the specifics of functioning of the family of a child burdened by a disability constitutes a topic that is important both in the perspective of holistic support of child development, as well as in areas of analysis of the integration of disabled people and the normalisation of the social environment. The societal and cultural changes taking place, as well as transformations of paradigms

in special-needs education¹ cause the family, as the environment closest to the disabled person, to also fall under specific influences. Through changes and transformations, it thus creates new areas of scientific exploration. The disability of a child influences the formation of a new quality of family functioning. Hence, learning about the process of coping with the emotional crisis caused by the child's disability, as well as the formation of the identity of the parent, is key both from the standpoint of the support offered to the family, as well as the meanings societally bestowed upon the family of a disabled child. Long years of practice in the area of work with parents, as well as analyses of subject literature and the scientific research conducted by me on the functioning of the family of the disabled child had made me aware of exactly just how important is exactly the parent's coping with the emotional crisis for the relation of the parent with the child, the therapist, and the societal environment.

Own research

I would like to develop my thoughts on the crisis of the parents, after they had received the disability diagnosis of a child, based on two of my studies:

- a netnographic study concerning the societal functioning of the family of an intellectually-disabled child, conducted as part of a problem reconstruction of the research of H. Borzyszkowska;
- a pilot study concerning the coping by parents with the emotional crisis constituting the aftermath of a child's disability diagnosis – in the form of interviews with 20 parents of disabled children, who are covered with early development support;

¹ Conf.: A. Krause, *Współczesne paradygmaty pedagogiki specjalnej*, Oficyna Wydawnicza „Impuls”, Kraków 2011.

The first of these studies, concerning the societal functioning of the family of a disabled child, was an inspiration to develop the indicated topic. This study constituted a vital component of the problem reconstruction of the study by H. Borzyszkowska, concerning the societal isolation of the families of intellectually-disabled children.² The study made use of netnography and an analysis of visual material. The study group was composed of a forum and six blogs written by parents of children with intellectual disabilities. The study had a qualitative character, and the analysis was conducted within the constructivist paradigm. Conclusions stemming from it thus do not have the properties of generalisations. They indicate, however, certain tendencies and possibilities that may mark the functioning of contemporary families of disabled children. An important category that came up during the analysis of the research material were specifically new normalisation tools. I consider this term to encompass the possibilities utilised by those under study in the coping strategies they had developed. These are, among others, making use of the Internet, cooperation with associations and foundations, general access to psychological and therapeutic help. Being aware that the described study concerns a specific group – parents that are active on-line – I conclude that the indicated possibilities constitute normalisation tools influencing the societal and emotional situation of families of disabled children, of which these parents can make use.

The societal and emotional situation of the family seems to be, in the perspective of my studies and analysis, the aftermath of coping with stress and difficulties (crises) implied (generally speaking) by the child's disability. Specifically in this area, the meaning of new normalisation tools that can be of importance to the coping strategies developed by the parents increases. For instance, the Internet as a source of knowledge makes it easier for parents to seek and find information both on difficulties, diseases, as well as on the

²Conf.: H. Borzyszkowska, *Izolacja społeczna rodzin mających dziecko upośledzone umysłowo w stopniu lekkim*, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk 1997.

possibilities of searching for support. This is important in the area of the parents countering problems, and makes them feel more competent e. g. in the relations with medical personnel or therapists. At the same time, through forums and blogs, the internet forms for parents the place of formation of social relations and where they receive emotional support from, even contributing to the formation of the identity of a parent of a disabled child.³

The main constituent components of analyses of the situation of the parent of a disabled child are the emotional crisis of the parents of children with disabilities, and the stress they feel.

*"A crisis within the family is a transitional state of system disarrangement, requiring the implementation of changes in order to restore internal stability and balance. These changes pertain to rules, patterns of interaction, the roles taken and the family structure. A family in crisis is characterised by a particular set of properties that, from the societal point of view, are unwanted, and it does not fulfil its functions."*⁴ In this perspective, the crisis appears as a process of adaptation of the family to the new situation caused by factors of change. The force of the child's disability, as the factor determining the crisis, is dependent on other aspects of functioning of the family – its socio-economic situation, the characteristics of the parents, their bonds as well as abilities to adapt and fit in. The crisis of the parents is described in most cases of musings in this topical area. Changes taking place in our society seem, however, important in the perspective of coping with the crisis, as does – as I have already indicated – the possibility of usage of new normalisation tools in the coping strategies developed by the parents.

In literature on the subject, in characterising the situation of the family of a child suffering from a disability, the authors frequently refer to the descriptions of emotional experiences after they receive

³ Conf.: J. Doroszuk, *Sytuacja społeczna rodzin dzieci z niepełnosprawnością. Rekonstrukcja problemowa badań H. Borzyszkowskiej*, Uniwersytet Gdańsk, 2015, unpublished thesis, pp. 233–270.

⁴ B. Matyjas, *Dzieciństwo w kryzysie: etiologia zjawiska*, Wydawnictwo Akademickie „Żak”, Warszawa 2008, p. 107.

news of their child's disability, by A. Twardowski. He indicated the following periods: of emotional shock or distress, also referred to as the critical period, of emotional crisis, of apparent adaptation, and the period of constructive adaptation.⁵ The description of the process of the family adapting itself to the disability of the child by A. Twardowski emerged based on a reference of the author to research conducted in the 1970s by J.C. Ewert, M.M. Green and L. Rosen. The indicated emotional states, experiences or tendencies may for the most part be universal and timeless in character. Very important in the indicated description is also e. g. the presentation of the shaping of the acceptance of the parent with respect to the disabled child as a process, as well as the indication of the possibility of existence of a dichotomy between the behaviour of the parent and their emotions (e. g. in the period of the so-called apparent adaptation).

Worth considering, however, seems the fact that the strategies of coping by the parents with a crisis situation were at the time (1970s) not determined by such factors as e. g. support groups, on-line forums or training seminars and courses for parents of children with disabilities. In addition, due to the societal and cultural changes, the domination of the humanist direction over the medical direction, as well as the increase of individualistic tendencies (yielding a positive meaning to being different), questions emerge on the current influence of external factors on the situation of parents of disabled children. Meaningful in this perspective seem also changes in the structural and functional arrangement of the family.⁶ In addition, contemporaneously, even A. Twardowski indicates a systemic foundation of relations within the family.⁷ As a consequence, new areas emerge that are worth scientific study, e. g. strategies implemented

⁵ A. Twardowski, *Sytuacja rodzin dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, ed. by I. Obuchowska, WSiP, Warszawa 1991, pp. 21–27.

⁶ Conf.: F. Adamski, *Rodzina. Wymiar społeczno-kulturowy*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2002, p. 145.

⁷ Conf.: A. Twardowski, *Wczesne wspomaganie rozwoju dzieci z niepełnosprawnościami w środowisku rodzinnym*, Wydawnictwo Naukowe UAM, Poznań 2012.

by the parents for obtaining help or the sphere of communication of the parents with medical personnel or with other specialists working with the child, as well as the roles taken on by the parents and their influence on the level of acceptance of the disability of the child.

Understanding the acceptance of a child's disability by the parent as a linear process characterised by specific stages is confronted in literature of the subject with the presentation of the acceptance of the child by the parent as a cyclical process dependent on external factors.⁸ Developmental progress of the child or the support received may contribute to positive changes in the psycho-societal situation of the parent and the meanings assigned by them thereto. Specific issues and challenges, in turn, which the parent stumbles upon, seem to be akin to distracting factors, negatively burdening the situation of the parent and causing the stress they experience to increase.

The stress of parents is described as one of the consequences of a child's disability.⁹ It applies to the fact of the disability or illness of the child itself, and is also a consequence of the difficulties (related for instance to the functioning of the child, reactions of the environment or additional obligations) that the parents have to face every day. The type of impediment to the functioning of the child is indicated as a factor of importance for the level of stress experienced by parents.¹⁰ As those most susceptible to experiencing stress are indicated the mothers of children with disorders from the autism spectrum, which may be conditioned, among others, both by the impaired possibility of forming the mother-child relation (due to the spectrum of disorders of the autistic child), as well as by reactions from the social environment (the disability of the child is in

⁸Conf.: D. Poston, A.P. Turnbull, J. Park, H. Mannan, J. Marquis, M. Wang, *Family quality of life: a qualitative inquiry*. "Mental Retardation" 2003, no. 41, pp. 313–328.

⁹Conf.: E. Pisula, *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwo Uniwersytetu Warszawskiego, Warszawa 1998, pp. 48–94.

¹⁰Conf.: R.M. Hodapp, R.C. Urbano, *Adult siblings of individuals with Down syndrome versus with autism. Findings from large scale US survey*, "Journal of Intellectual Disability Research" 2007, no. 51, pp. 118–129.

many cases not clear, whereas their behaviour differs from socially acceptable norms).¹¹ The stress experienced by mothers – in particular in the perspective of the research of M. Sekułowicz – is even indicated as one of the factors – besides hopelessness, frustration or isolation – influencing the exhaustion of strength of parents of children with disabilities.¹²

Understanding the situation of the parent of a child with a disability as marked by the experienced stress and the coping with the crisis (or crises) against the backdrop of the changes in the functioning of the family as indicated above makes me inclined to perform a problem reconstruction of the phenomenon of the crisis of a parent of a disabled child. For this purpose, I have conducted a pilot study, the main aim of which was to get to know the socio-emotional situation of parents of children with disabilities in the first years of life of the child. Aiming to perform an analysis of the experiences and trials of parents, I have oriented the studies towards quality.¹³ The main problem was for me the question of the perception by the parents of their socio-emotional situation against the backdrop of their child's disability. I have arranged the specific detailed issues around such phenomena as: obtaining the diagnosis of disability, defining the disability by the parent, support received by the parent, roles taken by the parents as well as the support of the child's development.

M. Łobocki points out that "*understanding the phenomenon means as much as seeing it from the perspective of people that it applies to, meaning, recreating the subjective traits of significance assigned to it [...]*".¹⁴

¹¹ Conf.: Cunningham C.C., *Families of children with Down syndrome*, "Down Syndrome Research and Practice" 1996, no. 4, pp. 87–95.

¹² Conf.: M. Sekułowicz, *Wypalanie się sił rodziców dzieci z niepełnosprawnością*, Wydawnictwo Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław 2013.

¹³ Conf. M. Szymański, *O znaczeniu badań jakościowych nad wartościami*, [in:] *Z badań nad wartościami w pedagogice*, ed. by W. Furmanek, Zakład Dydaktyki, Techniki i Informatyki Uniwersytetu Rzeszowskiego, Rzeszów 2006, p. 51.

¹⁴ M. Łobocki, *Wprowadzenie do metodologii badań pedagogicznych*, Oficyna Wydawnicza „Impuls”, Kraków 1999, p. 87.

Considering the singular and unique dimension of experiences within the field of parenthood marked by disability, the qualitative interview seemed to me to be the effective route towards getting to know the perspective of the parent, with the purpose of this interview being – as S. Kvale points out – “[...] achieving an interpretation of the description of the world of experiences of the interviewed person”.¹⁵

The interviews were conducted by female students of the IIInd year of master's complementary studies in the field of special education – early child development support, at the University of Gdańsk, within the framework of the course I teach – working with the family of a little child. Before commencing the interviews, I determined together with the students the key issues in the area of methodology of the study and the questions aimed at appropriately guiding and steering the interview towards learning the answers to the set research problems. I analysed the interviews personally. I did, however, also discuss them with the students as part of the university lectures, thanks to which I was able to learn the interpretations by the special education guides beginning their professional careers and, also, their work with parents.

The research sample was composed of 20 parents (19 mothers and one father), the children of which make use of early development support. Each of the studied persons has a child (or children) with a mobility disability (five parents), an intellectual disability (two), a sensory disability (two) or with multiple disabilities (four), or experiencing disorders from the autism spectrum (seven). The interviews varied in size and level of detail due to the different modes of narration by the parents, as well as due to the amount of time that they were able to devote to me to provide the interviews. The research material in total covers several dozens of pages of transcriptions.

The material analysis process encompassed:

- reading the research material, with simultaneous marking of fragments of importance in terms of the research questions;

¹⁵ Kvale S., *InterViews. Wprowadzenie do jakościowego wywiadu badawczego*, Wydawnictwo Uniwersyteckie „Trans Humana”, Białystok 2009, p. 17.

- reading the marked fragments, underlining key words or sentences, creating specific categories based on these;
- assigning selected fragments to research questions;
- a synthesis of specific research problems according to the topics of issues;
- an analysis and verification of the delineated categories.

The categories that I have delineated are:

1. The conscious and demanding parent;
2. Fixed assignment of roles in the family of a disabled child;
3. Parent "in action" – focus of the parent on coping with difficulties;
4. The Internet as an important source of knowledge;
5. Fear related to the child's future.

In the descriptions of these, I shall provide examples from the statements of the parents, and I will also endeavour to indicate the areas that to me seem meaningful for the purpose of further analyses and scientific exploration.

Ad. 1. The conscious and demanding parent

The decisive majority of the analysed parents described their expectations concerning the child's therapy and education very precisely. The statements of the parents encompassed both the way the child should be guided, the exercises that the therapist should choose, and the attitude that they were supposed to represent, as well as the types and forms of support that were due to the child from therapeutic and educational agencies.

Sample statements by parents:

Paulina's mother¹⁶: *"It looks the way it looks, there is talk that schools should implement everything that the consultation offices prescribe. On the other hand, there is the act of law that when it comes to the headmaster, they get... Paulina received very good additional financing, because she has multiple disabilities, and the headmaster re-*

¹⁶Out of respect for privacy, the children's names were altered.

ceives per each division, meaning, per any given class, financing for ten hours per week, meaning, if there are five children, these are two classes, and if Paulina should be attending sensory integration, a course with a speech therapist, rehabilitation and eye therapy, these are already four classes, and there are five children. So it is like that, two children in rehabilitation, while she should be exercising only and exclusively so to speak very precisely focusing on the given exercise and rehabilitation type so that she, well, would be doing sit-ups, but not all the way, or not reaching the floor all the way with her bottom, more at a right angle at the knees, she has habitual dislocation of the patellae, so these patellae can make holes in the knees, the patellae are on the side, because she has such soft joints. Also to be guided by the therapist, she should not be doing this on her own. So the therapist chooses exercises if I may say so blah blah, because this is the way rehabilitation is in school. I tell You, the consulting agencies say one thing, the law says another, the headmasters are all confused and we have to look elsewhere. And this is what it really looks like"

Jaś's father: "In order to be a good therapist, one has to empathise with the child. Simply, if they don't want to do it, then the child does not have to do it. The courses have to be attractive, so the child can eagerly participate. If they are not attractive, they won't cooperate."

Bartek's mother: "Sadly umm the process of finding the preschool that would be an integrated one, that would offer the therapy that I wanted, was very long, so I kept searching and searching."

Characteristic in this regard were also other statements of the interviewees concerning changes of the location, therapies or therapists that would not fulfil the parents' requirements.

I look for the cause of such conscious and demanding attitudes of parents both in the limited capacities of the system on the level of early child development support, as well as in the better access to knowledge, even specialised knowledge. The lack of systemic support (even in terms of provision of information) for the parent in the area of medical care and therapy for the child qualifies the shift onto

them of the responsibility for the development of their disabled child. Common access to the Internet, literature as well as training courses and seminars, in turn, causes the parent of a disabled child to more often have – in the given area concerning the specifics of functioning and needs of their descendant – knowledge that surpasses that of the education specialist or therapist, particularly of those that are just beginning their professional work.

The indicated modes of behaviour, attitudes or needs of the interviewees seem impactful against the backdrop of the cooperation of parents with education specialists, therapists or the education or therapy agencies. A parent with knowledge and one that is certain of their convictions concerning the support for the child's development is a challenge to the people working with their child. In this aspect, accordingly, considerations and analyses concerning the quality and the forms of cooperation with parents, as well as those applying to the place and role of the parent within the interdisciplinary team working with the disabled child, seem to be key.

Ad. 2. Fixed assignment of roles in the family of a disabled child

The fixed assignment of roles in the family of a child, in the form of the person providing care and the one providing for the family by gainful work, is traditional in character, however, it can still be seen in many families, irrespective of the level of fitness or abilities of the child. In analysing the statements of the interviewed mothers, however, I have noticed factors accentuating their situation. Namely, the burden on the interviewees is decidedly greater. Activities amounting to care are in many cases maximised due to the limited level of self-sufficiency of the child, or due to their needs (e. g. catheterisation). In addition, the interviewees indicated, among others, the need to take the child to the therapy by road, continue therapy at home, arrange additional financing as well as purchasing and maintaining rehabilitation equipment. Significant is also the fact that the time spent by the parent of a disabled child at home is not transitional (as is the case with maternity leave or child care leave), but can continue for many years, or even all of the child's life. However,

the increased costs of supporting the development and functioning of the disabled child imply engaging the second parent in gainful work. The fixed assignment of roles in the family of a disabled child and the negative emotions and stresses this may cause between the parents are described e. g. by the statement of the mother of Julek about her relationship with the husband:

"There were fights between us. There was lack of understanding. I envied him that he's going to work, getting out. At the time I thought that his life had not changed at all, that he's got it great. He goes to work, sees people and does what he ever did. And my life turned upside down, didn't it... Because I had to arrange everything, I had to let go for instance my off days, thoughts about myself. Anything, even simple shopping, because my thoughts were just the clinic, the hospital, the agency, rehabilitation, prescriptions and caring for the ill child. I thought I'd go crazy and this also impacted the fact of my arguments with Krzysiek."

In this regard, the phenomenon that I would call a systemic conditioning of the fixed assignment of roles, as indicated e. g. by the mother of Michał, would seem significant:

"One thing! Another thing that could be useful, it's related to finances and organisation, so that one could tie their benefits with gainful employment. Because now you either work or you don't work at all and you get your benefits. When you get benefits, you cannot work at all, and work in a case like that is often like salvation. In the sense that if you go to work, you forget what you leave behind at home."

Beside the specific characteristics of the functioning of a child that might require care and the presence of a parent around the clock, conditions of receiving financial benefits constitute an important factor imposing a fixed assignment of roles in the family. Its consequences in the socio-emotional situation of the mothers (who usually remain home with the child), the internal family relations, even in the aspect of acceptance of the disability of the child by the

parents are described by me as important for further scientific analyses research, as well as in terms of considerations on the optimisation of systemic support.

Ad. 3. Parent "in action" – focus of the parent on coping with difficulties

Paulina's mother: "*However this focus on Paulinka for health reasons is very strong. Kajka has quite a few problems with nutrition. And I constantly sit in the kitchen. Paulinka can only eat very little. Yesterday it was just the pancakes for Paulina that she had for yesterday and today, I froze some of them, and the time I spent on these pancakes is 2.5 hours. [...] We try to live normally in these abnormal conditions.*"

The above quite is one of the many statements of parents concerning the additional duties that arise from the specifics of functioning and the needs of a disabled child (duties that often are great burdens for the parents). The majority of the interviewees spoke of additional activities concerning care, preparation of educational aids, implementation of the recommendations of therapists or including therapy in everyday life, arranging equipment supporting the functioning of the child, hospital visits, visits to therapy centres or rehabilitation tours at special facilities. The day of the interviewees is in many cases backed from dawn until dusk by activities that they have, or feel obligated, to do.

Significant in this area is also the importance ascribed by the parents to therapy in the process of support of the child's development. The majority of the analysed children participates in the week in many different therapies that almost completely take up their free time (and fill the time of the parent who participates in therapy or waits for the child). An example here can be a fragment of the statement of the mother of Martyna describing her day:

"Short quick breakfast and at 8 we go to the integrated preschool. Martyna stays there for six hours. At two, I pick Her up from pre-

school and we go to additional courses. The courses are varied, every day they're different and take place elsewhere. When we get home, we continue work at home and around six, Martyna goes to bathe [...] After her bath, around eight, she falls asleep, and sometimes she sleeps eight hours, sometimes four, it's really varied here with us. This is what our typical day looks like. On Saturdays we additionally go to courses in Bydgoszcz."

Referring to the research of M. Sekułowicz on the burn-out of the strength of mothers of disabled children¹⁷, as indicated above, I stress the importance that the psychological and physical condition of the parent, lack of rest, time for themselves, the ability to form a distance to their role may have to their emotional fitness. The statements of the interviewees also show tension between the experienced weariness and the burdens on the one hand, and such categories as acceptance of the 'difficult' behaviour of the child, cooperation with therapists or forming social relations. Important in this regard seems consideration of the optimum support of the disabled child at the simultaneous burden of the parent. In the perspective of analyses of the research material, this seems important in terms of the parent processing and handling the issue of the child's disability, and for the purpose of reinforcing their relationship with the child.

Ad. 4 The Internet as an important source of knowledge

In their statements, all interviewees underscored the importance of the Internet as a significant source of knowledge, both on the illness or the disability of the child, as well as the options of treatment or therapy and obtaining system support. Important, however, in light of my earlier research, seems to be the fact that none of the parents mentioned the Internet as the "place" they receive social and emotional support. Thus, blogs or on-line forums constitute

¹⁷Conf.: M. Sekułowicz, *Wypalanie się sił rodziców dzieci z niepełnosprawnością*, Wydawnictwo Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław 2013.

normalisation tools that in this aspect are unused by the interviewees, even though the great majority describes themselves in their statements as lonely or isolated from their social environment (by lack of time as well). In this regard, there arise questions concerning the formation of social relations of parents of little disabled children and position of the Internet in the area of their social activities.

Ad. 5 Exposure of the difficulties in accepting the disability of a descendant in the process of setting out the goals for the support of the child's development

During analyses of the interviews, it came to light that a reply to the question concerning the future of the child posted a great difficulty for almost half of the interviewees. Observed can also be a broad dichotomy in the emotional charge of statements concerning on the one hand the daily functioning, therapy or relations with the child and those concerning the goals set in the framework of support of the child, and the way the parent sees their descendant in a few years, exemplified e. g. by the statement of the mother of Martyna:

"I cannot imagine that Martyna would not be able to speak... It is still difficult for me to cope with the thought that Martyna has an intellectual disability... Thanks to our work, Martyna started to walk when she was two. I don't know what it would be like today, if I wouldn't have worked on it, she probably would not be walking today. We struggle all the time, we don't give up. Let's hope it just gets better and time will tell what happens. Frankly, I sometimes have enough of this... In reality, I am all alone with this, but I struggle on, struggle for Martyna to have a better future. Maybe once, one day, she would stand in my room, we could watch old photos together, the way it once was and the way it is now... We would speak about what we've fought out in these difficult times. Maybe she would thank me for this once and I still have it in my head that she would once tell me I LOVE YOU MUM!"

The question concerning the future of the child confronted the parents with their own fear, sorrow and hope. The majority of the

interviewees seems quite strongly focused on the present, a fact that is also determined by the great burdens I have indicated above. In this perspective, a "parent in action" is a parent who has no ability and no time to process the topic of the disability of their child, and, in consequence, to accept it. Contrary to what may seem the case, the attitude of the parent that is often expected from the therapeutic and education environment, meaning – strong engagement of the interviewees in the therapy, setting goals, compensating, balancing and facilitating – can make coping with the negative emotions difficult.

The properties of the process of acceptance of the child and their disability by the parent constitute an area of scientific research that I intend to explore further. The discussed pilot study indicates activity in the category of parenthood and motherhood burdened by disability in areas such as acceptance of disability or support for the child's development.

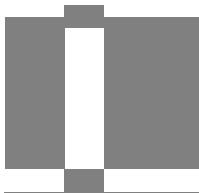
Summary

To summarise the conducted pilot study and my thoughts on the topic of the emotional crisis of the parent of a disabled child, I would like to stress just how important and complex the process of formation of parenthood is in light of the child's disability, in the period of their early childhood. Characteristically, the new attitudes of the parents of disabled children, their greater knowledge and awareness of the expectations of therapies and therapists or the focus on the child's rehabilitation process, do not exclude difficulties or burdens that mar being a parent of a disabled child. The socio-emotional situation of the interviewed parents, an outline of which I had attempted to convey, encourages to conduct further reflections and studies concerning the factors implying the parents coping with emotions and difficult (crisis) situations, and suggests an aim towards studying the moments of "transition" between the subsequent stages of emergence of the identity of the parent of

a disabled child. Understanding the drivers behind the behaviour of parents by special education professionals may in turn contribute to an expansion of the area of their considerations of support offered to the family of a disabled child.

References

- Adamski F. (2002), *Rodzina. Wymiar społeczno-kulturowy*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków.
- Borzyszkowska H. (1997), *Izolacja społeczna rodzin mających dziecko upośledzone umysłowo w stopniu lekkim*, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk.
- Cunningham C.C. (1996), *Families of children with Down syndrome*, "Down Syndrom Research and Practice", no. 4.
- Doroszuk J. (2015), *Sytuacja społeczna rodzin dzieci z niepełnosprawnością. Rekonstrukcja problemowa badań H.Borzyszkowskiej*, Uniwersytet Gdańsk, unpublished thesis, pp. 233-270.
- Hodapp R.M., Urbano R.C. (2007), *Adult siblings of individuals with Down syndrome versus with autism. Findings from large scale US survey*, "Journal of Intellectual Disability Research", no. 51.
- Krause A. (2011), *Współczesne paradygmaty pedagogiki specjalnej*, Oficyna Wydawnicza „Impuls”, Kraków.
- Kvale S. (2009), *InterViews. Wprowadzenie do jakościowego wywiadu badawczego*, Wydawnictwo Uniwersyteckie „Trans Humana”, Białystok.
- Łobocki M. (1999), *Wprowadzenie do metodologii badań pedagogicznych*, Oficyna Wydawnicza „Impuls”, Kraków 1999.
- Matyjas B. (2008), *Dzieciństwo w kryzysie: etiologia zjawiska*, Wydawnictwo Akademickie „Żak”, Warszawa.
- Pisula E. (1998), *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwo Uniwersytetu Warszawskiego, Warszawa.
- Poston D., Turnbull A.P., Park J., Mannan H., Marquis J., Wang M. (2003), *Family quality of life: a qualitative inquiry*. "Mental Retardation", no. 41.
- Sekułowicz M. (2013), *Wypalanie się sił rodziców dzieci z niepełnosprawnością*, Wydawnictwo Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław.
- Szymański M. (2006), *O znaczeniu badań jakościowych nad wartościami*, [in:] *Z badań nad wartościami w pedagogice*, ed. by W. Furmanek, Zakład Dydaktyki, Techniki i Informatyki Uniwersytetu Rzeszowskiego, Rzeszów.
- Twardowski A. (1991), *Sytuacja rodzin dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, ed. by I. Obuchowska, WSiP, Warszawa.
- Twardowski A. (2012), *Wczesne wspomaganie rozwoju dzieci z niepełnosprawnościami w środowisku rodzinnym*, Wydawnictwo Naukowe UAM, Poznań.



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From early signs of autism to attachment relationship – development of social relationships of children with autism spectrum disorders in contacts with relatives

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Autism is a vast developmental disorder with significant delays and problems in participation in alternate social interactions. Studies show that nearly half of the population with various forms of autism participates in social life, although their profile of emotional and social deficits remains highly diversified. Impairment within a social sphere includes a limited disposition and ability to recognize, to understand and to engage in human contact and interpersonal communication. Parents / guardians are the first observers of disturbing behaviors of a child and the first initiators of building a close relationship with their offspring. Their observations are the determinants of the criteria of early detection of autism spectrum disorders. The biggest problem for parents is the inability of their children with autism to show affection. The goal of this article is to show the development profile of social relationships of young children with autism in contacts with their relatives and the analysis of conditions in the child – parent attachment relationship in this group of disorders.

KEY WORDS: autism spectrum disorders, early signs of autism, early social-emotional development, relationships with loved ones, autism and attachment

Introduction

Following contemporary diagnostics criteria autism spectrum disorders are characterised by qualitative disorders of the ability to participate in alternate social interactions¹. It is stressed that in the population with the autism spectrum disorders a significant diversity of the social-emotional relations demonstrated in contact with relatives is observe². Research show that nearly half of the people with autism in various forms participate in social life³, despite the fact that their social-emotional skill-deficit profile is highly diversified⁴. Disabilities related to social sphere are multifaceted within the population. It covers limited abilities and skills to recognise, comprehend and engage in a contact with another person as well as distorted social skills enabling them to enter in, initiate, or engage in proper social interactions and interpersonal communication⁵. Characteristic symptoms of irregularities in establishing social-emotional relations by children with autism spectrum disorders are gradually displayed with intensity changing in time. The ability to establish close relationships is perceived as a continuous process, yet also a dynamic one⁶.

¹ E. Pisula, *Od badań mózgu do praktyki psychologicznej. AUTYZM*, Wydawnictwo GWP, Sopot 2012, pp. 30–40; S. Ozonoff, G. Dawson, J.C. McPartland, *Wysokofunkcjonujące dzieci ze spektrum autyzmu. Poradnik dla rodziców*, Wydawnictwo Uniwersytet Jagielloński, Kraków 2015, pp. 213–43.

² K. Markiewicz, *Charakterystyka zmian w rozwoju umysłowym dzieci autystycznych*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2007, pp. 88–89.

³ M. Talarowska et al., *Psychologiczne koncepcje rozwoju autyzmu*, [in:] T. Pietras, A. Witusik, P. Gałecki (ed.), *Autyzm – epidemiologia, diagnoza i terapia*, Wydawnictwo Continuo, Wrocław 2010, p. 111.

⁴ C. Saarni, *Kompetencja emocjonalna i samoregulacja w dzieciństwie*, [in:] P. Salovey, D. Sluyter (ed.) *Rozwój emocjonalny a inteligencja emocjonalna*, Dom Wydawniczy REBIS, Poznań 1999, p. 80; E. Pisula, *Mate dziecko z autyzmem. Diagnoza i Terapia*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2005, p. 32.

⁵ A.J. Cotugno, *Terapia grupowa dla dzieci z zaburzeniami ze spectrum autyzmu. Rozwijanie kompetencji i umiejętności społecznych*, Wydawnictwo Fraszka Edukacyjna, Warszawa 2011, p. 43.

⁶ S.L. Greenspan, S. Wieder, *Dotrzeć do dziecka z autyzmem. Jak pomóc dzieciom nawiązywać relacje, komunikować się i myśleć. Metoda Floortime*, Wydawnictwo Uni-

Parents/ guardians become first observers of disquieting behaviour of their child, but also are the first to initiate the process of establishing close relationship with their offspring. The observations they make become indicators for the criteria of early detection of autism spectrum disorders. The greatest problem for the parents is inability of autistic children to display attachment, and even to differentiate between relatives and strangers. The development of attachment in this group of disorders is to a high extent conditioned by the level of social-emotional development of a child. However, it should be emphasized that in terms of expressing emotional bonds with parents, internal diversity is observed within the whole population of people with autism spectrum disorders. Different forms of expressing attachment are equivalent to neither inability to establish emotional bonds, nor to a particular type of bond⁷.

First contacts of a child with close relatives vs. signs of autism

Social skills disorders of children with autism spectrum become evident quite early. Some of the worrying symptoms become vivid during the development process, before the child is diagnosed with autism. The first social bonds of a child are established in its contact with its mother, therefore disorders pertaining to this relation are perceived as a highly significant signal indicating the development of autism⁸. Difficulties in expressing emotions, distorted social contact or a total lack of such contact in young children is considered a warning signal and one of the first indicators of disorders in

wersytu Jagiellońskiego, Kraków 2014, p. 27; S.J. Rogers, G. Dawson, *Early Start Denver Model dla małych dzieci z autyzmem. Wspieranie komunikacji, uczenia się i rozwoju społecznego*, Wydawnictwo Fundacja rozwiązać Autyzm, Warszawa 2015, pp. 4–8.

⁷ E. Pisula, *Autyzm i przywiązywanie. Studia nad interakcjami dzieci z autyzmem i ich matek*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2003, p. 51.

⁸ H. Jaklewicz, *Autyzm dziecięcy*, [in:] A. Popielarska, M. Popielarska (ed.), *Psychiatria wieku rozwojowego*, Wydawnictwo Lekarskie PZWL, Warszawa 2000, p. 118.

expressing and understanding emotions and establishing proper social relations with other people, which appear in future in this population. Moreover, the problem is noticed by parents relatively early, since it causes specific difficulties in contact with a child⁹.

Studies devoted to mother-child interaction indicate that a healthy newborn is equipped with the ability to fine-tune to social situations, particularly in terms of synchronizing interactions, imitating, seeking eye contact in reaction to a mother's voice. From the very moment it is born, a healthy newborn child prefers human faces and sounds related to speech. Around 6 weeks of age the so-called social smile appears, and around 6–8 months an infant can distinguish between faces of the close relatives and reacts with fear to the faces of strangers¹⁰.

From numerous observations it follows that already in the first months of a child's life it is disturbing if a child fails to show that it cares about its contact with the mother, a close guardian¹¹. It shows poor eye contact, lack of facial expressions and a typical inability to assume a bodily posture expressing readiness and desire to be taken into someone's arms¹². It most often prefers solitude, shows lack of interest in physical contact with another person, displays indifference, and even unwillingness with regard to such contact. It acts as if the members of its family were outside its field of interest¹³. It does not react with emotional excitement when seeing its mother, does not return a smile, does not cuddle. When a close relative holds it in their arms – it seems to be "distant", "withdrawn",

⁹ E. Pisula, *Małe dziecko..., op. cit.*, pp. 67–68.

¹⁰ G. Jagielska, *Objawy autyzmu dziecięcego*, [in:] J. Komender, G. Jagielska, A. Bryńska (red.), *Autyzm i zespół Aspergera*, Wydawnictwo Lekarskie PZWL, Warszawa 2009, p. 36.

¹¹ T. Gałkowski, *Usprawnianie dziecka autystycznego w rodzinie*, Wydawnictwo PTWK, Warszawa 1980.

¹² L. Wing, *Związek między zespołem Aspergera i autyzmem Kanner'a*, [in:] U. Frith (ed.), *Autyzm i zespół Aspergera*, Wydawnictwo Lekarskie PZWL, Warszawa 2005, p. 117.

¹³ E. Pisula, *Wspomaganie osób z zaburzeniami należącymi do autystycznego spektrum w perspektywie psychopatologii rozwojowej*, [in]: J. Trempała (ed.), *Psychologia rozwoju człowieka*, Wydawnictwo PWN, Warszawa 2011, p. 449.

"absent". When held in someone's arms it may become stiff or frail, actively defend itself against being hugged or, when taken into someone's arms, fail to interact with the guardian¹⁴. It generally dislikes play involving frolicking or tickling. A child can even fail to react with joy and excitement seeing its mother approach or remain indifferent when she walks away. It can make an impression that it needs no presence and attention of the close relatives, being often too calm or agitated. Majority of the autistic children in an early period of their life fails to display the so-called separation anxiety related to the separation from an important, close persons, most frequently their mother. They demonstrate evident satisfaction when left to themselves and act as if there were no other people around them¹⁵.

Although some children display some emotional attachment to their guardians, yet they do not react to the love and emotions they are shown in a way which might be expected by those who offer them. As it follows from the parents' remarks, their children are reluctant to open their arms and cuddle when experiencing pain, anxiety, threat or to seek consolation. They even seem to be unaware that such possibility exists. The parents are disturbed by the fact that the children do not distinguish between them and objects they are fascinated with and that they prefer a contact with their favourite toy instead of a physical closeness with their parent¹⁶. Usually a child seeks a contact with objects and mechanisms, rejecting a close contact with a person, since inanimate objects do not evoke the most important, and thus the strongest emotions: bond, joy caused by emotional contact, sense of security or closeness. Due to their oversensitivity to external stimuli and emotional overload,

¹⁴ J. Morrison, *DSM-5 Bez Tajemnic. Praktyczny przewodnik dla klinicystów*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2016, p. 41.

¹⁵ G. Jagielska, *Objawy autyzmu..., op. cit.*, p. 38; Morrison J., *DSM-5 Bez Tajemnic..., op. cit.*, p. 41–42; J. Ball, *Autyzm a wczesna interwencja. Rzeczowe pytania, życiowe odpowiedzi*. Wydawnictwo Harmonia Universalis, Gdańsk, 2016, pp. 55–56.

¹⁶ P. Randall, J. Parker, *Autyzm. Jak pomóc rodzinie*, Gdańskie Wydawnictwo Psychologiczne, Sopot 2010, p. 99, 146.

a child selectively withdraws from the contact with close relatives preferring inanimate objects, which are emotionally neutral, therefore predictable and safe. One of the most crucial mechanisms of that kind is lack of intentional staring at people, seeking to contact with them. Such symptom gradually grows to become the essence of autism and its axial feature¹⁷.

Young children with suspected autism display huge diversity of emotions expressed in social contact with the close relatives. From indifference, "alienation", ignoring, panic fear in reaction to separating them from their mothers, to strong and richly diversified emotions proving the attachment to close relatives¹⁸. Ability to experience powerful emotions may be demonstrated, for instance, by the feeling of longing for a guardian and home when faced with a temporary or long separation¹⁹. However, such reactions are rather rarely observed. Family members find it hard to recognise and understand such emotional states, especially given the fact that a child with speech impairment, disturbed facial expressions, gestures, eye contact and bodily posture is unable to precisely inform its close relatives and the environment of its experiences and needs. Moreover, its capability to express emotions is considerably constrained. It uses some kind of a special private communication code. It employs such code in an idiosyncratic non-universal way often based on irrelevant associations established in result of one random event and then schematically ingrained²⁰.

Sometimes we even observe different forms of establishing specific contact with close relatives by the children with autism spec-

¹⁷ H. Olechnowicz, R. Wiktorowicz, *Dziecko z autyzmem. Wyzwalanie potencjału rozwojowego*, Wydawnictwo PWN, Warszawa 2012, pp. 10–11; M. Piszczek, *Autyści. Indywidualne i grupowe metody terapii. Zajęcia adresowane dla Rodziców*, Wydawnictwo STECKO, Warszawa 2014, p. 64.

¹⁸ K. Markiewicz, *Charakterystyka zmian...*, op. cit., p. 89; E. Pisula, *Autyzm i przywiązywanie...*, op. cit., p. 51.

¹⁹ A. Rynkiewicz, *Zespół Aspergera. Inny mózg. Inny umysł*, Wydawnictwo Harmonia, Gdańsk 2009, p. 50.

²⁰ L. Wing, *Związek między...*, op. cit., p. 116.

trum disorder. They may appear particularly in relation to a chosen person who spends most time with them, taking care of them, playing or meeting their needs and desires. It seems reasonable since other adults, (e. g. older siblings) do not evoke the same sense of closeness or security, when the children feel threatened or are in need of something²¹. It has been observed that some of them demonstrate their need of contact by standing sideways, or even turning their backs on the person talking to them. Sometimes they tend to employ objects which are important for them, the so-called talismans (e. g. a string, a crayon, a building brick) when they want to express their need, show some emotions or achieve their goal²². They pull, jerk, pinch, tap with their favourite object on the close person, they let the person touch the object and hold it. They schematically repeat the same question or expression (e. g. "How are you?"), demanding an immutable reply ("ok., I'm fine"), caress their hair, the same parts of the body, they admit the person to come close, and sometimes even give a handshake or a hug. Usually an emotional expression of a child in such contact is bizarre, unclear, lacking precision or subtlety, namely the whole range of gestures, facial expressions, bodily posture. Such child sends numerous contradicting unreadable signals. It sometimes happens that a complete stranger may be hugged, caressed, whereas dissatisfaction with a member of a close family may be demonstrated in a way inadequate to the situation²³. They are definitely incapable of adjusting their own behaviour to reactions and behaviour of other people²⁴. They however employ non-typical forms of establishing contact with close relatives. What makes matters even worse is that the children with autism spectrum disorders fail to receive non-verbal signals, which form a significant part of communication. They

²¹ S.L. Greenspan, S. Wieder, *Dotrzeć do dziecka...*, op. cit., pp. 26–27.

²² A. Rybka, A. Garncarz, *Stymulowanie rozwoju emocjonalnego u osób z autyzmem*, [in:] J. Kossewska (ed.), *Kompleksowe wspomaganie rozwoju uczniów z autyzmem i zaburzeniami pokrewnymi*, Wydawnictwo „Impuls”, Kraków 2009, p. 143.

²³ T. Attwood, *Zespół Aspergera*, Wydawnictwo Zysk i S-Ka, Poznań 2006, p. 50.

²⁴ R.H. Schaffer, *Psychologia dziecka*, Wydawnictwo PWN, Warszawa 2009, p. 178.

neglect the tone of voice, facial expression, body talk, in other words all the clues which are learnt to be recognised by children displaying regular development through everyday contact with other people²⁵.

What draws particular attention is avoiding eye contact by a child. Parents indicate that a child actively avoids such contact or is unable to maintain it. It may cover its eyes, turn its face away when called, observe objects out of the corner of its eye, demonstrate a far-off look, as if staring into an empty space", "through a person"²⁶. A child is only slightly interested in a human face, the sight and voice of its mother²⁷. It does not fix its eyes on its mother's face, does not follow her eyes, reacts with no emotional excitement to her, particularly to her look, smile or gestures²⁸. Disturbed facial expressions are among characteristic features ("mask-like face"), as well as lack of warm joyful expression accompanying a look, a rare smile and a typical inability to assume bodily posture, expressing readiness and willingness to be taken in someone's arms²⁹. A social smile appears rarely, sometimes looks artificial, stiff, as if stuck onto a child's face³⁰. Also the time spent looking at people is quite short³¹. Children rarely move their eyes from an object to a person's face. Studies devoted to the analysis of a direction in which they look indicate that children displaying this kind of disorder less often look into the eyes of the observed people, whereas they prefer to follow their lips moving as well as the rest of the body (cf.:

²⁵ J. Ball, *Autyzm a wczesna interwencja...*, op. cit., p. 36.

²⁶ G. Jagielska, *Objawy autyzmu...*, op. cit., p. 38;

²⁷ J. Błeszyński, *Autyzm a niepełnosprawność intelektualna i opóźnienie w rozwoju. Skala Oceny Zachowań Autystycznych*, Wydawnictwo Harmonia Universalis, Gdańsk 2011, p. 61; D. Senator, *Przejawy autyzmu w pierwszym roku życia*, „Pediatria Polska” 2006, No. 2, p. 128.

²⁸ H. Jaklewicz, *Autyzm dziecięcy...*, op. cit., p. 118.

²⁹ L. Wing, *Związek między...*, op. cit., p. 117.

³⁰ E. Pisula, *Małe dziecko...*, op. cit., p. 32; H. Jaklewicz, *Autyzm dziecięcy...*, op. cit., p. 118–119.

³¹ P. Randall, J. Parker, *Autyzm. Jak...*, op. cit., p. 99, 146.

L. Speer et al., 2007)³². A child does not react when called by its name, at the same time paying attention to other sounds in its environment. Sometimes a child's name must be repeated many times before its attention is drawn to the person calling it³³. A visible deficit is also a difficulty related to imitating emotional states of other people. A child is incapable of sharing joy, sorrow, pain or fear with other people. Lack of vocal-emotional expression in the forms of "ooo", "uu" and negligent or completely absent repertoire of interactive gestures, e. g. waving "bye-bye" seems to be typical too³⁴. It is accompanied by lack of proper gestures and expressing emotions by bodily posture. As a result a limited repertoire of social behaviour combining a look, mimic expression, tone of voice and gestures is prevailing³⁵.

A child engages in relations mostly with family members in order to satisfy its need, e. g. it wants a toy. It often uses a palm of a person standing nearby (treating an adult's hand as a tool for satisfying its needs)³⁶. It is incapable of participating in regular social interactions, based on a scheme "giving - taking". Its inability to alternately participate in a dialogue is quite disturbing. Even if a child initiates a contact with a participant of the interaction it can rarely maintain such contact³⁷. It cannot use body language or other non-verbal behaviour to communicate, e. g. smiling or nodding which is used by most of us to express approval³⁸. A young child at this phase of development of autism is already unaware that people

³² E. Pisula, *Wspomaganie osób..., op. cit.* p. 448.

³³ D. Senator, *Przejawy autyzmu..., op. cit.*, p. 129.

³⁴ M. Skórczyńska, *Wczesne diagnozowanie autyzmu – perspektywy i dylematy*, [in:] B. Winczura (ed.), *Autyzm Na granicy zrozumienia*, Wydawnictwo „Impuls”, Kraków 2009, p. 48.

³⁵ E. Pisula, *Wspomaganie osób..., op. cit.*, p. 449.

³⁶ H. Jaklewicz, *Autyzm dziecięcy..., op. cit.*, p. 119.

³⁷ E. Pisula, *Stres rodzicielski związany z wychowaniem dzieci autystycznych i z zespołem Dawna, „Psychologia Wychowawcza”, 1993, No. 1, p. 45; M. Piszczeck, Autyści. Indywidualne..., op. cit., pp. 12-13.*

³⁸ J. Morrison, *DSM-5 Bez Tajemnic..., op. cit.*, p. 41.

communicate and exchange thoughts, using looks, body language and speech sounds. It sees the movements and hears sounds of speech, yet does not know that there is some meaning hidden behind them, a message to be read and used³⁹.

Parents often claim that their child is too quiet, silent, withdrawn from any contact, hardly active, even apathetic and uninterested in an environment or playing with siblings and other children⁴⁰. It hardly ever purposefully focuses its attention on other people, fails to create a common field of attention, does not exchange messages with its parent or sibling, which is particularly noticeable during play. At the end of the 1 year of age the environment may notice lack of play consisting in imitating, and later no "make-believe" play related to pretending and using objects in a symbolic way. The play is often solitary, involves no contact with people, usually sensorimotor and/or ritualistic, lacking imagination. A young child may repeatedly place objects in a row, in piles or spin them. It may arrange or organize toys always in the same way, collect certain objects, arrange sticks, building bricks according to a certain repetitive scheme⁴¹.

With its development a child gradually begins to display further symptoms of spectrum of autism in the field of communication, expressing and understanding emotions and establishing social relations⁴². The observations most frequently signalled by the parents or close guardians of these children are:

³⁹ S.J. Rogers, G. Dawson, L.A. Vismara, *Metoda wczesnego startu dla dziecka z autyzmem (ESDM). Jak wykorzystać codzienne aktywności, aby pomóc dzieciom tworzyć więzi, komunikować się i uczyć*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2015, p. 68.

⁴⁰ E. Pisula, *Autyzm u dzieci. Diagnoza, klasyfikacja, etiologia*, Wydawnictwo PWN, Warszawa 2000, p. 117.

⁴¹ E. Wiekiera, *Strategia postępowania z dziećmi autystycznymi*, Przekład z „Engagement”, *Poradnik praktyczny dla rodziców*, Wydawnictwo Krajowe Towarzystwo Autyzmu Oddział w Krakowie, Kraków 1995, p. 13; G. Jagielska, *Objawy autyzmu...*, op. cit., p. 40.

⁴² B. Nason, *Porozmawiamy o autyzmie Przewodnik dla rodziców i specjalistów*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2017, pp. 321–234.

- is incapable of establishing close relationships with family members,
- does not greet people, lacks spontaneous reaction to its parent/guardian,
- is poor at expressing emotions, or does it in an improper way yet typical only of it, hardly ever shares its emotions with its relatives,
- fails to notice and read emotions of other people, relatives in its environment, does not share joy, sorrow or fear⁴³
- does not use typical gestures in order to establish social contact,
- its facial expression is quite poor, especially while interacting with its mother,
- does not understand 'personal space' – comes too close or runs too far away from people in its immediate environment,
- is unable to initiate a play with toys, when instructed by its parent, it can play with simple objects, fragments of toys; however, it is seldom spontaneous in interaction with others⁴⁴,
- displays no natural interest in children (peers) or may even ostentatiously avoid them,
- expresses no readiness to play with its parents, siblings, no interests in social play⁴⁵,
- displays limited ability to imitate and fails to participate in play connected with pretending with other children; routine models are observed instead, as well as stiffness, lack of ingenuity or imagination involved in play⁴⁶,

⁴³ A. Wolski, *Diagnoza autyzmu u malego dziecka – implikacje do pracy w rodzinie, „Rewalidacja”* Czasopismo dla nauczycieli i terapeutów, 2010, No. 2 (28), p. 24; A. Wolski, *Dominujące i drugorzędne kryteria diagnostyczne – ich struktura u dzieci, u których zdiagnozowano autyzm*, [in:] T. Żółkowska, M. Włazło (ed.), *Edukacja i Rehabilitacja osób niepełnosprawnych OBLICZA TERAPII, Pedagogika Specjalna – koncepcje i rzeczywistość*, vol. IX, Wydawnictwo Naukowe WH MINERWA, Szczecin 2013, pp. 323–347.

⁴⁴ S.L. Greenspan, S. Wieder, *Dotrzeć do dziecka...*, op. cit., p. 28.

⁴⁵ A.J. Cotugno, *Terapia grupowa...*, op. cit., p. 45.

⁴⁶ E. Pisula, *Autyzm u dzieci...*, op. cit., p. 118; E. Pisula, *Wspomaganie osób...* op. cit., p. 447.

- contacts with relatives assume unusual form, mainly as attachment to routine, related to one particular person, its behaviour, forms of communication, satisfying a child's needs, yet quite rarely with emotional bond⁴⁷,
- is unable to share its interests and feelings with other people, or establish peer relations proper for its age,
- fails to employ non-verbal behaviour (such as eye contact, facial expressions, bodily posture and gestures) to modify social contacts⁴⁸,
- does not recognise or understand the need for social exchange with other people and its correlations,
- finds it difficult to understand and appreciate other people's thoughts and emotions (theory of mind deficit) and shows no empathy or care with regard to feelings and emotions of others⁴⁹,
- seeks no consolation from either parents or anyone else (siblings, grandparents),
- has no social imagination and reciprocate no social relations⁵⁰.

In the studies carried out by G. Dawson and J. Osterling⁵¹, on the grounds of the analysis of the video recordings taken by parents, it was observed that between 8 and 12 months of age such children spend less time watching other people, their reactions are weaker when relatives try to draw their attention (e. g. calling them by their names) and make no early gestures (such as pointing), typically made by children and helpful in making progress in social communication. The way such children experience contact with the environment, relatives, differs to a great extent from that of their peers. They spend less time [on such contact], concentrating mainly

⁴⁷ E. Wiekiera, *Strategia postępowania..., op. cit.*, p. 13.

⁴⁸ E. Pisula, *Wspomaganie osób..., op. cit.*, p. 447.

⁴⁹ S. Baron-Cohen, *Mindblindness: An essay on autism and theory of mind*, Cambridge Mass., MIT Press, London 1995.

⁵⁰ A.J. Cotugno, *Terapia grupowa..., op. cit.*, p. 45.

⁵¹ G. Dawson, J. Osterling, *Early recognition of children with autism: A study of first birthday home videotapes*, "Journal of Autism and Developmental Disorders" 1994, No. 24, pp. 247–257.

on objects and have significantly limited experience in terms of communication⁵².

The most significant symptoms in recognising autism spectrum disorders are social-emotional disorders and disturbed social communication. Early assessment of autism spectrum disorders in young children is usually introspective in character and is based mainly on information supplied by parents/relatives/guardians of such children. On average parents begin to notice developmental problems around nineteenth month of age; a relatively small group notices various irregularities during the first year of life of a child, and a significant majority only about two years of age⁵³. Although it is assumed that the observations made by the parents are highly subjective, vitiated by an error of emotional involvement, and sometimes even distorted by the passage of time and the knowledge of possible, erroneous earlier opinions, it is still their remarks on the child's development and behaviour, most often described and justified with precision, that facilitate and accelerate the detection of disorders of the child contributing to formulating a proper diagnosis and thus to the choice of an adequate therapy for a child⁵⁴.

It is well known that parents' participation in the process of early intervention for a child threatened with autism is essential and decisive. Studies show that therapies conducted by parents may increase a child's verbal and non-verbal skills, as well as those connected with play, thus improving their mutual relations⁵⁵.

⁵² S.J. Rogers, G. Dawson, L.A. Vismara, *Metoda wczesnego startu dla dziecka z autyzmem (ESDM)...*, op. cit., p. 68; R. Palomo, M. Belinchón, S. Ozonoff, *Autism and family home movies: a comprehensive review*, "Journal of Developmental and Behavioral Pediatrics" 2006, No. 27 (2, Suppl.), pp. 59–68.

⁵³ M. Skórczyńska, *Wczesne diagnozowanie...*, op. cit., p. 56.

⁵⁴ H. Jaklewicz, *Autyzm dziecięcy...*, op. cit., p. 117; E. Pisula, *Autyzm u dzieci...*, op. cit., p. 51; E. Pisula, *Małe dziecko...*, op. cit., p. 62; J.L. Crane J.L., A. Winsler, *Early Autism Detection, Implications for Pediatric Practice and Public Policy*, "Journal of Disability Policy Studies" 2008, vol. 18, 4, pp. 245–253.

⁵⁵ S.J. Rogers, G. Dawson, L.A. Vismara, *Metoda wczesnego startu dla dziecka z autyzmem (ESDM)...*, op. cit., pp. 76–80; op. cit., p. 57; S. J. Rogers, G. Dawson, *Early Start Denver Model dla małych dzieci...*, op. cit., p. 57.

Building a relation of a child with autism spectrum disorder in contact with relatives – attachment

Already in the 1940s L. Kanner, was the first to notice that children affected by autism are born with “innate inability to establish normal biologically conditioned contacts with people”. In his opinion, a fundamental symptom of autism is “inability of such children to react normally to people and situations”⁵⁶. The author stated: “from the very beginning extreme autistic loneliness is present with them, and, whenever it is possible, despises, ignores and rejects everything which comes to a child from outside”⁵⁷. In his clinical descriptions of his patients he emphasized lack of attention directed at people, unawareness of other people’s feelings, treating them as if they were inanimate objects and “indifference”, demonstrated by those children with regard to their relatives. He suggested that they do not experience early establishing of bonds and relations, which should be considered one of the most significant symptoms of autism⁵⁸. Contemporary considerations and studies of attachment in autism do not explicitly confirm the character of such form of deficit as indicated by L. Kanner. Over many years the view has undergone significant verifications with the results of studies pointing at a complex nature of the phenomenon⁵⁹.

Attachment system is an element of a genetic pre-programming of a human, conditioning the appearance of three typical behaviours in case of threat (or sense of insecurity): searching, monitoring closeness to a protecting attachment figure (most often a mother), ‘using the attachment figure as a safe base and a recourse to an attachment figure as a “safe harbour” when threatened or worried.

⁵⁶ L. Kanner, *Autistic disturbances of affective contact*, “Nervous child” 1943, No. 2, p. 242; J. Blacher, L. Christensen, *Sowing The Seeds of The Autism Field: Leo Kanner (1943)*. “Intellectual and Developmental Disabilities”, 2011, Vol. 49, No. 3, pp. 172–191.

⁵⁷ L. Kanner, *Autistic disturbances...*, op. cit., p. 242.

⁵⁸ U. Frith, *Autyzm. Wyjaśnienie tajemnicy*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2008, p. 136.

⁵⁹ E. Pisula, *Rodzice dzieci z autyzmem*, Wydawnictwo PWN, Warszawa 2012, p. 86.

Among the reactions indicating a child's attachment to its guardian we may differentiate between signalling behaviour (crying, smiling, babbling) and behaviour consisting in seeking closeness (sticking to an adult, following him/her, reaching out)⁶⁰. According to M.D.S. Ainsworth⁶¹ attachment is something more than just affection or devotion, it is a deep emotional bond established between two entities, which joins them together in space and proves persistent in time⁶².

Studies devoted to attachment play a particularly significant part with regard to autism since it is perceived as the disturbance of a bond. Since the observations proved that some children with autism make an impression that they are completely indifferent to their parent's presence, whereas other children display clear signs of attachment and even emotional addiction to a guardian, therefore it is difficult to establish a unilinear profile of the parent-child relation in the whole population of children with autism spectrum disorders. Moreover, the differences in expressing attachment are not equivalent to either inability to establish an emotional bond, or to a particular bond. Due to a highly distorted social – emotional development of such children, we also face the problem of deciding which behaviour of a child can be considered as main attachment indicators typical of such population, and which should be analysed solely as a derivative of deficits typical of autism⁶³. It is particularly related to behaviour such as: physical contact and eye contact, sharing attention and intentional communication. Faced with a strange situation children with autism communicate with their guardian less frequently, in terms of both verbal and non-verbal communication, are less willing to share their interest in an object, which is related mainly to a defect of establishing a common field of attention. They are unable to draw somebody's attention to certain

⁶⁰ M. Piszczeek, *Autystyci. Indywidualne...*, op. cit., p. 11.

⁶¹ M.D.S. Ainsworth, *Attachment as related to mother – infant interaction*, "Advances in the Study of Behavior" 1979, No. 9, pp. 2-51.

⁶² H.R. Schaffer, *Psychologia dziecka...*, op. cit., p. 165.

⁶³ E. Pisula, *Autyzm i przywiązanie...*, op. cit., pp. 52-53.

objects or events, to monitor somebody's attention or to pay attention to whatever this person wants to show⁶⁴. They are incapable of finding a relation between looking at something and the desire to have it or manipulate it out of curiosity⁶⁵. They find it difficult to read the message indicated by the direction in which people look⁶⁶. Disturbed ability to establish common attention of the people with autism is closely related to inability to read the states of mind, differentiating between their thoughts and the thoughts of other people and is combined with inability to participate in alternate social interactions and disorders in intentional communication⁶⁷. Proper understanding of sharing common attention develops as a result of numerous interactions with close relatives and requires awareness of the scope of orientation in the surroundings of the partners of social interaction⁶⁸.

Complete lack of or hardly any eye contact, seeking to maintain physical distance, reluctance to receive tender gestures from a relative, and particularly seeking no consolation from other people in difficult situations, makes it impossible for them to display attachment in the way their peers do. They seem to show no interest in establishing eye contact and watching human faces in order to read their needs, desires and intentions. It seems unclear for them that the meaning of a look is determined by a state of mind shared by two people⁶⁹. For children who do not understand the states of

⁶⁴ E. Pisula, *Autyzm u dzieci...*, op. cit., p. 80.

⁶⁵ E. Pisula, *Autyzm i przywiązywanie...*, op. cit., p. 48.

⁶⁶ K. Markiewicz, *Charakterystyka zmian...*, op. cit., p. 99.

⁶⁷ E. Pisula, *Rodzice i rodzeństwo dzieci z zaburzeniami rozwoju*, Wydawnictwo Uniwersytetu Warszawskiego, Warszawa 2007, p. 48; U. Frith, *Autyzm. Wyjaśnienie...*, op. cit., pp. 131–132.

⁶⁸ M. Talarowska et al., *Psychologiczne koncepcje...*, op. cit., p. 109; S.R. Leekam, C. Ramsden, *Dyadic orienting and joint attention in preschool children with autism*, "Journal of Autism and Developmental Disorders" 2006, No. 36, pp. 185–169; H.H. Schertz, S.L. Odom, *Promoting joint attention in toddlers with autism: a parent-mediated developmental model*, "Journal of Autism and Developmental Disorders" 2007, No. 37(8), pp. 1562–1575.

⁶⁹ U. Frith, *Autyzm. Wyjaśnienie...*, op. cit., p. 134.

mind hidden under such looks, eye contact is irrelevant and does not fulfil its (intentional) social or communicative function⁷⁰.

What is more, children from this group of disorders rarely demonstrate their feelings and hardly ever do it in the same way as others do. They do not seek help from their relatives, quite often making an impression that they are unaware that it is at all possible. They cannot cooperate with other people, particularly their parents/guardians. They display specific exploration models, related rather to non-typical reception of stimuli from the senses than the presence of a guardian. Many children with autism spectrum disorders do not differentiate between relatives and strangers, treating them alike. All of this makes it difficult to consider their behaviour a model pattern of attachment. Therefore it needs to be underlined that in order to analyse and conclude about attachment of children with autism spectrum disorder it is indispensable to take into account characteristic problems in their social and emotional development⁷¹.

The studies devoted to attachment of children with autism spectrum disorder a paradigm of a strange situation is predominant. The main purpose of such experimental procedure – STRANGE SITUATION TEST – is measuring a safe and no longer-safe emotional attachment of children to their parents⁷². The main criteria for drawing plausible conclusions about child's attachment are the following: a child's behaviour in a frightening situation of a separation from a mother and in a situation of a mother's return. Also differences in a child's behaviour towards its mother and a strange woman. This method of measuring quality of a parent-child relation in controlled conditions allows to observe a child's reaction to its parent's presence, as well as to their absence and a child's reaction to seeing a strange person⁷³.

⁷⁰ S. Baron-Cohen, *Mindblindness: An essay...* op. cit.

⁷¹ E. Pisula, *Autyzm i przywiązywanie...*, op. cit., p. 53.

⁷² M.D.S. Ainsworth, *Attachment as related...*, op. cit., pp. 2–51.

⁷³ S. Gerhardt, *Znaczenie miłości. Jak uczucia wpływają na rozwój mózgu*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2010, p. 4.

The results of many studies show that children with autism display the signs of attachment in their behaviour and in a stressful situation they seek comfort from their relatives (cf. studies: C. Dissanayake, S.A. Crossley, 1996; S.J. Rogers, S. Ozonoff, C. Maslin-Cole 1991; A.H. Rutgers et al. 2004)⁷⁴. The occurrence of all patterns of attachment were observed, e. g. secure, avoidant and ambivalent, as well as disorganized. There is, however, no agreement as to frequency of occurrence of such patterns. Some studies indicated that they appear in similar proportions to that of the population of healthy children, whereas over 50% of such children manifest the signs of safe attachment. The occurrence of secure attachment was less frequently observed, whereas the proportion of the children with disorganized attachment is relatively high in this population. According to a predominant view children with autism spectrum disorder are able to form secure attachment, and differences between them and their peers undergoing proper development refer mostly to its emotional expression (cf. studies: A.H. Rutgers i in. 2004; F. Naber et al. 2007)⁷⁵. Problems with regulating emotions may play a significant role in the development of attachment in the whole population of children with autism spectrum disorders⁷⁶.

The result of an experiment carried out by C. Dissanayake i S.A. Crossley speaks in favour of occurrence of attachment indicators among children with autism in their relation with their mothers. The experiment involved children with autism aged 2 to 5. Their behaviour was compared to that of non-autistic children at the similar mental age, yet with impaired learning ability. The experiment consisted in a child spending some time playing with its mother. Then the mother leaves and a child is left with a stranger. After a while the mother comes back. The attachment indicator is an increase of spontaneous reactions to its mother after her return. What is particularly important is the child's anxiety when the moth-

⁷⁴ E. Pisula, *Rodzice dzieci...*, op. cit., p. 86.

⁷⁵ E. Pisula, *Rodzice dzieci...*, op. cit., p. 86.

⁷⁶ E. Pisula, *Autyzm i przywiązywanie...*, op. cit., p. 61.

er leaves the room, followed by its satisfaction when she returns to the child. Children from both groups reacted in a similar way, when left alone with a stranger, and also after their mother's return. When meeting the mother for the second time all children displayed a significant growth of social behaviours towards the mother. Thus we may conclude that children with autism demonstrate behaviour proving their attachment to relatives. However their behaviour towards their mothers and a strange woman is diverse. They react to the separation and return of the mother seeking her support in a threatening situation. However the problem is related to non-typical indicators of attachment. Rare eye contact was particularly visible as well as reluctance towards physical contact, sharing attention and forms of communication with the mother⁷⁷. Such irregularities with regard to attachment can be translated into social-emotional functioning.

It is not surprising that for the development of social skills and emotional competence, as well as for the theory of mind the most welcome is the secure style. It is considered to be a model, also the one allowing to achieve proper functioning in future⁷⁸. Children with autism spectrum disorder who established this kind of attachment, find it easier to modify their emotions, can quite effectively reduce their tension, properly recognise their own emotional states and those of other people, tend to be more optimistic towards people and display a positive attribution of events and other people's intentions. Majority of researchers analysing attachment in a mother - child relation claims that it is also attributable to mothers who establish safe bonds with their children, treating them more objectively and carefully reading their needs, emotions and desires. Moreover, it has been observed, that children with secure attachment to their guardians treat them as a reliable source of information and trust them much more than children with the

⁷⁷ E. Pisula, *Autyzm i przywiązywanie...*, op. cit., p. 62.

⁷⁸ J. Smogorzewska, G. Szumski, *Rozwijanie kompetencji społecznych dzieci przedszkolnych. Teoria – Metodyka – Efekty*, Wydawnictwo PWN, Warszawa 2015, p. 24.

avoidant or ambivalent attachment style (cf. studies: K.H. Corriveau et al., 2009)⁷⁹. Due to relations based on the sense of secure attachment, a child acquires the skill to mentalise and modify emotions. Such relation is also characterised by intersubjectivity, since a child learns about itself in the process of getting to be known by the guardian⁸⁰.

It has also been stated that there is a relation between mother's sensitivity during an interaction and a pattern of attachment of a child. As understood by M. Ainsworth (1973) maternal sensitivity (or to extend the term – parental), means greater accessibility of a guardian, ability to receive, interpret and adequately react to signals present in a child's behaviour, as well as readiness to cooperate with it, acceptance and offering closeness which is more comfortable for it⁸¹. L. Capps at al.⁸² stated that mothers of children displaying secure attachment were characterised by higher sensitivity than the mothers of children displaying other styles of attachment. Such relation within a group of children with the autism spectrum disorder has been confirmed in many studies (cf. studies: N. Koren-Karie et al., 2009; M.H. van IJzendoor et al., 2007). It has also been observed that children with the autism spectrum disorder, whose parents had a representation of secure attachment styles, were better at initiating communication with the use of gestures and with responding to such signals during pre-symbolic interactions, and more often engaged in imaginary thinking and symbolic play and were better at verbal communication⁸³. Moreover, the studies indicated that constant active interest of a mother in everything a child does, in everything that draws its attention and communicating it to a child, "replying to" a child's behaviour, not necessarily addressed

⁷⁹ J. Smogorzewska, G. Szumski, *Rozwijanie kompetencji...*, op. cit., p. 25.

⁸⁰ M. Piszczeck, *Autyści. Indywidualne...*, op. cit., p. 14.

⁸¹ J. Wycisk, *Rozwój systemu sprawowania opieki u matek w świetle teorii przywiązań społecznego, „Psychologia Rozwojowa”* 2012, vol. 17, No. 2, p. 16.

⁸² L. Capps et al., *Attachment security in children with autism. “Development and Psychopathology”* 1994, No. 6(2), pp. 249–261.

⁸³ E. Pisula, *Rodzice dzieci...*, op. cit., p. 87.

at an adult, is just introducing a child in the process of interactive exchange of reactions and interpersonal development⁸⁴. Such correlation is quite obvious and universal in character – attachment is an interactive process⁸⁵ (cf. Studies on the model of interpersonal development in autism: S.J. Rogers, B.F. Pennington, 1991, M. Carpenter, M. Tomasello, 2000).

Establishing proper emotional bonds of child-parent relationship does not depend merely on parents. A personal involvement of a child is indispensable. It is well known that pathological emotional disorders of a child with autism become the source of their negative emotions: anger, fear, worries of their parents. The most painful aspects of such disorders in those children as stated by parents are: verbalisation problems, inconsistency and unpredictability of behaviour, indifference with regard to closeness and parental love, contradictions on the level of various cognitive functions, lack of expressing and communicating needs, permanent state of anxiety. Parental stress is intensified by specific deficits of expressing emotions by a child with autism, considerably disturbing empathy between a child and its relatives⁸⁶.

Intensification of such stress depends to a great extent on its age, level of development, intensity of disorders (motor disturbances, communication, emotional, social), the so-called "difficult" behaviours, degree of intellectual disability, adaptability and a general set of requirements, which should be met by a parent with regard to a child's functioning. Yet it is impossible to determine a simple relation between a parental stress and separately analysed aspects of a child's development, e. g. ability to communicate. A presence

⁸⁴ B. Bokus, *Nawiązywanie interakcji społecznych przez małe dziecko*, „Monografie Psychologiczne” Ed. T. Tomaszewski, Zakład Narodowy Imienia Ossolińskich, Wydawnictwo Polskiej Akademii Nauk, Wrocław, Warszawa, Kraków, Gdańsk, Łódź 1984, p. 12.

⁸⁵ E. Pisula, *Autyzm i przywiązywanie...*, op. cit., p. 62.

⁸⁶ E. Pisula, *Stres rodzicielski związany z wychowaniem dzieci autystycznych i z zespołem Dawna*, „Psychologia Wychowawcza” 1993, No. 1, pp. 130–138; E. Pisula, *Rodzice dzieci...*, op. cit., pp. 84–85.

of a couple of disorders in a child results in a significant increase of the stress level of parents⁸⁷.

Every non-typical behaviour of a child with autism spectrum disorder requires adaptation from its parents. It is connected with the necessity to work out certain strategies, as well as styles of attachment, taking into account a specific activity of a child. It has been observed that the approach of parents towards their children with autism follows a certain pattern. It is connected with an increased control, more frequent orders, as well as trying to make the children more submissive. Parents also tend to spend less time playing with them. Even if they initiate an interaction with them, they at the same time formulate more orders and control the child's behaviour more often. It may be caused by an attempt to achieve "normality" of a child, namely to trigger the behaviour consistent with their expectations. If we consider children with autism spectrum disorder as partners in social-emotional interaction, they are definitely less active. They rarely initiate contact, less willing to accept the partner's suggestions and to cooperate with him. Activities like smiling, looking at the partner, coming closer are less frequent in children more willing to demonstrate negative emotions. The attempts to direct their attention to a certain object result in failure, not to mention transferring attention from one object to another. All of this makes an impression in a parent that a child is uninterested in its mother's suggestions. It definitely causes the parents to experience stress and frustration. As many studies confirm, the frequency of the child's contacts with its parents decreases with age. It is not, however, equivalent to a poorer quality of such contacts. As the child develops the responsiveness of the mother increases. With the child's age they learn to read the child's messages more precisely, work out their ways of interpreting their meaning which improves their contact with the child. Parents learn how to understand their child, communicate with it and read its behaviour, which significantly broadens their parental competences⁸⁸.

⁸⁷ E. Pisula, *Rodzice i rodzeństwo...*, op. cit., p. 46.

⁸⁸ E. Pisula, *Autyzm i przywiązywanie...*, op. cit., pp. 11-19.

On the other hand a child with autism spectrum disorder, given an unlimited number of interactions with a relative, buzzing with activity, smiles, friendly emotional gestures, learns to read social and emotional clues and react to them as well as to convey its own signals. Such significant schemes, covering alternate reading and reacting to emotional signals, allow the child to begin to establish its own social-emotional schemes, cultural norms and rules typical of its family and environment in which it lives. The ability to read other people's schemes and create self-awareness as a result of recognising its own schemes is the basis for developing the theory of mind namely reading beliefs, desires and intentions of other people. Such skill is indispensable for the child to learn when and how to expect certain reactions from the guardian, or to realise, what it is to feel love, closeness, tenderness and the joy of being in relation with a parent/guardian⁸⁹. A close relationship based on openness, awareness and sensitivity of a parent is the basis for a child to acquire the greatest social – emotional skills in its interactions with people⁹⁰.

References

- Ainsworth M.D.S. *Attachment as related to mother – infant interaction*, "Advances in the Study of Behavior" 1979, No. 9.
- Attwood T., *Zespół Aspergera*, Wydawnictwo Zysk i S-Ka, Poznań 2006.
- Ball J., *Autyzm a wczesna interwencja. Rzeczowe pytania, życiowe odpowiedzi*. Wydawnictwo Harmonia Universalis, Gdańsk 2016.
- Baron-Cohen S., *Mindblindness: An essay on autism and theory of mind*, Cambridge Mass., MIT Press, London 1995.
- Blacher J., Christensen L., *Sowing The Seeds of The Autism Field: Leo Kanner (1943). "Intellectual And Developmental Disabilities"* 2011, Vol. 49, No. 3.
- Bleszyński J., *Autyzm a niepełnosprawność intelektualna i opóźnienie w rozwoju. Skala oceny zachowań autystycznych*, Wydawnictwo Harmonia Universalis, Gdańsk 2011.

⁸⁹ S. L. Greenspan, S. Wieder, *Dotrzeć do dziecka...*, op. cit., pp. 408–410.

⁹⁰ S.J. Rogers, G. Dawson, L.A. Vismara, *Metoda wczesnego startu dla dziecka z autyzmem (ESDM)...*, op. cit., pp. 16–17.

- Bokus B., *Nawiązywanie interakcji społecznych przez małe dziecko*, „Monografie Psychologiczne” ed. T. Tomaszewski, Zakład Narodowy Imienia Ossolińskich, Wydawnictwo Polskiej Akademii Nauk, Wrocław, Warszawa, Kraków, Gdańsk, Łódź 1984.
- Capps L., Sigman M., Mundy P., *Attachment security in children with autism. “Development and Psychopathology”* 1994, No. 6(2).
- Cotugno A.J., *Terapia grupowa dla dzieci z zaburzeniami ze spektrum autyzmu. Rozwijanie kompetencji i umiejętności społecznych*, Wydawnictwo Fraszka Edukacyjna, Warszawa 2011.
- Crane J.L., Winsler A., *Early Autism Detection, Implications for Pediatric Practice and Public Policy*, „Journal of Disability Policy Studies” 2008, vol. 18, 4, pp. 245–253.
- Dawson G., Osterling J., *Early recognition of children with autism: A study of first birthday home videotapes*, „Journal of Autism and Developmental Disorders” 1994, No. 24, p. 247–257.
- Frith U., *Autyzm. Wyjaśnienie tajemnicy*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2008.
- Gałkowski T., *Usprawnianie dziecka autystycznego w rodzinie*, Wydawnictwo PTWK, Warszawa 1980.
- Gerhardt S., *Znaczenie miłości. Jak uczucia wpływają na rozwój mózgu*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2010.
- Greenspan S.L., Wieder S., *Dotrzeć do dziecka z autyzmem. Jak pomóc dzieciom nawiązywać relacje, komunikować się i myśleć. Metoda Floortime*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2014.
- Jagielska G., *Objawy autyzmu dziecięcego*, [in:] J. Komender, G. Jagielska, A. Bryńska (ed.), *Autyzm i zespół Aspergera*, Wydawnictwo Lekarskie PZWL, Warszawa 2009.
- Jaklewicz H., *Autyzm dziecięcy*, [in:] A. Popielarska, M. Popielarska (ed.), *Psychiatria wieku rozwojowego*, Wydawnictwo Lekarskie PZWL, Warszawa 2000.
- Kanner, L., *Autistic disturbances of affective contact*, „Nervous child” 1943, No. 2.
- Leekam S.R., Ramsden C., *Dyadic orienting and joint attention in preschool children with autism*, „Journal of Autism and Developmental Disorders” 2006, No. 36.
- Markiewicz K., *Charakterystyka zmian w rozwoju umysłowym dzieci autystycznych*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2007.
- Morrison J., *DSM-5 Bez Tajemnic. Praktyczny przewodnik dla klinicystów*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2016.
- Nason B., *Porozmawiamy o autyzmie Przewodnik dla rodziców i specjalistów*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2017.
- Olechnowicz H., Wiktorowicz R., *Dziecko z autyzmem. Wyzwalanie potencjału rozwojowego*, Wydawnictwo PWN, Warszawa 2012.
- Onzonoff S., Dawson G., McPartland J.C., *Wysokofunkcjonujące dzieci ze spektrum autyzmu. Poradnik dla rodziców*, Wydawnictwo Uniwersytet Jagielloński, Kraków 2015.

- Palomo R., Belinchón M., Ozonoff S., *Autism and family home movies: a comprehensive review*, "Journal of Developmental and Behavioral Pediatrics" 2006, No. 27 (2, Suppl.), pp. 59–68.
- Pisula E., *Stres rodzicielski związany z wychowaniem dzieci autystycznych i z zespołem Dawańskim*, „Psychologia Wychowawcza”, 1993, No. 1.
- Pisula E., *Autyzm u dzieci. Diagnoza, klasyfikacja, etiologia*, Wydawnictwo PWN, Warszawa 2000.
- Pisula E., *Autyzm i przywiązywanie. Studia nad interakcjami dzieci z autyzmem i ich matek*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2003.
- Pisula E., *Małe dziecko z autyzmem. Diagnoza i Terapia*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2005.
- Pisula E., *Rodzice i rodzeństwo dzieci z zaburzeniami rozwoju*, Wydawnictwo Uniwersytetu Warszawskiego, Warszawa 2007.
- Pisula E., *Wspomaganie osób z zaburzeniami należącymi do autystycznego spektrum w perspektywie psychopatologii rozwojowej*, [in]: J. Trempała (ed.), *Psychologia rozwoju człowieka*, Wydawnictwo PWN, Warszawa 2011.
- Pisula E., *Rodzice dzieci z autyzmem*, Wydawnictwo PWN, Warszawa 2012.
- Pisula E., *Od badań mózgu do praktyki psychologicznej AUTYZM*, Wydawnictwo GWP, Sopot 2012.
- Piszczek M., *Autyści. Indywidualne i grupowe metody terapii. Zajęcia adresowane dla Rodziców*, Wydawnictwo STECKO, Warszawa 2014.
- Randall P., Parker J., *Autyzm. Jak pomóc rodzinie*, Gdańskie Wydawnictwo Psychologiczne, Sopot 2010.
- Rogers S.J., Dawson G., Vismara L.A., *Metoda wczesnego startu dla dziecka z autyzmem (ESDM). Jak wykorzystać codzienne aktywności, aby pomóc dzieciom tworzyć więzi, komunikować się i uczyć*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2015.
- Rogers S.J., Dawson G., *Early Start Denver Model dla małych dzieci z autyzmem. Wspieranie komunikacji, uczenia się i rozwoju społecznego*, Wydawnictwo Fundacja Rozwiązać Autyzm, Warszawa 2015.
- Rybka A., Garncarz A., *Stymulowanie rozwoju emocjonalnego u osób z autyzmem*, [w:] J. Kossewska (ed.), *Kompleksowe wspomaganie rozwoju uczniów z autyzmem i zaburzeniami pokrewnymi*, Wydawnictwo Impuls, Kraków 2009.
- Rynkiewicz A., *Zespół Aspergera. Inny mózg. Inny umysł*, Wydawnictwo Harmonia, Gdańsk 2009.
- Saarni C., *Kompetencja emocjonalna i samoregulacja w dzieciństwie*, [in:] P. Salovey, D. Sluyter (ed.), *Rozwój emocjonalny a inteligencja emocjonalna*, Dom Wydawniczy REBIS, Poznań 1999.
- Schaffer H.R., *Psychologia dziecka*, Wydawnictwo PWN, Warszawa 2009.
- Schertz H.H., Odom S.L., *Promoting joint attention in toddlers with autism: a parent-mediated developmental model*, "Journal of Autism and Developmental Disorders" 2007, No. 37(8).

- Senator D., *Przejawy autyzmu w pierwszym roku życia, „Pediatria Polska”* 2006, No. 2
- Skórczyńska M., *Wczesne diagnozowanie autyzmu – perspektywy i dylematy*, [in:] B. Winczura (ed.), *Autyzm Na granicy zrozumienia*, Wydawnictwo Impuls, Kraków 2009.
- Smogorzewska J., Szumski G., *Rozwijanie kompetencji społecznych dzieci przed-szkolnych. Teoria – Metodyka – Efekty*, Wydawnictwo PWN, Warszawa 2015.
- Talarowska M., Florkowski A., Gałecki P., Zboralski K., *Psychologiczne koncepcje rozwoju autyzmu*, [in:] T. Pietras, A. Witusik, P. Gałecki (ed.), *Autyzm – epidemiologia, diagnoza i terapia*, Wydawnictwo Continuo, Wrocław 2010.
- Wiekiera E., *Strategia postępowania z dziećmi autystycznymi*, Przekład z „Engagement”, *Poradnik praktyczny dla rodziców*, Wydawnictwo Krajowe Towarzystwo Autyzmu Oddział w Krakowie, Kraków 1995.
- Wing L., *Związek między zespołem Aspergera i autyzmem Kanner'a*, [in:] U. Frith (ed.), *Autyzm i zespół Aspergera*, Wydawnictwo Lekarskie PZWL, Warszawa 2005.
- Wolski A., *Diagnoza autyzmu u małego dziecka – implikacje do pracy w rodzinie, „Rewalidacja”* Czasopismo dla nauczycieli i terapeutów, 2010, No. 2(28).
- Wolski A., *Dominujące i drugorzędne kryteria diagnostyczne – ich struktura u dzieci, u których zdiagnozowano autyzm*, [in:] T. Żółkowska, M. Wlazło (ed.), *Edukacja i Rehabilitacja Osób Niepełnosprawnych OBLICZA TERAPII, Pedagogika Specjalna – koncepcje i rzeczywistość*, vol. IX, Wydawnictwo Naukowe WH MINERWA, Szczecin 2013.
- Wycisk J., *Rozwój systemu sprawowania opieki u matek w świetle teorii przywiązymania społecznego, „Psychologia Rozwojowa”* 2012, vol. 17, No. 2.



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Sexual behaviour of children and teenagers with autism spectrum disorders. Pilot study results

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In the article the results of pilot studies concerning manifestation of sexuality in a group of children and youth with autism spectrum disorder were presented. The research is divided into two fundamental parts. In the first part – the shorter one, definitions and conceptions were outlined. The subject of sexuality and functioning of people with autism spectrum disorders regarding social behaviours was also discussed. In the second part, the findings of own studies conducted on a group of mothers of children and youth with autism spectrum disorder were presented.

KEY WORDS: autism, children, sexual behaviors, youth

1. Theoretical background

1. Human sexual behaviours are not an isolated field of life which might be separated from other activities. They constitute an integral part of personality, even the one developing and manifesting itself in a non-normative and non-typical way. The more so, in the functioning of people with particular disorders, separating the

sexual sphere from other aspects of life seems impossible. It influences those aspects, which in return affect the sexuality. "A man is born with a physiological potential of sexuality which is continuously formed by life experience; sexuality is conditioned by integrated activity of biological, psychological and social-cultural factors" (Imieński 1986 s: 28). Sexuality is a permanent human attribute, constantly dynamic – undergoing changes, both in biological (physiological) sphere, as well as in psycho-social one. Moreover also within the transactions taking place between these areas. The aforementioned assumptions underlie the ecological model of sexuality of Whalen and Schmidta (*ibid.*), treating sexual appetition as a disposition formed on the grounds of innate features and developed under the influence of acquired features. The first area is formed by biophysiology – with an appropriate genetic programme, proper development of organism, including cortical centres, subcortical centres, peripheral nerves, receptors and hormones. The other area is formed by acquired characteristics – created in the process of learning and gaining experience, related mostly to educational and culture-related factors (Imieński 1986: 40; Gulczyńska 2009; Jankowiak 2010, Steinberg, Monahan 2010).

Applying the aforementioned assumptions to people with autism spectrum disorders we state that: dysfunctions displayed by them are non-specific, therefore it is difficult to indicate a specific damage of cortical centres or peripheral nerves connected with sexual behaviours. Given the state of the art we might presume that biological (physiological) background of sexual behaviour is similar to that of people with no development disorders. The existing differences in sexual functioning are caused rather by limited ability to establish, maintain and develop interpersonal relations, particularly by deficits within the theory of mind¹.

¹ The concept of theory of mind (related terms: *mentalizing*, – *mindreading*) refers to a system of concepts and rules, enabling people to predict and explain other people's behaviours by referring to unobservable states of mind, namely desires, beliefs, intentions etc. It is the ability to interpret one's own actions and those of

2. With regard to people with autism spectrum disorders, social functioning sphere constitutes, apart from communication and activity disorders, the area with significant deficits observed. They refer to establishing contacts with people, social understanding, recognising and understanding emotions, as well as disorders of the theory of mind – basis for proper existence among people. The area of social functioning in classification DSM-5 was combined with communication abilities of people with autism spectrum disorders and was given a term of social communication disorders (DSM- 5). Such approach shows how significant the communication sphere is within the social context thus more aptly characterising the problem which plays an important role in considerations on the sexuality of children and adolescents with autism spectrum disorders.

Analysing diagnostics criteria (see ICD-10, DSM-5) and subject literature (see e. g. Maljaars et al. 2011; Pisula 2012; Frith 2008; Winczura 2005), we might conclude that the greatest difficulty in the school years for children and adolescents with autism spectrum disorders lies in undertaking interactions, maintaining contact with another person and building relations based on mutual benefits and exchange. Such behaviour is based on proper development of the theory of mind. The ability to comprehend that a human has feelings, thoughts and beliefs which might not be a precise and realistic reflection of reality, is a significant aspect of social understanding referred to as the theory of mind (the ability of mindreading or, as referred to by other authors, the ability to metalize (see Baron-Cohen 1995; Castelli, Frith, Happe, Frith 2002). Such ability enables to approach psychological states of other people and predict their behaviour (Colle, Baron-Cohen, Hill 2006). The authors also emphasize that assessment of this particular sphere is related to verbal abilities of a person, and the knowledge of the development of this ability in speech-impaired children and autistic people with intellectual disability is scarce (*ibid.*).

others as driven by the states of mind (Baron-Cohen 1995; Frith 2003; Winczura 2008).

Researchers also observe that people with autism spectrum disorders displaying proper early development followed by later regression of the developed skills, contrary to children whose autism was detected already during the first year of their lives, display better skills in the early development of the theory of mind (Matthews et al. 2012).

This aspect is significant also with regard to sexual behaviours of children and adolescents with autism spectrum disorders. It indicates that social perception of reality is not only related to intellectual capacity, but to linguistic abilities of such person as well, which should considerably determine (in its wider sense) the education of children and adolescents displaying the development disorders in question.

To sum up, a person with autism spectrum disorders in the period of adolescence is subject to the same changes as a teenager at the same age displaying no developmental disorders. However, the perception of oneself and the process of accepting changes taking place in one's organism depends on many factors, not only external, but also cognitive abilities and social-emotional skills (Wojciechowska 2013a). It is by identification with a social group and assuming new roles, that a young man begins to perceive himself/herself as other people's peer or the one different from the surrounding people. A student with autism spectrum disorders functioning on the level of intellectual standards often notices his/her distinctness from their peers. And the older he/she gets, the more aware he/she is of difficulties in establishing peer relationships (Atwood 2013; Wojciechowska 2013b).

2. Research method and research sample characteristics

The original questionnaire prepared on the grounds of literature analysis was used (including: Ballan 2012; Aylaz, Yilmaz, Polat 2012; Zielona-Jenek, Chodecka 2010; Hellemans, Colson, Verbraeken, Vermeiren, Deboutte 2007; Kościelska 2004; Atwood 2013;

Bellon-Harn, Harn 2006; Castelli 2005) as well as the observation of children and adolescents with autism spectrum disorders. Since this is the pilot study, mothers taking part in it were asked to provide remarks and comments which would be taken into account while producing the final version of the tool.

Although the assumed target research sample were parents of children and with autism spectrum disorders, yet the questionnaire was filled in only by mothers. It is most probably caused by the fact that mothers have the most extensive knowledge comprising information required by the questionnaire and they spend the most time with their child.

Eighteen mothers of children from grades IV-VI of primary school and twenty mothers of junior high school (gymnasium) students. The questionnaire was anonymous – filled in in paper or through a website. Due to discomfort caused by the subject of the study as declared by the parents, 38 questionnaires were received altogether for the purpose of this pilot study.

The respondents filling in the questionnaire about primary school students were mothers – mostly of boys (69%), the oldest respondent was 55, the youngest 34, coming mostly from towns (up to 200 residents). Most of the mothers describe themselves as Catholic believers, yet irregularly practising.

The respondents filling in the questionnaire on junior high school students were mothers of boys, the oldest respondent being 51, the youngest 38, coming mostly from big cities (over 200 thousand of residents). Except for the people regarding themselves religiously undeclared, forming the smallest group, the remaining part of the results distributed among: non-believers, believers, non-practising believers, irregularly practicing believers, regularly practicing believers was the same (20% each).

The decision was made to present the result in percentage, in order to demonstrate the frequency of occurrence of a given opinion or behaviour in the sample. The Authors emphasize that the application of percentage results in such a small research sample is only supposed to indicate a certain tendency, the direction of

which shall be verified in further studies. Yet it by no means authorises to generalise about the results with regard to the whole population.

3. Research problems

The demonstration of the results of the pilot study aims at presenting of mothers' opinions on sexual behaviours of their children (grades 4–6 of primary school) and youth (junior high school – gimnasium) with autism spectrum disorders. Both their type and the frequency of occurrence was analysed.

The following research problems were stated:

1. What sources of knowledge on the sexual development are used by the mothers of children and teenagers with autism spectrum disorders?
2. What sources of knowledge on their sexual development are used by children and teenagers with autism spectrum disorders?
3. Are there any differences – and if so, what are they – according to the mothers of autistic children and teenagers, in the sexual development of their children compared to the children and teenagers with no autism spectrum disorders.
4. What symptoms of precocious puberty in children and youths with autism spectrum disorders are observed by mothers and what is their frequency of occurrence?

4. Results of the pilot studies

1. Primary school:

Behaviours described by the mothers concerned the majority of boys with autism spectrum disorders. Almost half of the children display standard intellectual capacity, and the other half is diagnosed with intellectual disability. Most of the children speak, only

some of them use alternative communication. Children attend special schools, mass education schools or integration classes. Sexual education classes are conducted in almost half of the schools, are not conducted in almost half of the schools, and a couple of respondents have no knowledge of that. Majority of children do not participate in the classes. Over half of the mothers claim that they were not asked to give their consent to the child's participation in the classes of preparation to family life (sexual education classes).

In the question about the source of knowledge on the sexual development of their children, mothers could give more than one answer (table 1).

Literature is on the first place, followed by: the Internet, other parents, teachers, therapists and other (including a lecture given by a specialist).

Table 1. The source of knowledge on the sexual development of primary schools children

No.	Source	Per cent
1	Scientific literature and popular-science literature	81
2	Internet	62
3	Other parents	50
4	Therapists	42
5	Teachers	29
6	Other	10

Source: proprietary research

According to the mothers, their children gain knowledge on sexual development from the Internet (over 80%), TV (over 50%), therapists and literature (18% each), as well as other sources, for instance parents.

Subsequently, the question was asked, what difference there is between the sexual development of non-autistic children and that of the children with autism spectrum disorders?

The answers given were classified into six categories: no difference, no awareness of the changes taking place in their organism and no sense of socially accepted behaviour (the aforementioned answers constituted 90%, with a similar distribution between groups), the remaining categories being: no symptoms of the child's sexuality observed and: "children with autism spectrum are more sensitive in this respect, more sensitive to their own sexuality" and I don't know (the answers constituted 10%).

Further on a question was asked, how often a particular behaviour is observed in a child (mothers could choose between answers from: 0 – never to 4 – permanent occurrence).

The question about observable symptoms of precocious puberty in their children was answered by 20% respondents with the declaration that they do not notice any, for 30% such symptoms are still present or quite frequent (20%), for the remaining 30% they are observed only seldom or sometimes. The answers to the question if the mothers observe the increased need for privacy in their children correspond with the aforementioned. Almost 20% answers "no", 45% seldom notices such a need, the remaining respondents – very often or constantly. Majority of mothers (over 70%) however states that they do not observe any embarrassment or increased shyness related to sexuality issue or changes in their bodies, 20% rarely notice such behaviour, and hardly 10% constantly. A similar percentage (over 70%) observes no fear of their own normality, 20% rarely notices its symptoms, and 10% quite often.

Over 50% of mothers were not asked by their children about sexuality, almost 30% rarely, 20% often and very often. Interest in the opposite sex is not observed by over 60% of respondents, and about 40% seldom notices such symptoms. 60% of the mothers notice the interest in the topic of how babies are made, namely 30% seldom, 30% often and very often. It corresponds with the observed interest in differences in the way boys and girls are built: seldom 35%, often and very often 30%.

For a majority of mothers the most difficult behaviours are those related to taking clothes off in public, cuddling and kissing other

people (30% each), followed by masturbation, and further: seeking pornographic content on the Internet and uttering comments of sexual nature aloud (almost 20% each utterance).

No respondents observe kissing or attempts made by their children from grades IV–VI of both peers – of the same sex, as well as of opposite sex. At the same time, over 80% of the mothers observed no exhibitionistic behaviour. A similar percentage of respondents noticed no masturbation symptoms of their children. Over 60% of the mothers thinks that their children do not touch their intimate parts in the presence of other people, 30% claims that such behaviour occurs very seldom, and nearly 10%, that often. When an emotional factor is added – fear or excitement – the results undergo changes only with regard to distribution of rarely (20% with such behaviour) and often (20%). 90% of the respondents states that they haven't noticed their children seeking sexual content on the Internet or TV or demonstrate their intimate parts to other children.

Including sexual behaviour in the element of play is rare (80% lack such behaviour, 20% occurs rarely). Similarly, participation in plays considered proper for the opposite sex (with over 70% it does not occur, with 20% occurs rarely, only with 10% occurs often). Majority of the mothers (over 70%) failed to observe negative comments on children of the opposite sex (e. g. girls are stupid or: boys are dumb and noisy), such behaviour being rarely observed by 10% of the respondents, and often by almost 20%. Peeping at children, when they are in the bathroom is absent from a majority (90%) of children, and 10% does it constantly. Whereas the attempts at entering a toilet with other people rather do not occur (60%), rarely occur (20%), often or very often in the case of 10%.

45% of children do not strive for being hugged and do not cuddle to other children, whereas most children demand being hugged by adults (40% very often and often, 50% seldom), yet a considerable majority (over 70%) makes no attempts at kissing adult women at school, foundation, counselling centre, and occasional behaviours are rarely observed. Over half of the respondents claim to observe imitations of teen dancing (over 30% rarely, 10% often and very often as well).

2. Junior high school:

The analysed behaviour concerned only boys, the oldest being 18, the youngest 14 years old. Majority of the respondents' children display standard intellectual capacity. All of them demonstrate verbal communication. Adolescents attend special schools, mass education schools or integration classes. Sexual education classes took place in over half of the schools, and only a couple of the respondents have no knowledge in this topic. Over half of the teenagers participate in such classes. Nearly half of the respondents claim that they were asked to give consent to the child's participation in the preparation to family life (sexual education) classes), the same number declares that they were not asked.

When asked the question about the source of knowledge on sexual development of their children mothers could give more than one answer (table 2). They enumerated in the following order: literature (scientific, popular – science), other parents, Internet, therapists, conversation with a child, TV, teachers, their own studies and training.

According to the mothers, their children learn about sexual development from the Internet (nearly 80%), from peers (over 60%), TV (over 50%) and therapists (over 20%).

Table 2. Sources of knowledge about sexual development of their junior high school children

No.	Source	Per cent
1	Scientific Literature and popular-science literature	65
2	Other parents	62
3	Internet	57
4	Therapists	55
5	Conversations with a child	29
6	TV	10
7	Teachers	10
8	Own studies and training	10

Based on author's own research

Further on a question was asked, what, according to them, is the difference between sexual development of children with no autism spectrum disorders and that of the children suffering from such disorders?

The answers were distributed into five groups: no parallelism between physical and emotional development (delayed emotional development) 50%, no differences perceived – 20%, no idea – 10%, too much sincerity and openness (10%) and difficulties in communication (10%).

Next they were asked how often a particular behaviour was observed in a teenager (parents could choose between answers scaled from: 0 – never to 4 – persistent). Questions formulated in this particular way are supposed to reflect subjective observations and feelings of mothers.

Symptoms of precocious puberty in teenage children were observed by all respondents, majority of whom claims them to be still present (60%), very frequent or frequent (over 30%). The answers given to the question if mothers observe the increased need for privacy among their children correspond with the aforementioned. Such observations were shared by all the respondents, 90% of whom declares that behaviour proving such need are very frequent and frequent, and 10% rarely observes such need. Over half of the mothers (55%) knows that their children masturbate rarely (45%) or constantly (10%), whereas 45% fail to observe the acts of autoeroticism among their sons. However, over half of the mothers (55%) state, that they observe no signs of embarrassment or increased shyness related to sexual issues and changes taking place in their body build, over 30% seldom notices such behaviour, and nearly 10% does it often. Over half of the mothers observe their children fear about their normality (20% rarely, over 30% often, very often and permanently).

Over 50% of mothers were asked by their children about the issues related to sexuality. Interest in the opposite sex is absent from the observations of merely 20% respondents, they occur often or very often in over 40% adolescents, over 30% – rarely. It corresponds to

the interest in the differences between physique of boys and girls: 20% of the youth is completely uninterested, over 50% incidentally displays such interest, 30% does it often and permanently.

For the majority of the mothers participating in the survey, the most difficult behaviours are those related to masturbation (55%), uttering loud comments of sexual nature (over half), undressing in public (over 30%), hugging and kissing other people (over 20%), and further on seeking pornographic content on the Internet.

Mothers fail to observe in their maturing sons the following behaviour: entering (or attempts to enter) a toilet with other people, kissing (or attempts to kiss) their peers of the same or opposite sex in public, as well as people employed in the centres (schools, counselling centres) or showing their intimate parts. Exhibitionistic acts followed by an escape are also quite rare. Peeping at others when they are in a bathroom, is not observed in the majority (80%), and the remaining part states they do it very rarely.

Over 40% mothers declare that their children do not touch their private parts in the presence of other people, 30% claims that such behaviour occurs rarely, 20% thinks that it happens often or constantly. When an emotional component is added – fear or excitement, it has no influence with 30% of the described cases, happens often and very often in 40% teenagers, rarely with 20%.

Seeking sexual content on the Internet is observed by 55% of the mothers (including over 30% rarely, and 20% frequently), whereas on TV by 45% (including over 30% rarely, and 10% frequently).

Including sexual behaviour aspect in their activity is rarely observed (80% display no such behaviour, 20% occurs rarely). Over half of the mothers did not hear their sons speak negatively of girls.

90% of boys do not seek to be hugged or themselves hug adults of their age or does it seldom (45% each). Hugging peers is also occasional (45%) or absent (55%). 45% of the respondents' children had no experience with the first boyfriend or girlfriend, 45% has such meetings very rarely, and only over 10% often. Half of the respondents (55%) observes no imitation of teenage dance, an half observes it frequently.

Conclusions

The concept of the studies was prepared on the basis of the literature accessible in this subject, observation (including participant observation) of IV-VI grades children, junior high school students and talks with their parents. Owing to the involvement of the mothers filling in the questionnaire, the study could be extended with certain categories of answers, which previously were not taken into account.

Primary school: a majority of mothers taking part in the survey observed the symptoms of precocious puberty in their children, however rather poorly visible. The increased need for privacy occurs rather rarely. Embarrassment and shyness related to sexuality or the changes in the body build is also rarely observed. Similarly, they display no fear of their normality.

Mothers complemented their knowledge of sexuality by: reading available literature, visiting websites, talking to other parents, further on: from therapists and teachers. In their opinions their children learn about their sexuality mainly from the Internet and TV, further on from therapists and teachers. In over half of the cases they themselves were not asked by their children about sexuality issues.

The majority of the respondents state that the development of sexuality in their children with autism spectrum disorders differs from the same process observed in children who were not diagnosed with autism. The main difference, in their opinion, is unawareness of the changes in the organism and socially accepted behaviour.

The most difficult behaviour displayed in this period is for them undressing in public, hugging and kissing other people.

Junior high school: All mothers participating in the study observed the signs of precocious puberty and an increased need for privacy. Their knowledge on this subject was complemented with: reading available literature, talking to other parents, searching websites, from therapists, by talking to a child, watching TV, from teachers or their own studying and training.

In their opinions, their growing sons learn about sexuality issues mostly from the Internet and their peers, less frequently from TV and therapists, to be followed by teachers and other parents. Literature, as the source of knowledge on sexuality, is listed as the last one. A majority of the respondents claim that sexuality development of adolescents with autism spectrum disorders takes place unlike in people without such diagnosis; the main difference is delayed emotional development and their focus on physical components of puberty displayed by their sons. The most difficult behaviour displayed in this period is, in their opinion, masturbation, loud comments of sexual nature, next undressing in public, seeking pornographic content on the Internet or kissing other people. They also draw attention to shyness of the young men, related to sexual topics and precocious puberty which is rarely observed or almost absent. Over half of the mothers were invited to talk or asked by their children about sexually related topics. The important thing is that over half of the mothers notice fear related to their own normality and related dilemmas. The first experience with dating refers to half of the sons of the respondents, however their quality and duration was not subject to this study. While characterising sexual behaviours of their sons, mothers described the increased masturbation, considerable interest in the anatomy of sexual organs and differences observed in women (girls) and men (boys) and the interest in how the children are made. Other types of observed sexual behaviour are: imitating teenage dance, touching private parts in the presence of other people and touching their own sexual organs when feeling excitement or fear, seeking to be hugged or seeking sexual content on the Internet or TV.

Discussion

The analysis of the material collected in the course of the pilot studies aiming at learning the opinion of mothers on the sexual behaviour of children and adolescents with autism spectrum disor-

ders, indicated the significance of the problem and the necessity to carry on with the scientific research. They helped to detect probable difficulties with which mothers of children with autism spectrum disorders struggle and also indicated that the problem causes fear among mothers.

The replies given by the mothers of primary school children to part of the questions seem to apparently contradict themselves. Namely, mothers claim that their children learn about sexual development mainly from the Internet or TV, at the same time declaring that their children do not seek sexual content on the Internet. The achieved results become the source of hypotheses for further studies, namely: it is possible that the mothers treated children as a main category, seeking sexually related content on the Internet (there was no reference to their own children in the question) or think that children become only an unintentional recipient of sexually related content.

The signs of growing were rarely observed and adequately – mothers noticed the need for privacy. In case of junior high school children – signs of precocious puberty appear in all of them, whereas as embarrassment or shyness related to sexuality and changes within their bodies – rarely, remaining on the level similar to that of children from grades IV–VI.

While analysing the literature on the subject we may observe that sexual growth, sexual behaviours and sexual education of people with autism spectrum disorders are rarely discussed in Polish publications. In 2008, foreign literature database accessible through EBSCO system contained only 20 publications on the sexuality of people with autism spectrum disorders (Sullivan, Caterino 2008). In September 2014 the search engine found 46 publications (autism, sexuality).

Physical growth in people with autism spectrum disorders usually takes place in a regular way, indicated by the appearance of secondary sexual characteristics, yet emotional growth and the accompanying sexual growth is considerably extended and delayed (Sullivan, Caterino, 2008) or happens in a way typical of a particular person, which was also confirmed by the mothers' opinions provided in the study.

Persons displaying standard intellectual capacity with autism spectrum disorders feel the need for social contacts and sexual intercourses; failure to realise such behaviours is caused by disability to properly understand and establish relationships. Behaviours of the fifteen-year-olds with autism spectrum disorders participating in the studies were corresponding to those of ten-year-olds with no such diagnosis (Stokes, Kaur 2005), which is also observed by the Polish respondents.

The difference can be perceived in the approach to sexuality issues by the parents of children with autism spectrum disorders in Poland, when compared to the results of the foreign studies. The studies proved that sexuality of autistic people was placed high on the list of main problems parents sought help and support with. (van Son-Schoones, van Bilsen 1995). It may be caused by the fact that sexuality in Poland is a taboo, and the sexuality of the disabled people is all the more the issue rarely discussed, even among specialists and in research.

In other studies (Stokes, Newton, Kaur 2007) no insight into the motives of one's action was indicated, as well as limited comprehension and awareness of social situations, limited empathy, lack of restraint and knowledge, as well as care, reduced recognition of emotions and permanent, repetitive schematic behaviour. The results achieved in the pilot studies correspond to the aforementioned conclusions.

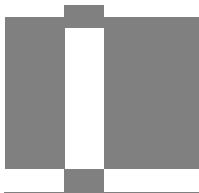
Different studies (Henaul 2006) emphasize an increased need for knowledge of the changing body and functions of the organism of people with Asperger Syndrome. In the pilot studies in question adolescents' parents claim that physiological issues are recognised by their sons, whereas emotional development is expected to improve the acquisition of higher competencies.

The studies discussed above were aimed at contributing to deeper and more extensive analyses and exploration of the topic, and in future – also to formulating wider conclusions and translating them into practice.

References

- Atwood T. 2013, Zespół Aspergera. Kompletny przewodnik, Harmonia Universalis, Gdańsk.
- Aylaz R., Yilmaz U., Polat S. 2012, Effect of Difficulties Experienced by Parents of Autistic Children on Their Sexual Life: A Qualitative Study, "Sexuality and Disability", 30, 395–406.
- Ballan M.S. 2012, Parental Perspectives of Communication about Sexuality in Families of Children with Autism Spectrum Disorders, "Journal of Autism and Developmental Disorders", 42, 676–684.
- Baron-Cohen S. 1995, Mindblindness: An essay on autism and theory of mind. Dept of Experimental Psychology, US: The MIT Press; Cambridge.
- Bellon-Harn M.L., Harn W.E. 2006, Profiles of social communicative competence in middle school children with Asperger syndrome: Two case studies, "Child Language Teaching and Therapy", 22, 1, 1–26.
- Castelli F. 2005, Understanding emotions from standardized facial expressions in autism and normal development, "Autistic Society", 9, 4, 428–449.
- Castelli F., Frith C., Happe F. Frith U. 2002, Autism, Asperger syndrome and brain mechanisms for the attribution of mental states to animated shapes, "Brain" Vol. 125(8), 1839–1849.
- Colle L., Baron-Cohen S., Hill J. 2007, Do Children with Autism have a Theory of Mind? A Non-verbal Test of Autism vs. Specific Language Impairment. J Autism Dev Disord 37, 716–723.
- Diagnostic and statistical manual of mental disorders. Fifth edition. DSM-5. 2013. American Psychiatric Association.
- Frith U. 2003, Autism: Explaining the Enigma. Cambridge, MA: Blackwell Pub.
- Frith, U. 2008, Autyzm. Wyjaśnienie tajemnic, GWP, Gdańsk.
- Gulczyńska A. 2009, Rodzinne uwarunkowania aktywności seksualnej młodych dorosłych, Wydawnictwo Uniwersytetu im. A. Mickiewicza, Poznań.
- Hellemans H., Colson K., Verbraeken C., Vermeiren R., Deboutte D. 2007, Sexual behavior in high-functioning male adolescents and young adults with autism spectrum disorders. "Journal of Autism and Developmental Disorders", 37, 260–269.
- Henault I. 2006, Asperger's Syndrome and Sexuality: From Adolescence through Adulthood, London.
- Imieliński K. 1986. Zarys seksuologii i seksuatrii, Państwowy Zakład Wydawnictw Lekarskich, Warszawa.
- Jankowiak B. 2010, Aktywność seksualna nauczycieli a jakość i trwałość ich związków partnerskich. Wydawnictwo Naukowe UAM, Poznań.
- Kościelska M. 2004, Nieuchciana seksualność. O ludzkich potrzebach osób niepełnosprawnych intelektualnie, Wydawnictwo Jacek Santorski & Co, Warszawa.

- Kryteria diagnostyczne według DSM-IV-TR. 2008, Redakcja wydania polskiego Jacek Wciórka. Wyd. Elsevier.
- Maljaars J., Noens I., Jansen R., Scholte E., van Berckelaer-Onnes I. 2011, Intentional communication in nonverbal and verbal low-functioning children with autism, "Journal of Communication Disorders", Vol. 44, Issue 6, pp. 601-614.
- Matthews N.L., Goldberg W.A., Lukowski A.F., Osann K., Abdullah M.M., Ly A.R., Thorsen K., Spence M.A. 2012, Does theory of mind performance differ in children with early-onset and regressive autism? "Developmental Science" 15, 1, 25-34.
- Pisula E. 2012, Autyzm. Od badań mózgu do praktyki psychologicznej, Sopot.
- Sullivan A., Caterino L.C. 2008, Addressing the Sexuality and Sex Education of Individuals with Autism Spectrum Disorders, "Education and Treatment of Children" vol. 31, No. 3, 381-394.
- Rybakowski F., Bialek A., Chojnicka I., Dziechciarz P., Horvath A., Janas-Kozik M., Jeziorek A., Pisula E., Piwowarczyk A., Słopień A., Sykut-Cegielska J., Szajewska H., Szczęsuba K., Szymańska K., Urbanek K., Waligórska A., Wojciechowska A., Wroniszewski M., Dunajska A. 2014, Zaburzenia ze spektrum autyzmu - epidemiologia, objawy, współzachorowalność i rozpoznawanie, „Psychiatria Polska”, 48(4), 653-665.
- Steinberg L., Monahan K.C. 2010, Adolescents' Exposure to Sexy Media Does Not Hasten the Initiation of Sexual Intercourse. "Developmental Psychology", Vol. 47, No. 2, pp. 562-576.
- Stokes M., Newton N., Kaur A. 2007, Stalking, and social and romantic functioning among adolescents and adults with autism spectrum disorder, "Journal of Autism and Developmental Disorders" 37, 1969-1986.
- Stokes M.A., Kaur A. 2005, High functioning autism and sexuality: A parental perspective. "Autism", 9(3), 266-289.
- Van Son-Schoones N., Van Bilsen P. 1995, Sexuality and autism: a pilot study of parents, health care workers and autistic persons, "International Journal of Adolescent Medicine and Health" 8, 87-101.
- Winczura B. 2008, Dziecko z autyzmem, Terapia deficytów poznawczych a teoria umysłu, Oficyna Wydawnicza „Impuls”, Kraków.
- Wojciechowska A. 2013a, Pomiędzy dzieciństwem a dorosłością - o dorastaniu osób z zespołem Aspergera, „Studia Edukacyjne” 25/2013, pp. 137-148.
- Wojciechowska A. 2013b, Wśród ludzi na własnych zasadach? O możliwościach i ograniczeniach w budowaniu relacji z rówieśnikami przez młodzież z zespołem Aspergera, „Studia Edukacyjne” 28/2013, pp. 227-242.
- Zielona-Jenek M., Chodecka A. 2010, Jestem dziewczynką, jestem chłopcem. Jak wspomagać rozwój seksualny dziecka, GWP, Gdańsk.



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Parental stress observed among mothers of autistic children

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The aim of the research presented in this article was to determine the level of parental stress among mothers of autistic children. Thirty-nine mothers of autistic children, forty mothers of children with Down syndrome as well as forty mothers of children with developing normally took part in the study. We used the Questionnaire on Resources and Stress (QRS, designed by J. Holroyd) to assess the parental stress among families of developmentally delayed children or children with intellectual disabilities. The results of the study indicate that, comparing to mothers of children with Down syndrome and mothers of children developing well, mothers of autistic children are the ones who experience the highest level of parental stress. Potential sources of coping strategies among mothers of children that suffer from autism are associated with relatively low stress levels as a result of disharmony within the family, personal issues, the child's health situation and financial problems

KEY WORDS: autism, parental stress, mothers

Introduction

So called *autism spectrum disorders* (ASD) are currently classified as neural development disorders. According to the latest version of the DSM-V Diagnostic and Statistical Manual of Mental Disor-

ders¹ of the American Psychiatric Association, autism spectrum disorders are characterised by difficulties in social communication, the formation of social relations, accompanied by rigid/ limited behaviour, interest and activity patterns.

It is worth noting that despite numerous studies concerning the etiology of autism, frequently with the use of technologically advanced methods, we still do not know the root cause of this disorder. A multi-factor genetic and environmental basis is presently most often indicated within the pathogenesis of autism, stressing the importance of interactions between the nervous and immunological systems².

Contemporary knowledge also does not explain the rising volume of diagnoses of autism spectrum disorders among children. Autism, once included in the group of rare disorders, is currently included in the most common developmental problems in children. Research presented by the Centres for Disease Control and Prevention of the United States³ show that disorders from the autism spectrum are currently found in one in 68 persons. The results of tests⁴ from other countries also indicate a high and steadily rising tendency of diagnosing such disorders in children. This is the cause that year after year, more and more persons, e. g. children diagnosed with ASD and their families require professional support.

¹ APA 2013. In Poland, for the purpose of diagnosis of autism, utilised are criteria of the ICD-10 classification, drawn up by the WHO, 2002; however, the latest classification of the APA is noteworthy as it reflects very well the contemporary knowledge on autism. These issues, however, will not form a part of this paper.

² S.A. Currenti, *Understanding and determining the etiology of autism*, "Cellular and Molecular Neurobiology", 2010, vol. 30, pp. 161–171; L. Dodds et. al., *The role of prenatal, obstetric and neonatal factors in the development of autism*, "Journal of Autism and Developmental Disorders" 2011, vol. 41, pp. 891–902.

³ Centers for Disease Control and Prevention (2014). Data& Statistics on: <http://www.cdc.gov/ncbddd/autism/data.html> [access: 29.06.2014].

⁴ C.M. Zaroff, S.Y. Uhm, *Prevalence of autism spectrum disorders and influence of country of measurement and ethnicity*. "Social Psychiatry and Psychiatric Epidemiology" 2012, 47(3), 395–398.

Subject literature devotes much space to difficulties of parents related to the education and care for a disabled child. Mothers, perceived by the social environment as the main caretakers, are of particular interest to researchers. As a consequence of such social expectations, in many cases the mothers themselves see themselves as indispensable, irreplaceable in terms of the duties arising from the care and rehabilitation of a child.⁵ The execution of the role of the mother – the mother of a disabled child, is for many becoming the superordinate direction of self-fulfilment.

As proven by numerous studies⁶, development disorders in children markedly influence physical health, psychological well being of mothers as well as the evaluation of the quality of life. Permanent difficulties accompanying the mothers of children with development disorders can lead to changes in one's self image. As studies show⁷, such situations facilitate the reduction of one's

⁵ M. Parchomiuk, *Zasoby osobiste matek dzieci niepełnosprawnych*. „Człowiek-Niepełnosprawność-Społeczeństwo” 2012, no. 1(15), pp. 44–61.

⁶ A. Gretkowski, *Pomoc psychologiczno-pedagogiczna rodzinie i dziecku przewlekłe choremu*, [in:] *Pomoc dziecku i rodzinie w sytuacji kryzysowej, teoria, historia, praktyka*, ed. by I. Kurlak, A. Gretkowski, Wydawnictwo Diecezjalne i Drukarnia w Sandomierzu, Stalowa Wola – Sandomierz 2008, pp. 211–232; R. McConkey, M. Truesdale-Kennedy, *The impact on mothers of bringing up a child with intellectual disabilities: a cross-cultural study*, “International Journal of nursing Studies” 2008, 45, 65–74; M. Feldman, L. McDonald, L., Serbin, D., Stack, M.L, Secco, C.T., Yu, *Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay*, “Journal of Intellectual Disability Research” 2007, 51, pp. 606–619; E. Pisula, *Samotność wśród najbliższych. Interakcje dzieci z autyzmem z rodzicami*, „Czasopismo Psychologiczne”, 2009, 15, pp. 295–304; conf. E. Zasępa, *Poczucie koherencji rodziców dzieci z zaburzeniami rozwoju*, [in:] *Rodzina osób z niepełnosprawnością intelektualną wobec wyzwań współczesności*, ed. by Z. Żyta, Wydawnictwo Edukacyjne Akapit, Toruń 2010, pp. 71–84.

⁷ P.R. Benson, *The in past of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation*, “Journal of Autism and Developmental Disorders” 2006, 36, pp. 685–695; M. Parchomiuk, *Rodzice dzieci z mózgowym porażeniem dziecięcym wobec sytuacji trudnych*: Wydawnictwo UMCS, Lublin 2007, p. 100; L.E. Tobing, D.S., Glenwick, *Predictors and moderators of psychological distress in mothers of children with pervasive developmental disorders*, “Journal of Family Social Work” 2006, 10, 1–22.

self-appraisal, in particular in terms of the evaluation of one's parental competences, as well as the experience of lack of fulfilment in the mother role. There also exist empirical studies⁸, however that prove that the experiences gathered by mothers in course of caring for a child with developmental problems can become the source of the feeling of one's own self-worth, importance, and an improvement in one's self-appraisal.

It needs to be stressed that parents caring for a disabled child do not form a homogeneous group with respect to the represented properties, behaviour patterns or states⁹. Within the context of parental stress, this differentiation depends on three basic sets of factors, e. g. factors characterising the child (e. g. the type and degree of their disability, their personality and temperament); factors characterising the parent (e. g. age, gender, education level and psychological constitution) and so-called external factors, which include e. g. the way the diagnosis is conveyed to the parents, the quality of relations with specialists, the availability of special services for the child and themselves, the attitudes of the environment concerning the child's disability, membership in social organisations/ associations, the possibility of finding rest and the economic situation of the family.

The studies that analysed the influence of the type of disability in the child's development on parental stress do not permit a clear conclusion concerning the relationship between these variables. Some papers indicate the existence of a relation between the type of disorder and the level and character of the related stress. As certain

⁸ J. Barlow, L. Cullen-Powell, A. Cheshire, The effectiveness of the training and support program for parents of children with disabilities: a randomized controlled trial, "Journal of Psychosomatic Research" 2008, 64, 55-62; conf. E.M. Dykens, Toward a positive psychology of mental retardation, "American Journal of Orthopsychiatry" 2006, 76, 185-193; R.M. Hodapp, T.M., Ly, D.J. Fidler, L.A. Ricci, Less stress, more rewarding: parenting children with Down syndrome, "Parenting: Science and Practice" 2001, 1, 317-337

⁹ Por. M. Parchomiuk, *Zasoby osobiste matek dzieci niepełnosprawnych, „Człowiek, niepełnosprawność, społeczeństwo”* 2012, no. 1(15), pp. 43-65.

studies show¹⁰ it is higher in mothers of autistic children than in mothers of children with Down syndrome, as well as mothers of children with cerebral palsy. It must be noted that there exists research, the results of which do not confirm a difference¹¹. For instance, S. E. Waisbren¹² had shown that in terms of physical health, social activity, marriage relations or future plans, parents of disabled children did not differ from parents caring for a neurotypical child, of the same age.

Assumptions and organisation of own research

The research process was supposed to provide answers to the basic research problem formulated as follows: What is the level of experienced parental stress in mothers of autistic children (making up the basic group, GA) as compared to the stress disclosed by mothers of children with Down syndrome (first comparative group, GD) and mothers of properly-developing children (second comparative group, GN).

The hypothetical reply given based on an analysis of available theoretical and empirical studies assumes the presence of differences in terms of the level of experienced parental stress between the

¹⁰ P.R. Benson, *The in past of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation*, "Journal of Autism and Developmental Disorders" 2006, 36, pp. 685–695; E. Pisula, *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwo UW, Warszawa 1998, p. 220; L.A. Schieve, S.J. Blumberg, C. Rice, S.N. Visser, C. Boyle, *The relationship between autism and parental stress*, "Pediatrics" 2007, 1, pp. 114–121.

¹¹ W.S. Burnett, G.C. Boyce, *Effects of children with Down syndrome on parents activitie*, "American Journal on Mental Retardation" 1995, 100, pp. 115–127; M. Krauss, *Child-related and parenting stress:similarities and differences between mothers and fathers of children with disabilities*, "American Journal on Mental Retardation" 1993, vol. 97, no. 4, pp. 359–363.

¹² S.E. Waisbren, *Parents reactions after the birth of a developmentally disabled child*, "American Journal of Mental Deficiency" 1980, 84, pp. 345–351.

studied groups of mothers, whereby mothers of autistic children will be characterised by the highest levels of experienced stress.

The proprietary study utilised the following tools: an abbreviated, 11-factor version of the Questionnaire on Resources and Stress (QRS) for families with chronically ill or disabled members by J. Holroyd. as adapted by E. Pisula, and own survey questionnaires.

The QRS scale is composed of eleven scale units included in three main fields. They measure the subjective assessment of burdens by stressors related to care for the child, and the availability of aid resources for coping. The distinguished fields are: problems of the child (dependence on care cognitive disturbances and deficits, physical development limitations); issues of the interviewee (the perspective of the need of constant care for the child, lack of personal reinforcements, stress related to the terminal illness, preferences for institutional care, personal burdens); family problems (limitations of family options, disharmony within the family, financial issues).

The tool presented above fulfils the conditions of psychometric correctness (the Polish version also shows a high degree of reliability at $r = 0.70$), and was used on numerous occasions by researchers with different interviewee groups.

In order to determine the socio-demographic data for the three analysed groups of mothers, as well as information related to the child's disability (or lack thereof), proprietary questionnaires were used.

The study encompassed 39 mothers of children with autism, 40 mothers of children with Down syndrome and the same number of mothers of children developing correctly. All children of the analysed mothers attended schools or therapeutic facilities.

The mothers from the basic group were selected based on several criteria, e. g. the diagnosis of the child - childhood autism, made at least three years before the study; age of the child - 7÷17 years; no other disturbances present along with the autism (e. g. Down syndrome, cerebral palsy, other diagnosed deficiencies). The groups

compared with the group of mothers of autistic children were chosen based on a modified random choice.

The comparison of distribution of the demographic characteristics of the studied mothers, using the non-parametric Kolmogorov-Smirnov test showed that there were no differences between the group of mothers with autistic children and that of mothers with children with Down syndrome in terms of age, education level, the inhabited environment, professional activity and the age of the child. Similarly, no differences for the demographic variables were found in the comparative groups. A difference in child age was found between the group of mothers of autistic children and the group of neurotypical mothers – there were more children aged 12–17 in the group of mothers of properly-developing children.

The mean age of mothers with autistic children was ca. 40 years (mean 39.54; standard deviation 7.54), for mothers of children with Down syndrome it was 43 years (mean 42.9; standard deviation 7.65), and for mothers of neurotypical children it was 37 years (mean 37.15; standard deviation 4.94). Most of the analysed mothers had higher education (GA 29 persons, 39.2%; GD 18 persons, 45%; GN 22 persons, 55%) and came from large urban environments – above 100,000 inhabitants (GA 25 persons, 64.1%; GD 22 persons, 55%; GN 28 persons, 70%).

Results

Due to the lack of normality in the distribution of the measured variable across the individual mother groups, the analyses used the non-parametric Mann-Whitney U test.

Analysed were the results of the eleven scales of the QRS. The results of the analysis are presented in table 1.

As can be inferred from the table above, within five of the eleven scales of the QRS, mothers of children with autism had yielded results that were significantly higher than those for mothers of children with Down syndrome. If compared to results of mothers of correctly

Table 1. Parental stress levels in mothers of autistic children, mothers of children with Down syndrome and mothers of children developing correctly – descriptive statistics and results of the Mann-Whitney U test

Stress level indicator	Mothers of children with autism		Mothers of children with Down syndrome		Mothers of children developing correctly		Mothers of children with autism / Mothers of children with Down syndrome		Mothers of children developing correctly		Mothers of children with Down syndrome / Mothers of children developing correctly	
	M	SD	M	SD	U _(39;40)	P	U _(39;40)	P	U _(40;40)	P	U _(40;40)	P
QRS1	3.487	1.500	2.500	1.072	1.100	1.136	484.0	0.004*	172.0	0.000*	300.0	0.000*
QRS2	4.128	1.453	2.700	1.584	0.600	1.158	446.0	0.001*	58.0	0.000*	260.0	0.000*
QRS3	4.513	1.152	2.450	1.627	0.700	0.714	261.0	0.000*	6.0	0.000*	278.0	0.000*
QRS4	5.821	0.384	5.350	1.108	1.350	1.314	626.0	0.132	0.0	0.000*	40.0	0.000*
QRS5	1.513	1.615	1.000	1.140	0.600	0.800	651.0	0.208	520.0	0.011*	632.0	0.107
QRS6	1.410	1.644	1.150	1.276	1.250	0.942	745.0	0.735	729.0	0.620	688.0	0.283
QRS7	2.897	1.057	2.300	1.229	1.050	0.865	553.0	0.026*	126.0	0.000*	306.0	0.000*
QRS8	0.256	0.898	0.300	0.900	0.050	0.218	778.0	0.988	737.0	0.677	756.0	0.676
QRS9	4.282	1.085	2.700	1.646	2.700	1.847	345.0	0.000*	402.0	0.000*	794.0	0.958
QRS10	0.821	0.930	0.550	0.589	1.350	0.910	688.0	0.370	731.0	0.622	408.0	0.000*
QRS11	4.590	1.295	4.150	1.314	3.250	1.445	621.0	0.120	711.0	0.602	623.0	0.124

* – significant difference at a level of $\alpha < 0.05$; Scales of the QRS (1-11); ORS1 – care dependence; QRS2 – cognitive disturbances and deficits; QRS3 – physical development limitations; QRS4 – perspective of need of constant care for the child; ORS5 – lack of personal reinforcements; ORS6 – stress related to the health and / or terminal illness of the child; ORS7 – preference for institutional care; QRS8 – personal burdens; QRS9 – limitations of family options; QRS10 – disharmony within the family; QRS11 – financial problems.
M – arithmetic mean; SD – standard deviation; U – test value; p – significance level

developing children, mothers of children with autism had yielded significantly higher stress level results in seven scales. Below are presented detailed descriptions of the results achieved by the tested mothers in the groups distinguished by the type of the child's disturbance.

Field I – stress related to the problems of the child

Stress related to the dependence of the child on care (QRS 1)

In this field, mothers of children with development issues (e. g. with autism and Down syndrome) differed significantly from mothers of children developing correctly. They perceived their children as more dependent on care. In terms of the discussed stress indicator, differences were also noted between mothers of children with autism and mothers of children with Down syndrome. The former experienced more stress due to dependence on care than mothers of children with Down syndrome.

Stress related to cognitive disturbances and deficits (QRS 2)

Mothers of children with development issues perceived burdens related to cognitive disturbances and deficits of the child as greater than the mothers of children developing correctly. Statistically significant differences were also recorded between mothers of children with autism and mothers of children with Down syndrome. For mothers of children with autism, the stress level was in this area clearly higher than among mothers of children with Down syndrome.

Stress related to limitations in the child's physical development (QRS 3)

Limitations in the child's physical development were evaluated as higher by mothers of children suffering from developmental deficiencies as compared to the mothers of children developing cor-

rectly. It also turned out that mothers of children with autism experienced greater stress due to limitations in the child's physical development than mothers of children with Down syndrome.

Field II – issues of the interviewee

Stress related to the perspective of need of constant care for the child (QRS 4)

Both mothers of children with autism, as well as mothers of children with Down syndrome experienced stress related to the perspective of the need of constant care for the child at similar levels. As compared to mothers of children developing correctly, in turn, both among mothers of children with Down syndrome, as well as mothers of children with autism, the stress level in this area was significantly higher.

Stress related the lack of personal reinforcements (QRS 5)

The lack of personal reinforcements was evaluated as higher by mothers of children with autism as compared to mothers of children developing correctly. The evaluation of the discussed factor did not yield differences between mothers of children with autism and mothers of children with Down syndrome and mothers of children with Down syndrome as compared to mothers of children developing correctly.

Stress related to the health and/ or terminal illness of the child (QRS 6)

The analysis of the stress level between the mother groups did not yield any statistically significant differences between the analysed groups

Stress related to preferences for institutional care (QRS 7)

Mothers of children with development disorders (e. g. autism and Down syndrome) experienced higher levels of stress than

mothers of children developing correctly. Differences were also noted between the groups of mothers of children with autism and with Down syndrome. Mothers of children with autism experienced higher stress related to the preference for institutional care than mothers of children with Down syndrome.

Stress related to personal burdens (QRS 8).

Within this scale, the mothers of children with autism and with Down syndrome did not differ from the mothers of children developing correctly. There also were no significant differences between the groups of mothers of children with development issues.

Field III – issues of the family

Stress related to limitations of family options (QRS 9)

Limitations of family options related to care for the child were evaluated as higher by mothers of children with autism as compared to the mothers of children with Down syndrome and the mothers of children developing correctly. Within this scale, there were no differences between the mothers of children with Down syndrome and the mothers of children without disabilities.

Stress related to disharmony within the family (QRS 10)

Within the scope of the discussed stress factor, there were no differences between the mothers of children with autism and mothers of children with Down syndrome and mothers of children without disabilities. Mothers of children developing correctly, in turn, yielded in this regard a significantly hither stress level than mothers of children with Down syndrome.

Stress related to financial problems (QRS 11)

The analysis of stress levels in this area did not yield statistically significant differences.

Discussion

The present study assumed that mothers of children with autism would be characterised by a higher stress level than the mothers of children with Down syndrome and mothers of children developing correctly. As was estimated, the most differences were noted between the mothers of children with autism and mothers of children functioning correctly. In seven areas distinguished in the QRS, mothers of children with autism yielded higher results than mothers of children developing correctly. For five factors of the QRS, the results of mothers of children with autism were higher than those of mothers of children with Down syndrome.

Mothers of children with autism, compared to mothers of children without disabilities, evaluated their children as more dependent on care, and their cognitive development and physical development possibilities as more limited. They also experienced more stress related to the perspective of constant care for the child and with preferences for institutional care. Similarly, the lack of personal reinforcements was evaluated as higher by mothers of children with autism than by mothers of children developing correctly. Compared to mothers of children with Down syndrome, mothers of children with autism experienced a higher level of stress related to dependence on care, cognitive disturbances and deficits, limitations in physical development and limited abilities of the family. In addition, the mothers of children with autism, as compared to the mothers of children with Down syndrome, experienced higher levels of stress in relation to the preference for institutional care.

On the basis of the above results, one could conclude that the hypothesis assumed for the paper was confirmed. The yielded results correspond for the most part with the results of historic studies¹³. However, some of the obtained results necessitate comments.

¹³ E. Pisula, *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwo UW, Warszawa 1998, p. 219; A. Dąbrowska, E. Pisula, *Parenting stress and doping styles in mothers and fathers of pre-school children with autism and Down*

An unexpected result, one relatively difficult to interpret, was found for the studied mothers in terms of stress related to limitations in physical development. As it turned out, mothers of children with autism, as compared to mothers of children with Down syndrome, have evaluated the physical abilities of their child as much more limited. Theoretically speaking, physical development – including motor development – of children with autism could be considered to be superior as compared to that of children with Down syndrome. However, due to the limited contact with an autistic child, as well as their difficulties communicating, disturbances in the pupil's learning process and stubbornness in light of changes, the issue becomes much more complicated. Many children with autism are only fit physically in certain ranges¹⁴. For instance, a child can be very fit and do complicated puzzles with great precision, at the same time having great difficulty in mastering basic tasks around them such as eating, getting dressed or activities related to hygiene. A. Dąbrowska and E. Pisula¹⁵ have also shown differences between the mothers of children with autism and mothers of children with Down syndrome, with the reservation, however, that it is mothers of children with Down syndrome who experienced significantly higher stress levels in relation to the physical limitations of their child. One could assume with great certainty that the differences in the results of this research can be influenced by the child's age. The quoted study interviewed mothers of younger children (the child's age was between two and six). In this period,

syndrome, "Journal of Intellectual Disability Research" 2010, 54, pp. 266–280; G. Spratt, C.F. Sayler, M.M. Macias, *Assessing parenting stress in multiple samples of children with special needs* (CSN). Preview, "Families, Systems, Health" 2007, 25, pp. 435–449

¹⁴ J.R. Brasic, J.G. Gianutsos, *Neuromotor assessment and autistic disorder*, "Autism" 2000, 4, pp. 287–298; E. Pisula, *Małe dziecko z autyzmem – diagnoza i terapia*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2005, p. 50.

¹⁵ A. Dąbrowska, E. Pisula, *Parenting stress and doping styles in mothers and fathers of pre-school children with autism and Down syndrome*, 'Journal of Intellectual Disability Research' 2010, 54, pp. 266–280.

the motor development of a child experiences great changes. In addition, motor disharmonies in an autistic child of this age can be even less visible than later. A child of seven and older (with the children of the parents studied in this work being aged between seven and 17) is expected to show school-wise maturity, among others, independence in terms of its relevant daily activities as getting dressed or eating. A child within a peer group offers many opportunities for comparisons of their and other children's skills.

The result indicating a lack of differences between the studied groups of mothers in terms of stress related to financial problems also deserves attention. One could expect that due to the costs related to the assurance of professional medical care for the child, as well as the fact that it is most often the case that only one parent works professionally, the financial situation of families with developmental issues would be difficult. Many studies yield such an image¹⁶. In this study, however, it became evident that the standard of living of families raising children with development problems, despite all difficulties and resources invested in treatment and rehabilitation, was the same as for the families of children developing correctly. Perhaps the present socio-economic situation in Poland, the effects of post-transition changes (mass employee layoffs, shutting down uneconomic facilities, lack of creditworthiness of many families, etc.) touch upon both family groups to a similar extent. E. Minczakiewicz¹⁷ arrived at a similar result in terms of parents of children with Down syndrome and parents of children developing correctly. One should not forget however, that the studied group is not representative for the entirety of families with autistic children in Poland, and that conclusions from this study should not be overgeneralised.

¹⁶ A. Firkowska-Mankiewicz, *Jakość życia rodzin z dzieckiem niepełnosprawnym, „Psychologia Wychowawcza”* 1999, 2, pp. 134–145; conf. M. Parchomiuk, *Rodzice dzieci z mózgowym porażeniem dziecięcym wobec sytuacji trudnych*, Wydawnictwo UMCS, Lublin 2007, p. 36.

¹⁷ E. Minczakiewicz, *Sytuacja rodzin z dzieckiem z zespołem Downa na tle sytuacji współczesnych polskich rodzin statystycznych*, [in:] *Rodzina osób z niepełnosprawnością intelektualną wobec wyzwań współczesności*, ed. by Z. Żyta, Wydawnictwo Edukacyjne Akapit, Toruń 2010, pp. 41–55.

In summary, the analysis of the obtained data indicated these areas of the functioning of the child, parent and environment that are related to the greatest burdens to parents of children with autism. This data seems to have a lot of practical relevance. The knowledge of the sources of parental stress in persons providing aid to families of children with developmental disturbances may contribute to the planning of more adequate and required aid. Furthermore, knowledge of the specific purposes and behaviour of a child conditioning the increase of stress levels in parents, may contribute to the arrangement of the intervention in such a way so as to minimise this stress.

The above-presented analysis of results also indicated areas, in which no significant differences were noted among the studied groups of mothers. These areas may be sources of strategies facilitating coping. The lowest stress levels in mothers of autistic children was recorded for the area QRS 10, e. g. stress related to disharmony within the family, area QRS 8 – personal burdens, area QRS 11 – financial problems, and area QRS 6 – stress related to the child's health. As could be inferred, low results yielded by mothers in terms of stress related to personal burdens are related to the relatively good financial situation of the family, and accordingly, the possibility of simultaneous utilisation of aid from outside of the family.

The results concerning stress related to disharmony within the family, however, can support the notion that the fact of a child's disability may not necessarily influence the coherence, integration or bond among its members¹⁸. In actuality, it cannot be excluded that in many cases developmental difficulties of a child can facilitate the emergence of negative emotions or the exacerbation of certain problems in the family, but a disturbance in the development of a child most probably does not constitute their original cause. It needs to be noted that not all researchers had shown a lack of disharmony within the family of an autistic child. The already quoted study by

¹⁸ A. Żmijewska, *Zespół Aspergera w ujęciu rodzinnym – przegląd badań*, „Psychiatria Polska” 2010, 44, pp. 713–722.

A. Dąbrowska and E. Pisula had shown a markedly higher level of stress in this area in mothers of children with autism than in mothers of children with Down syndrome. It can not be excluded that the level of stress in this area varies depending on the age of the child, and, accordingly, also the duration of the parents' relationship.

The issues of stress of parents of children with autism was handled by many scientific studies, however, the multitude of interdependencies in this area was not conclusively analysed. Times of political and economic transformation, as well as progressing globalisation, force one to consider further determining factors in analyses of difficulties stemming from the inability of parents of children with development problems to cope. The variables worth of further study are certainly: the parents' awareness and activity in the struggle for the rights due to the child, the ability to use modern computer resources. Empirical conclusions in the area of parental stress should be verified on a permanent basis¹⁹.

Finally, certain limitations of the study presented in this paper should be noted, which advise caution in terms of the interpretation of its results. The first is the size of the studied groups and the lack of their representative character. Similarly, the fact that studies were conducted in but one region of Poland (Silesian voivodeship, county of Częstochowa) does not permit a broad generalisation of the conclusions stemming from this study. A further limitation stems from the fact that the study was not longitudinal. Of particular value with respect to the analysed issues would be longitudinal studies and studies that include the variable of the functional status of the child into the analysis. Studies²⁰ have accordingly shown that this variable better outlines the core of parental burdens than the typology of disability, and is of importance in terms of the final results concerning parental stress.

¹⁹ A. Krause, *Dziecko niepełnosprawne w rodzinie w perspektywie zmiany społecznej*, [in:] *Rodzina osób z niepełnosprawnością intelektualną wobec wyzwań współczesności*, ed. by Z. Żyta, Wydawnictwo Edukacyjne Akapit, Toruń 2010, pp. 15–25.

²⁰ Conf. M. Parchomiuk, *Rodzice dzieci z mózgowym porażeniem dziecięcym wobec sytuacji trudnych*, Wydawnictwo UMCS, Lublin 2007, p. 36.

References

- Barlow J., Cullen-Powell L., Cheshire A., The effectiveness of the training and support program for parents of children with disabilities: a randomized controlled trial, "Journal of Psychosomatic Research" 2008, 64, 55–62.
- Benson P.R., *The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation*, "Journal of Autism and Developmental Disorders" 2006, 36, s. 685–695.
- Brasic J.R., Gianutsos J. G., *Neuromotor assessment and autistic disorder*, "Autism" 2000, 4, s. 287–298.
- Burnett W.S., Boyce G.C., *Effects of children with Down syndrome on parents' activities*, "American Journal on Mental Retardation" 1995, 100, s. 115–127.
- Centers for Disease Control and Prevention (2014). Data & Statistics na: <http://www.cdc.gov/ncbddd/autism/data.html> [dostęp: 29.06.2014].
- Currenti A., *Understanding and determining the etiology of autism*, "Cellular and Molecular Neurobiology" 2010, vol. 30, s. 161–171.
- Dąbrowska A., E. Pisula, *Parenting stress and parenting styles in mothers and fathers of preschool children with autism and Down syndrome*, "Journal of Intellectual Disability Research" 2010, 54, s. 266–280.
- Dąbrowska A., Pisula E., *Parenting stress and parenting styles in mothers and fathers of preschool children with autism and Down syndrome*, "Journal of Intellectual Disability Research" 2010, 54, s. 266–280.
- Dodds L. et.al., *The role of prenatal, obstetric and neonatal factors in the development of autism*, "Journal of Autism and Developmental Disorders" 2011, vol. 41, s. 891–902.
- Dykens E.M., Toward a positive psychology of mental retardation, "American Journal of Orthopsychiatry" 2006, 76, 185–193.
- Feldman M., McDonald L., Serbin L., Stack D., Secco M.L., Yu, C.T., *Predictors of depressive symptoms in primary caregivers of young children with or at risk for developmental delay*, "Journal of Intellectual Disability Research" 2007, 51, s. 606–619.
- Firkowska-Mankiewicz A., *Jakość życia rodzin z dzieckiem niepełnosprawnym*, „Psychologia Wychowawcza" 1999, 2, s. 134–145.
- Gretkowski A., *Pomoc psychologiczno-pedagogiczna rodzinie i dziecku przewlekłe choremu*, w: *Pomoc dziecku i rodzinie w sytuacji kryzysowej, teoria, historia, praktyka*, red. I. Kurlak, A. Gretkowski, Wydawnictwo Diecezjalne i Drukarnia w Sandomierzu, Stalowa Wola – Sandomierz 2008, s. 211–232.
- Hodapp R.M., Ly T.M., Fidler D.J., Ricci L.A., *Less stress, more rewarding: parenting children with Down syndrome*, "Parenting: Science and Practice" 2001, 1, 317–337.
- Krause A., *Dziecko niepełnosprawne w rodzinie w perspektywie zmiany społecznej*, [w:] *Rodzina osób z niepełnosprawnością intelektualną wobec wyzwań współczesności*, red. Z. Żyta, Wydawnictwo Edukacyjne Akapit, Toruń 2010, s. 15–25.

- Krauss M., *Child-related and parenting stress:similarities and differences between mothers and fathers of children with disabilities*, "American Journal on Mental Retardation" 1993, t. 97, nr 4, s. 359–363.
- McConkey R., Truesdale-Kennedy M., *The impact on mothers of bringing up a child with intellectual disabilities: a cross-cultural study*, „International Journal of nursing Studiem” 2008, 45, 65–74.
- Minczakiewicz E., *Sytuacja rodzin z dzieckiem z zespołem Downa na tle sytuacji współczesnych polskich rodzin statystycznych*, w: *Rodzina osób z niepełnosprawnością intelektualną wobec wyzwań współczesności*, red. Z. Żyta, Wydawnictwo Edukacyjne Akapit, Toruń 2010, s. 41–55.
- Parchomiuk M., *Rodzice dzieci z mózgowym porażeniem dziecięcym wobec sytuacji trudnych*: Wydawnictwo UMCS, Lublin, 2007.
- Parchomiuk M., *Zasoby osobiste matek dzieci niepełnosprawnych. „Człowiek-Niepełnosprawność-Społeczeństwo”* 2012, nr 1(15) s. 44–61
- Pisula E., *Małe dziecko z autyzmem – diagnoza i terapia*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2005.
- Pisula E., *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwo UW, Warszawa, 1998.
- Pisula E., *Samotność wśród najbliższych. Interakcje dzieci z autyzmem z rodzicami*, „Czasopismo Psychologiczne” 2009, 15, s. 295–304.
- Schieve L.A., Blumberg S.J., Rice C., Visser S.N., Boyle C., *The relationship between autism and parental stress*, "Pediatrics" 2007, 1, s. 114–121.
- Spratt G., Sayler C.F., Macias M.M., *Assessing parenting stress in multiple samples of children with special needs (CSN). Preview*, "Families, Systems, Health" 2007, 25, 435–449.
- Tobing L.E., Glenwick D.S., *Predictors and moderators of psychological distress in mothers of children with pervasive developmental disorders*, "Journal of Family Social Work" 2006, 10, 1–22.
- Waisbren S.E., *Parents reactions after the birth of a developmentally disabled child*, "American Journal of Mental Deficiency" 1980, 84, s. 345–351.
- Zaroff C.M., Uhm S.Y., *Prevalence of autism spectrum disorders and influence of country of measurement and ethnicity*. "Social Psychiatry and Psychiatric Epidemiology" 2012, 47(3), 395–398.
- Zasępa E., *Poczucie koherencji rodziców dzieci z zaburzeniami rozwoju*, w: *Rodzina osób z niepełnosprawnością intelektualną wobec wyzwań współczesności*, red. Z. Żyta, Wydawnictwo Edukacyjne Akapit, Toruń 2010.
- Żmijewska A., *Zespół Aspergera w ujęciu rodzinnym – przegląd badań*, „Psychiatria Polska” 2010, 44, s. 713–722.



How parents of autistic children deal with stress

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The appearance of a child with a disability is always a source of tremendous stress in the family. This problem is particularly evident in the case of an autistic child because of its unpredictable and untypical development. Every person during their life develops certain mechanisms to deal with difficult situations. According to Lazarus and Folkman (1987), dealing with stress mainly relies on specific intellectual activities and appropriate actions to control the requirements assessed by the person as burdensome or beyond his/her current possibilities. There are many ways of dealing with stress. The most common strategies include those focused on solving the problem (SSZ), emotional overreaction (SSE) and avoidance of stress (SSU) by engaging in substitute activities (ACZ) or seeking social interaction (CSA). It is assumed that an effective way to deal with stress consists in relating the needs and capabilities of an individual. The aim of this article was to investigate the ways of dealing with stress among 130 parents of autistic children.

KEY WORDS: autism, family, stress, dealing with stress,

Introduction

A child's illness or developmental disorder affects the family system and is a source of stress, anxiety and fear for every family member. Having a child with developmental problems affects the

existing order in the family and weakens the sense of security. Parents of children with developmental problems are exposed to specific stress factors in their family environment and have no chance to change their situation. Long-term care for a disabled child results in serious physical and mental costs for the parent.¹ This problem is especially evident when having a child with autism because of its unpredictable and untypical development.² Current research confirms that parents of children with autism experience significantly greater stress and anxiety than parents who care for children with the Down syndrome or cerebral palsy.³

An important factor affecting the extent and intensity of parental problems is the difficult and often late diagnosis of autism in the child. The socioeconomic status of the family is equally important, as well as parents' education, place of residence and access to specialized early diagnosis and treatment institutions and the professional organization of care and support for the autistic child. In the absence of these type of institutions, parents are responsible for organizing and coordinating the necessary therapies, education and rehabilitation of the child, and sometimes even providing therapy under the supervision of professionals.⁴ What is particularly bur-

¹ A. Twardowski, *Sytuacja rodzin dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, I. Obuchowska, ed., WSiP, Warsaw 2008. A. Garncarz-Podlaski, *Sytuacja psychospołeczna rodziców dzieci autystycznych w kontekście zespołu wypalania sit*, [in:] T. Gałkowski, J. Kossewska, ed., *Autyzm wyzwaniem naszych czasów*. Wydawnictwo Naukowe Akademii Pedagogicznej. Kraków 2001, pp. 209–217.

² M. Sekulowicz, *Niektóre problemy funkcjonowania rodziny dziecka autystycznego*, [in:] *Autyzm kontrowersje i wyzwania*, W. Dykcik, ed., Wyd. Eruditus. Poznań 1994, pp. 201–207; K. Patyk, *Rodzice dzieci autystycznych wobec sytuacji trudnych. „Problemy Opiekuńczo-Wychowawcze”* 2009; pp. 34–42.

³ E. Pisula, *Małe dziecko z autyzmem*, Gdańskie Wyd. Psychologiczne 2005, pp. 13–23. N. Johnson, M. Frenn, S. Feetham, P. Simpson, *Autism spectrum disorder: parenting stress, family functioning and health-related quality of life*. Fam Syst Health, 2011, 29, pp. 232–252.

⁴ E. Pisula, D. Noińska, *Stres rodzicielski i percepja doświadczeń związanych z opieką nad dzieckiem u rodziców dzieci z autyzmem uczestniczących w różnych formach terapii. „Psychologia Rozwojowa”* 2011, Vol. 16, no 3, pp. 75–88.

densome for the parents is the lack of knowledge about the available therapies and the necessity to make the right choices concerning the child's therapeutic options (parents generally lack support in this area). In Poland, the situation of families with children with autism is still bad. Although access to diagnostic and therapeutic services has improved, it still depends on the economic possibilities of the family and their place of residence.⁵ In this situation, the Internet is becoming increasingly important. Parents with access to the Internet will find a lot of necessary information, as well as gain the opportunity to exchange opinions with others (Parental Forums).

The specificity of the problems related to the functioning of a child with autism means that it requires comprehensive help. This translates directly into the cost of treatment services – they are usually very high. Another major shortcoming is that most of the facilities offering therapeutic services are located in large urban centres. This means that some children who live away from the cities may use only consultative therapy or the services of persons who are not qualified.

The current trends in therapeutic and supportive measures for children with autism are aimed at the greatest possible activation and involvement of the parents. It is believed that for an effective therapy, it is necessary to ensure good health and well-being of both parents. Many authors emphasize the importance of professional therapeutic programs directed to parents of children with disabilities⁶, including those affected by autism.⁷

⁵ See: A. Rajner, M. Wroniszewski, *Można im pomóc. Specjalistyczne usługi opiekuńcze dla dzieci z autyzmem*. SYNAPSIS, Warsaw 2002.

⁶ E. g.: M. Dudek, *Dzieci z zespołem ADHD w środowisku rodzinnym. Studium empiryczne*. Wydaw. Adam Marszałek, Toruń 2015.

⁷ E. g.: P. Randall, J. Parker, *Autyzm. Jak pomóc rodzinie*. GWP, Gdańsk 2016; H. Jaklewicz, *Autyzm wczesnodziecięcy. Diagnoza, przebieg, leczenie*. GWP; Gdańsk 1993; T. Gałkowski, *Dziecko autystyczne w środowisku rodzinnym*, WSiP, Warsaw 1995.

Parental stress

The problem of stress of parents raising children with autism is an important issue because of the specificity of the emotional impact of the parent (especially the condition of the parent) on the child and the way the whole family functions. The confirmation of autism is a strong stress factor for all family members and has a significant impact on the relationships between them. This is confirmed by the results of research which has been carried out in the world for more than forty years. In the available literature, the authors tend to use a general definition of stress, in which they accentuate the causes, symptoms or consequences of stress. The variables that are most frequently mentioned in the basic definitions include: size, intensity, length and unpredictability of the stressors.⁸

According to H. Selye, the creator of the physiological theory of stress, it is a non-specific reaction of the body to the demands placed upon it.⁹ Stress can be positive (eustres) or negative (distress). The so-called *positive stress* leads to the development of a person's personality and motivates him/her to act, while distress leads to suffering and disorganization in action.

In psychological terms, due to the variety of theories relating to the theory of stress, it is described and defined in different ways. I.L.Janis, the creator of the theory of emotional tension, describes stress as a change in the environment, which in the case of an average person triggers a high degree of emotional tension that interferes with normal functioning.¹⁰

⁸ E. Pisula, *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwa UW, Warsaw 1998, p. 48; J. Pyżalski, *Wypalenie zawodowe a zdrowie i zachowania zdrowotne pedagogów placówek resocjalizacyjnych*, „Medycyna Pracy”, 2002, 6, 495–499; R. Lazarus, S. Folkman, *Stress, appraisal, and coping*. New York: Springer. International Classification of Diseases 10th Revision. World Health Organization. 2010. R.S. Lazarus, *Paradygmat stresu i radzenia sobie*, „Nowiny Psychologiczne” 1986, 3–4 (40–41).

⁹ H. Selye, *Stres okielznany*, PIW, Warsaw 1979, p. 25.

¹⁰ See: J.F. Terelak, *Psychologia stresu*, Oficyna Wydawnicza Branta, Bydgoszcz 2001, p. 77.

The definition of I. Janis includes two aspects of stress:

- 1) a stressful situation described by impulses causing behavioural disorders;
- 2) a stress reaction, understood as any change in external behaviour, feelings, attitudes, which are triggered by stress

A slightly different approach to stress is proposed by Heszen-Niejodek, who defines it "as a specific relation between a person and the environment that is perceived by the person as overburdening or exceeding his/her resources and threatening their well-being".¹¹

Although there is general agreement on the view that distress has a negative impact on every dimension of human life, there is a belief that it is not stress itself that is most harmful to man, but rather the **feeling of inability to control events that cause stress**.¹² The authors of this view assume that a person who has basic knowledge of the sources and effects of stress is able to identify its early signs more easily and more quickly, and to fully assess the pressure exerted on him/her.¹³ As a result, the person is also aware of the physical and psychological effects of stress.

Overloading of parents with long-term care for autistic children, accompanied by constant stress and lack of adequate family support, can lead to the appearance of the **burn-out syndrome**.¹⁴ It is mainly expressed in the form of loss of mental and physical strength.

¹¹ I. Heszen-Niejodek, *Teoria stresu psychologicznego i radzenia sobie*, [in:] *Psychologia*, Vol. 3, J. Strelau, ed., GWP 1999, p. 467.

¹² I.L. Janis, *Psychological stress: Psychoanalytic and behavioral studies of surgical patients*. Wiley, New York 1958.

¹³ A. Borowicz, *Stres rodziców wychowujących dzieci z niepełnosprawnością słuchową, „Niepełnosprawność – zagadnienia, problemy, rozwiązania.”* No II/2012(3), p. 58 (55–80).

¹⁴ T. Galkowski, *Dziecko autystyczne w środowisku rodzinny*, WSiP, Warsaw 1995; Pisula E., *Zespół wypalania się sił u rodziców dzieci autystycznych, „Nowiny Pedagogiczne”* 1994, p. 3.

Styles of coping with stress

It is believed that stress is an indispensable factor in the process of adapting to a difficult family situation in its daily functioning with a child with autism. The way people experience stress, as well as their ability to deal with it depends on various factors related to the social support system and personal resources. Authors dealing with this issue most often point to: optimism, mental agility, sense of coherence, internal control, and certain personality traits, such as: extraversion, ability to compromise, openness to experience.¹⁵

J. Strelau describes stress as a result of an imbalance between the requirements and capabilities of the individual and assigns a regulatory function to stress management that, according to the author, *means maintaining an adequate balance between requirements and capabilities or reducing the discrepancy between requirements and capabilities.*¹⁶

According to A.M. Colman, an individual style of dealing with stress involves a set of human traits that are directly related to stress-activated processes, and effective coping with stress is not so much the choice of style, but the skilful selection of available styles, adequate to the requirements of a specific stress situation.¹⁷

Literature on the subject depicts many ways to classify the styles of coping with stress. The classification provided by Endler and Parker is most commonly described and used in research, i.e. a style focused on the task, focused on emotions and focused on avoiding stress.¹⁸

¹⁵ E. g.: N. Ogińska-Bulik, Z. Juczyński, *Osobowość, stres a zdrowie*. Difin, Warsaw 2008; L. Huber, *Style adaptacyjne do sytuacji stresowych w różnych grupach wiekowych a choroby cywilizacyjne XXI wieku*. „Probl. Hig. Epidemiol” 2010, 91(2). pp. 268–275.

¹⁶ J. Strelau, *Temperament a stres: Temperament jako czynnik moderujący stresory, stan, i skutki stresu oraz radzenie sobie ze stresem*, [in:] I. Heszen-Niejodek, Z. Ratajczak, ed. *Człowiek w sytuacji stresu*, Wydaw. UŚ, Katowice 1996, p. 95.

¹⁷ A.M. Colman, *Słownik psychologii*, PWN, Warsaw 2009, p. 710.

¹⁸ N.S. Endler, J.D.A., Parker, *Coping Inventory for Stressful Situations (CISS): Manual. Multi-Health Systems*. Toronto 1990.

Aim of the work

The aim of the study was to try to answer the following research questions:

- What are the differences in the style of coping with stress in the group of mothers and fathers?
- What are the differences in the style of coping with stress in the groups of parents of autistic children and Asperger syndrome?
- What are the differences in the style of coping with stress in groups distinguished by the parents' place of residence?
- What styles of stress management are preferred by parents with children with autism?

Methodology

The study was based on the diagnostic test method using the following techniques:

1. The CISS Questionnaire (Endler, Parker) designed to measure stress management styles. The CISS questionnaire consists of 48 statements concerning various human behaviours taken in stressful situations. The surveyed person is supposed to determine on a 5-grade scale the frequency with which he/she undertakes a given activity in difficult, stressful situations. The results are presented on three subscales: SSZ - style focused on the task; SSE - style focused on emotions; SSU - style focused on avoidance. The latter style can take two forms: ACZ - engaging in substitute activities and PKT - looking for social interactions. The raw results were converted into standardized units called stens, taking into account the age criterion.

The CISS Questionnaire is characterized by high internal consistency of particular scales (coefficients in the range of 0.78–0.90) and satisfactory stability (correlation coefficients between the two tests at 2–3 weeks intervals ranging from 0.73 to 0.80).¹⁹

¹⁹ J. Strelau, A. Jaworowska, K. Wrześniowski, P. Szczepaniak, *Kwestionariusz Radzenia Sobie w Sytuacjach Stresowych. Podręcznik do polskiej normalizacji*. Pracownia Testów Psychologicznych PTP, Warsaw 2009.

2. Interview (own survey) concerning the socio-economic situation of the respondents.

Results of research

The presented research results form part of a wider research project implemented in the period from January 2016 to April 2017 in three provinces: Mazowieckie, Lubelskie and Podkarpackie. Of the total number of respondents, there were 132 parents of autistic children, including 105 mothers and 27 fathers. The average age of the respondents is 40.3 years, including fathers 41.9 and mothers 38.7.

Table 1 shows the data on the differences in the CISS scores achieved by mothers and fathers. The analysis of the results indicates that there is a difference between the parents in relation to the style focused on avoidance – SSU ($p < 0.05$) and involvement in substitute activities – ACZ ($p < 0.05$). In both cases, mothers show a greater tendency to use these styles than fathers.

Table 1. Differences in the arithmetic mean and standard deviation of the CISS scale for men and women (1–mothers, 2–fathers)

Styles of coping with stress	Sex	N	\bar{x}	s	p <i>U Mann Whitney's test</i>
SSZ – Style focused on the task	1	105	57.14	8.42	0.633
	2	27	57.96	6.58	
SSE – Style focused on emotions	1	105	42.28	11.81	0.131
	2	27	38.25	9.46	
SSU – Style focused on avoidance	1	105	44,70	8.52	0.020*
	2	27	40,22	9.54	
ACZ – involvement in substitute activities	1	105	19.94	5.06	0.028*
	2	27	17.37	4.93	
PKT – looking for social interaction	1	105	16.60	3.8	0.178
	2	27	15.55	3.895	

* $p < 0.05$

The arithmetic mean and standard deviation achieved by parents of children with autism and parents of children with Asperger syndrome on the CISS scale were then compared (Table 2). The differences have turned out to be insignificant in all subscales measuring the different styles of coping with stress.

Table 2. Differences in the arithmetic mean and standard deviation achieved by parents of children with autism and Asperger syndrome on the CISS scale (1 – parents of children with autism, 2 – parents of children with Asperger syndrome)

Styles of coping with stress	Groups	N	\bar{x}	s	P <i>U Mann Whitney's test</i>
SSZ – Style focused on the task	1	100	58.03	8.34	0.066
	2	32	55.06	6.77	
SSE – Style focused on emotions	1	100	41.90	11.54	0.592
	2	32	40.09	11.24	
SSU – Style focused on avoidance	1	100	44.59	9.11	0.096
	2	32	41.28	7.78	
ACZ – involvement in substitute activities	1	100	19.81	5.25	0.098
	2	32	18.18	4.58	
PKT – searching for social interaction	1	100	16.65	3.88	0.222
	2	32	15.56	3.78	

The literature on the subject often underlines that the place of residence has a great impact on the situation of the family with a child with a disability or developmental disorder.²⁰ For this reason it was considered necessary to compare the results obtained by parents living in different environments (Table 3). Comparison of the arithmetic mean and standard deviation (ANOVA) on the CISS scale obtained by people living in large cities, small towns and in the countryside shows significant differences in the SSZ scale – measuring

²⁰ E. g.: W. Otrębski, K. Konefał, K. Mariańczyk, M.M. Kulikn, *Wspieranie rodziny z niepełnosprawnym dzieckiem wyzwaniem dla pracy socjalnej*. Europoperspektywa Beata Romejko, Lublin 2011; A. Twardowski, *Sytuacja rodzin dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, ed. I. Obuchowska, WSiP, Warsaw 2008.

Table 3. Differences in the arithmetic mean and standard deviation obtained in the CISS scale by parents in relation to their place of residence (A - big city, B - small town, C - countryside)

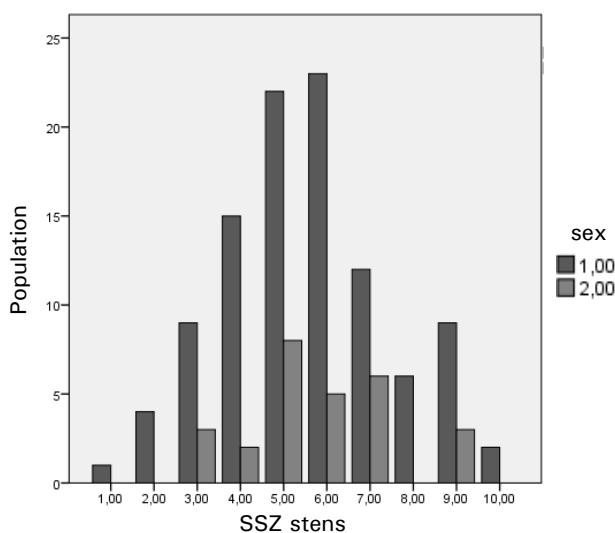
Styles of coping with stress	F	df	p	Gr	N	\bar{X}	S	Group comparison	p the NIR Post-test
SSZ - Style focused on the task	4.026	2	0.020*	A	52	57.25	8.04		
				B	36	54.58	7.72	B-C	0.005**
				C	44	59.61	7.84		
SSE - Style focused on emotions	0.122	2	0.885	A	52	41.53	11.58		
				B	36	42.11	10.81		
				C	44	40.84	12.03		
SSU - style focused on avoidance	1.415	2	0.247	A	52	43.46	9.45		
				B	36	42.19	7.90		
				C	44	45.47	8.88		
ACZ - involvement in substitute activities	0.096	2	0.908	A	52	19.34	5.15		
				B	36	19.19	4.94		
				C	44	19.68	5.35		
PKT - searching for social interaction	2.841	2	0.052*	A	52	16.15	3.89		
				B	36	15.44	3.62	B-C	0.022*
				C	44	17.43	3.87		

* p < 0.05; ** p < 0.01

the style focused on solutions/tasks $F(2) = 4.026$; $p < 0.020$ and PKT – measuring the style focused on searching for social interaction $F(2) = 2.841$; $p < 0.052$. The analysis of comparisons conducted with the NIR post-test indicates that in both cases, parents of children with autism who lived in the countryside were significantly more likely to apply the style focusing on the task ($p < 0.005$) and searching for social interaction ($p < 0.022$) than parents living in small towns.

Diagrams 1–5 show the profile of scores obtained on the CISS scale by parents of children with autism in each subscale.

Chart 1. Profile of converted results (in stens) obtained in the sub-scale measuring the style focused on the task (SSZ)

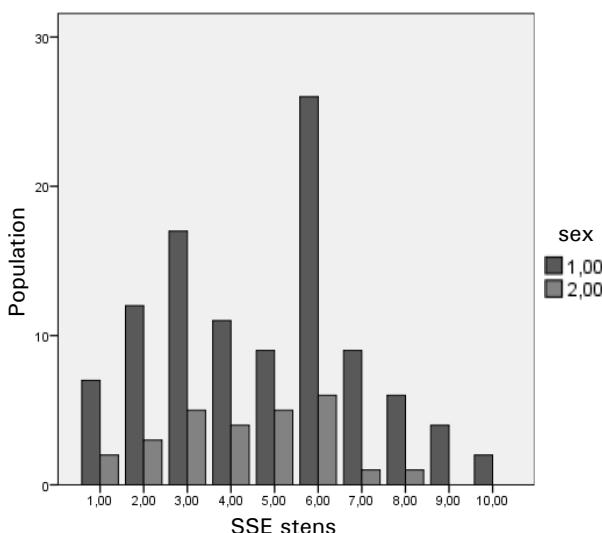


The results obtained on the CISS scale are shown in Chart 1 and indicate the dominance of average stens among parents of children with autism. **This means that the style focused on the task** is at an average level in the population studied. **The style focused on the task** characterizes people who, while experiencing stress, try to

identify the source of the problem and then **address the problem**. In situations where the solution is not possible, they try to adapt to life in the new, changed circumstances. **It is assumed that for a person with a style focused on the task this is usually very beneficial.** It allows the person who is experiencing stress to take action in a quick and effective manner and cope with the causes of stress.

Chart 2 shows the results obtained in the CISS scale defined as a style focused on emotions. The dominance of average and low stens indicates that the surveyed parents of children with autism, while experiencing stress, use the **style that focuses on emotions** in a low or average degree. Depending on what caused the stress, emotions may be different, but rather not pleasant. The strategies related to this style are mainly about **experiencing and trying to unload emotions**. This may include worrying about things, complaining to another person, as well as fantasizing or thinking "next time I'm going to do it", without taking any effort to succeed.

Chart 2. Profile of converted results (in stens) obtained in the sub-scale measuring the style focused on emotions (SSE)



The results of the subscale measuring **the style focused on avoidance - SSU** (Chart 3), clearly indicate the dominance of the average stens. This means that in the surveyed group, parents use **the style focused on avoidance** in an average degree, trying to **avoid thinking about the problem that is the source of stress**. According to the theoretical assumptions of the authors of the scale, the strategies that relate to this style focus on paying attention to something else and not thinking about the problem and its consequences.

Chart 3. Profile of converted results (in stens) obtained in the sub-scale measuring the style focused on avoidance (SSU)

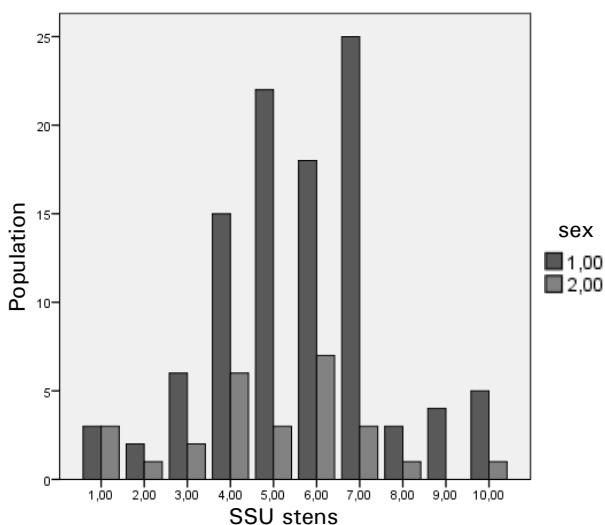


Chart 4. contains a profile of results obtained by the surveyed parents in the subscale that measures **the style focusing on engagement in substitute activities (ACZ)**. The dominance of average results indicates average involvement in substitute activities in the form of avoiding stressful situations by watching TV, eating, thinking about pleasant things, dreaming.

Chart 4. Profile of converted results (in stens) obtained in the sub-scale measuring the style focused on involvement in substitute activities (ACZ)

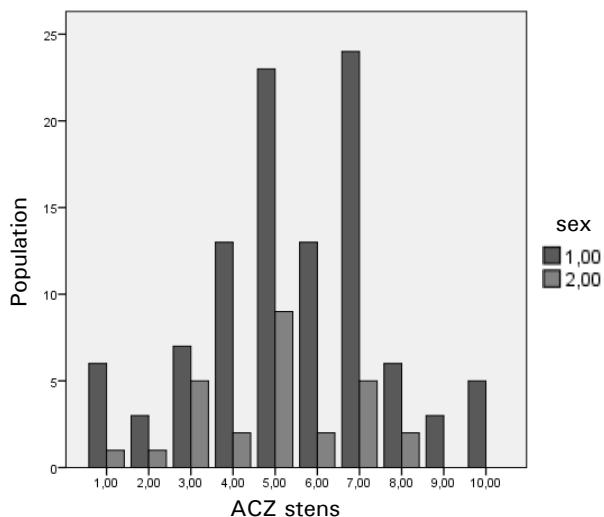


Chart 5. Profile of converted results (in stens) obtained in the sub-scale measuring the style focused on searching for social interactions (PKT)

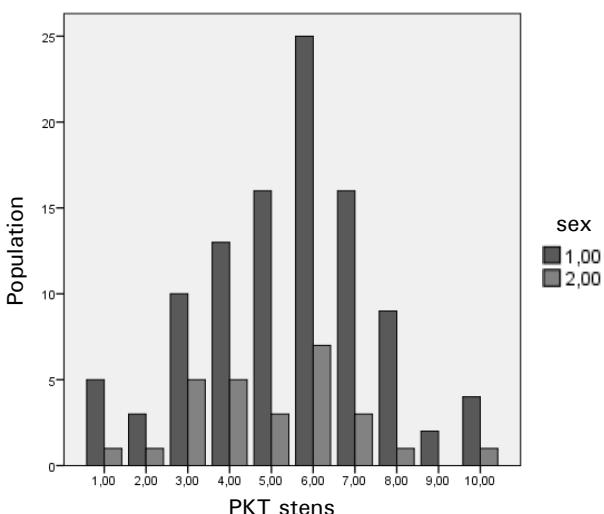


Chart 5 shows the results of the scale **searching for social interaction** (PKT). The dominance of average results indicates an average level of avoidance of stressful situations by entering into social interactions.

Generally, the analysis of the profiles of results obtained in individual CISS sub-scales shows that in the case of the surveyed parents of children with autism the style focused on emotions is the rarest. Other styles were chosen by the respondents at a similar level (average stens).

Discussion

The purpose of the study was to compare the coping styles of mothers and fathers, the parents of autistic children and parents of children with Asperger syndrome, groups of parents distinguished for their place of residence, and the analysis of dominant stress management styles among the respondents.

Comparison of the CISS scale results for mothers and fathers indicates that mothers are more likely than fathers to present the style focused on avoidance (SSU) and the style focused on involvement on substitute activities (ACZ). There is no difference in the style of coping with stress between parents with children with autism and parents with children with Asperger syndrome. In addition, parents of children with autism who live in the countryside are much more likely to apply the style that focuses on the task and searching for social interactions than parents living in small towns. The analysis of the CISS scale results allows to confirm that parents of children with autism use the style focused on emotions most rarely. The other styles were similarly (averagely) used by respondents.

The obtained results do not coincide with the views of some Polish and foreign authors. E. Pisula, referring to the different results of the study, concludes that parents of children with autism are more likely to use coping strategies that involve escaping from the stressor, and seek social support and search for solutions to the

problems less often than parents with children with other developmental disorders.²¹ At the same time, the author emphasizes that parents cope by accepting the unpredictability and randomness of events and focusing on the present, on the current problems.

L. Little observes that autism diagnosed in a child burdens the mother and the father to a different extent. Mothers are more stressed about raising a disabled child, they use the help of professionals more often, and are more pessimistic when thinking about the future of the child.²² Research by K.I. Pakenham, C. Samios and K. Sofronoff has shown that the most adaptive style of coping with stress in the case of families with children with Asperger syndrome has been the style that focuses on emotions.²³

According to the authors, the fact of having a child with Asperger syndrome is a chronic, uncontrollable stressor for these parents, therefore the strategy focused on tasks may not be feasible in their case. According to K. I. Pakenham, C. Samios, K. Sofronoff, task strategies can only be successful in situations where the source of stress is modifiable, which in their opinion does not apply to a child with developmental disorders. KI Pakenham, C. Samios and K. Sofronoff conclude that, in addition to the style of coping with stress that focuses on emotions, parents of children with Asperger syndrome, also show two other strategies, namely: giving importance to the child's disability and a positive perception of his/her disorder. The results of research by K.I. Pakenham, C. Samios and K. Sofronoff show that both of these factors positively correlate with social support, feeling of self-efficacy and adaptive styles of coping with stress.²⁴

²¹ E. Pisula, *Rodzice dzieci z autyzmem*, PWN, Warsaw 2012.

²² Little L. *Differences in stress and coping for mothers and fathers of children with Asperger's syndrome and nonverbal learning disorder*. Ped. Nurs. 2002; 28, 6, 565–570.

²³ K.I. Pakenham, C. Samios, K. Sofronoff, *Adjustment in mothers of children with Asperger syndrome: An application of the double ABCX model of family adjustment*. "Autism" 2005; 9, 2, 191–212.

²⁴ K.I. Pakenham, C. Samios, K. Sofronoff, *Finding meaning in parenting a child with Asperger syndrome: correlates of sense making and benefit finding*. "Res. Dev. Disabil." 2004; 25, 245–264.

Summary

The development of a child with autism is often uneven, inharmonious, unpredictable, and may indicate progress, lack of progress, as well as developmental regression. This results in the fact that the negative emotional states of parents associated with the care and education of a child with autism are present at every stage of the child's development, related to every new event in his or her life²⁵. That is why parents need constant support from loved ones, friends and professionals. ²⁶ Understanding the emotional situation of parents is a prerequisite for planning and implementing support. Parental stress management is one of the key factors to be considered in the therapy process.

The results of the analyses indicate the need for further, broader and longitudinal studies on the emotional functioning of parents of children with autism, as well as actions aimed at the support and therapy of the parents.

References

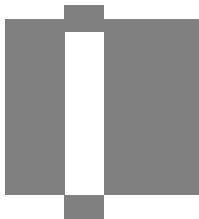
- Banasiak A., *Psychospołeczny wymiar jakości życia rodzin dzieci z autyzmem*, Prace Naukowe Akademii im. Jana Długosza w Częstochowie, Seria Psychologia, 2008, XV.
- Borowicz A., *Stres rodziców wychowujących dzieci z niepełnosprawnością słuchową, „Niepełnosprawność – zagadnienia, problemy, rozwiązania.”* No II/2012(3) p. 58 (55–80).
- Colman A. M., *Słownik psychologii*, PWN, Warsaw 2009.
- Dudek M., *Dzieci z zespołem ADHD w środowisku rodzinnym. Studium empiryczne*. Wydaw. Adam Marszałek, Toruń 2015.

²⁵ A. Banasiak, *Psychospołeczny wymiar jakości życia rodzin dzieci z autyzmem*, Prace Naukowe Akademii im. Jana Długosza w Częstochowie, Seria Psychologia, 2008, XV.

²⁶ See: M. Pągowska *Psychospołeczna sytuacja rodziny dziecka z autyzmem – etapy adaptacji do niepełnosprawności dziecka*, „Szkoła Specjalna” 2010, No 4, pp. 258–266.

- Endler N. S., Parker J.D.A., *Coping Inventory for Stressful Situations (CISS): Manual. Multi-Health Systems*. Toronto 1990.
- Gałkowski T., *Dziecko autystyczne w środowisku rodzinnym*, WSiP, Warsaw 1995.
- Garncarz-Podlasko A., *Sytuacja psychospołeczna rodziców dzieci autystycznych w kontekście zespołu wypalania sił*, [in:] T. Gałkowski, J. Kossewska, ed., *Autyzm wyzwaniem naszych czasów*. Wydawnictwo Naukowe Akademii Pedagogicznej. Kraków 2001, pp. 209–217.
- Heszen-Niejodek I., *Teoria stresu psychologicznego i radzenia sobie*, [in:] *Psychologia*, Vol. 3, J. Strelau, ed., GWP 1999.
- Huber L., *Style adaptacyjne do sytuacji stresowych w różnych grupach wiekowych a choroby cywilizacyjne XXI wieku*. „Probl. Hig. Epidemiol” 2010, 91(2), pp. 268–275.
- Jaklewicz H., *Autyzm wczesnodziecięcy. Diagnoza, przebieg, leczenie*. GWP, Gdańsk. 1993.
- Janis I.L., *Psychological stress: Psychoanalytic and behavioural studies of surgical patients*. Wiley, New York 1958.
- Johnson N., Frenn M., Feetham S., Simpson P., *Autism spectrum disorder: parenting stress, family functioning and health-related quality of life*. Fam Syst Health, 2011, 29, pp. 232–52.
- Lazarus R.S., Folkman S., *Stress, appraisal, and coping*. International Classification of Diseases 10th Revision. World Health Organization. Springer. New York 2010.
- Lazarus R.S., *Paradygmat stresu i radzenia sobie „Nowiny Psychologiczne”* 1986, 3–4 (40–41).
- Little L. Differences in stress and coping for mothers and fathers of children with Asperger's syndrome and nonverbal learning disorder. Ped. Nurs. 2002, 28, 6, pp. 565–570.
- Ogińska-Bulik N., Juczyński Z., *Osobowość, stres a zdrowie*. Difin, Warsaw 2008.
- Otrębski W., Konefał K., Mariańczyk K., Kulikn M.M., *Wsparcie rodziny z niepełnosprawnym dzieckiem wyzwaniem dla pracy socjalnej*. Europoperspektywa Beata Romejko, Lublin 2011.
- Pakenham K.I., Samios C., Sofronoff K., *Finding meaning in parenting a child with Asperger syndrome: correlates of sense making and benefit finding*. “Res. Dev. Disabil.” 2004, 25, pp. 245–264.
- Pakenham K. I., Samios C., Sofronoff K., *Adjustment in mothers of children with Asperger syndrome: An application of the double ABCX model of family adjustment*. “Autism” 2005, 9, 2, pp. 191–212.
- Patyk K., *Rodzice dzieci autystycznych wobec sytuacji trudnych*. „Problemy Opiekuńczo-Wychowawcze” 2009, pp. 34–42.
- Piągowska M., *Psychospołeczna sytuacja rodziny dziecka z autyzmem – etapy adaptacji do niepełnosprawności dziecka*, „Szkola Specjalna” 2010, No 4, pp. 258–266.
- Pisula E., *Male dziecko z autyzmem*, Gdańskie Wyd. Psychologiczne 2005.
- Pisula E., Noińska D., *Stres rodzicielski i percepceja doświadczeń związanych z opieką nad dzieckiem u rodziców dzieci z autyzmem uczestniczących w różnych formach terapii*, „Psychologia Rozwojowa” 2011, Vol. 16, No 3, pp. 75–88.

- Pisula E., *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwa UW, Warsaw 1998.
- Pisula E., *Rodzice dzieci z autyzmem*, PWN, Warsaw 2012.
- Pisula E., *Zespół wypalania się sił u rodziców dzieci autystycznych*, „Nowiny Pedagogiczne”, 1994, 3.
- Pyżalski J., *Wypalenie zawodowe a zdrowie i zachowania zdrowotne pedagogów placówek resocjalizacyjnych*, „Medycyna Pracy”, 2002, 6, 495–499.
- Rajner A., Wroniszewski M., *Można im pomóc. Specjalistyczne usługi opiekuńcze dla dzieci z autyzmem*. SYNAPSIS, Warsaw 2002.
- Randall P., Parker J., *Autyzm. Jak pomóc rodzinie*. GWP, Gdańsk 2016.
- Sekułowicz M., *Niektóre problemy funkcjonowania rodziny dziecka autystycznego*, [in:] W. Dykcik, ed., *Autyzm kontrowersje i wyzwania*, Wyd. Eruditus. Poznań 1994, pp. 201–207.
- Selye H., *Stres okielznany*, PIW, Warsaw 1979.
- Strelau J., Jaworowska A., Wrześniowski K. i wsp., *Kwestionariusz Radzenia Sobie w Sytuacjach Stresowych. Podręcznik do polskiej normalizacji*. Pracownia Testów Psychologicznych Polskiego Towarzystwa Psychologicznego, Warsaw 2009.
- Strelau J., Jaworowska A., Wrześniowski K., Szczepaniak P., *Kwestionariusz Radzenia Sobie w Sytuacjach Stresowych. Podręcznik do polskiej normalizacji*. Pracownia Testów Psychologicznych PTP, Warsaw 2009.
- Strelau J., *Temperament a stres: Temperament jako czynnik moderujący stresory, stan i skutki stresu oraz radzenie sobie ze stresem*, [in:], Heszen-Niejodek I., Ratajczak Z., ed., *Człowiek w sytuacji stresu*, Wydaw. UŚ, Katowice 1996.
- Twardowski A., *Sytuacja rodzin dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, Obuchowska I. ed., WSiP, Warsaw 2008.



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Specificity of verbal and non-verbal communication of a child with Asperger syndrome in the context of their role as a pupil and colleague

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Communication is one of the most important elements of human existence, because man as a social being strives to communicate with others. Communication skills influence the degree of acceptance of the person by other members of the community and help to achieve success in various aspects of life and social roles. The article focuses on the analysis of communication skills, both verbal and non-verbal, of a child with Asperger syndrome (AS). The purpose of this article is to show the specific way in which people with Asperger syndrome communicate, which makes it difficult for them to find themselves in the school community – being a good pupil and a good colleague.

KEY WORDS: Asperger syndrome, verbal communication, non-verbal communication, social role

Social role – meaning of the concept

In sociology, the concept of social role is associated with social position, social status that places people in the community. A social role can be defined as “[...] a set of rights and obligations associated with a given position [...]”¹. Certain biological or psychological characteristics of a person can hinder or prevent social roles. This is the case of people with various disabilities, developmental disorders, including Asperger syndrome (AS).

The social role determines the behaviour of a person occupying a particular social position, i.e. it defines the norms of behaviour that are applicable. These standards also apply to communication, [...] linguistic behaviours define and illustrate the possibility of human existence in a social group”². The role of a school colleague requires behaviours that involve cooperation, interaction, the point of view of another person, mutual understanding, mutual help, compromise and empathy. The role of a student requires the respect of the school rules, attendance, punctuality, doing homework, classroom activity, concentration, observance of the communication rhythm in the classroom, respect for teachers, teamwork skills.

The violation of norms related to a specific social role involves sanctions, which are more or less formal. A woman who does not fulfil the role of a mother may face formal punishment: she may be deprived of parental rights, or a less formal sanction: criticism and condemnation from the environment. A child who does not fulfil the role of a student is subject to sanctions in the form of a warning, an oral reprimand from the teacher, a negative evaluation, or a lack of promotion to the next class. The penalty for violating the standards of being a “good colleague” may include exclusion from the class community, lack of invitations to school parties, exclusion from fun and games, mocking or teasing. We must bear in mind

¹ B. Szacka, *Wprowadzenie do socjologii*, Oficyna naukowa, Warsaw 2008, p. 149.

² S. Grabias, *Postępowanie logopedyczne. Diagnoza, programowanie terapii, terapia*, „Logopedia” 2008, Vol. 28, pp. 13–37.

that the assessment of the behaviour of a person who performs a specific role depends on the person who makes the assessment. In the case of the role of a school colleague, there may be differences between the views of parents and teachers and the children themselves, who allow peer-to-peer collaboration, such copying homework or cheating on tests. Since social roles are related to being in the community (among other people), the important issue is how to communicate.

Verbal and non-verbal communication

Communication is the exchange of information, demands, requests, views, feelings between the sender and the receiver, it is a bilateral, interactive activity. In speech therapy, interaction is defined as "[...] a system of two interrelated processes: the process of giving meaning to human behaviour and the process of adapting one's own behaviour to the behaviour of members of a given social group"³. Therefore, communication, understood as interaction, is a mutual adjustment of the parties involved.

In communication we use different codes: linguistic, para-linguistic and non-linguistic⁴. In linguistic communication the means of communication is language. In para-linguistic communication it is the melody, accent, rhythm and non-linguistic communication uses facial expressions, gestures, body movement, look, proxemics. Verbal communication is a communication based on words, which Bożydar Kaczmarek treats as one of the elements of linguistic communication, apart from written and signalling⁵. Non-verbal communication uses para-linguistic and non-linguistic means. Usually in the communication process, we use all the codes

³ S. Grabias, *Interakcja językowa i jej uwarunkowania. Perspektywa lingwistyczna*, [in:] *Bariery i pomosty w komunikacji językowej Polaków*, ed. J. Bartmiński, U. Majer-Baranowska, Wyd. UMCS, Lublin 2005, p. 19.

⁴ B. Kaczmarek, *Misterne gry w komunikacji*, Wyd. UMCS, Lublin 2010.

⁵ B. Kaczmarek, *Misterne gry w komunikacji*, Wyd. UMCS, Lublin 2010.

simultaneously, we convey intentions through the spoken words, appropriate accent, intonation, but also with facial expressions or gestures.

When analysing the communication process one has to take into account: the people involved in the information exchange, the so-called communicators, the purpose of communication, the manner and the channel of information, the message itself, namely the text, the message code, and the situation (circumstances) in which communication occurs⁶. The causes of communication difficulties may include all of the listed elements. In order to communicate effectively, both sides (the sender and the receiver) should know the same transmission codes (linguistic, para-linguistic and non-linguistic) and properly interpret the messages. The context in which information is exchanged is also important, failure to take it into consideration, and consequently the inability to adapt the communication to the circumstances may distort communication. Factors impeding communication also include biopsychological limitations of both the sender and the receiver (communicators), as is the case of mentally disabled people or autistic people.

Communication requires co-operation. The philosopher of language, Paul Grice, mentions the following principles of linguistic communication: the quantity (we speak as much as we need), the quality (we say what we know is the truth, we avoid what is false), reference to the subject (we talk about what is related to the subject), manner (we speak in an understandable manner)⁷.

Most people use speech in the communication process. According to Stanisław Grabias, it is "[...] a system of activities performed by man with the participation of language, when exploring the

⁶ S. Gajda, *Jak się porozumiewamy?*, [in:] *Logopedia. Pytania i odpowiedzi. Podręcznik akademicki. Interdyscyplinarne podstawy logopedii*. Vol. I, ed. T. Galkowski, G. Jastrzębowska, Wyd. UO, Opole 2003, pp. 19–26.

⁷ H.P. Grice, *Logic and conversation*, [in:] *Syntax and semantics* ed. P. Cole, J.L. Morgan, V/3, New York 1975: Academic Press, pp. 41–58; translated by J. Wajszczyk H.P., Grice H.P., *Logika i konwersacja*, „Przegląd Humanistyczny” 1977, no 6, pp. 85–99.

world and passing on knowledge about him/herself and the world to other participants of social life"⁸. The definition implies that language plays not only a communicative, but also a cognitive role. Language allows people to interpret the world and at the same time communicate what we know about the world to other people, influence them. Both language functions (cognitive and communicative) complement each other. It is emphasised that "our success in a variety of situations depends, to a large extent, on how we are able to exploit the opportunities contained in speech"⁹, i.e. the possibilities offered by language.

Asperger syndrome – diagnostic criteria

One of the diagnostic criteria for Asperger syndrome is the specific way of communicating, specific speech. The disorder known today as Asperger syndrome was first described by the Vienna psychiatrist and paediatrician, Hans Asperger, who described patients with specific characteristics related to behaviour and communication in his work published in 1944¹⁰. The term Asperger syndrome was disseminated and introduced into the literature of the subject in 1981 by Lorna Wing.

In the International Statistical Classification of Diseases and Health Problems ICD-10, the Asperger syndrome is located among overall developmental disorders and is denoted by the symbol (84.5)¹¹.

⁸ S. Grabias, *O ostrość refleksji naukowej. Przedmiot logopedii i procedury logopedycznego postępowania*, [in:] *Logopedia. Wybrane aspekty historii, teorii i praktyki*, ed. S. Milewski, K. Kaczorowska-Bray, Harmonia Universalis, Gdańsk 2012, p. 61.

⁹ S. Gajda, *Wprowadzenie*, [in:] *Logopedia. Pytania i odpowiedzi. Podręcznik akademicki. Interdyscyplinarne podstawy logopedii*. Vol. I, ed. T. Gałkowski, G. Jastrzębowska, Wyd. UO, Opole 2003, p. 12.

¹⁰ D. Graaisma, *Rozstrojone umysły. Dzieje chorób i historie chorób*. PIW, Warsaw 2009.

¹¹ S. Pużyński, J. Wciórka (ed), *Klasyfikacja zaburzeń psychicznych i zaburzeń zachowania w ICD-10. Badawcze kryteria diagnostyczne*. Uniwersyteckie Wyd. Medyczne „Vesalius”. Institute of Psychiatry and Neurology, Warsaw 2007.

The American Psychiatric Association included it in its official classification in 1994. In the latest 5th revision, DSM was classified as an autism spectrum disorder, without providing separate diagnostic criteria¹².

There has been a lot of controversy around AS. It is discussed whether it is a separate clinical unit or a variant of autism, which is reflected in its position in various classifications (see: ICD-10, DSM-IV, DSM-V). There is also a lack of agreement as to the initial stages of speech development in individuals with this diagnosis. There are two positions in academic publications and diagnostic criteria. One emphasizes the lack of delay in the development of speech in children with AS¹³, others allow for the existence of such a delay¹⁴. This is how an American psychiatry lecturer, James Morrison, commented on the statement on the lack of delay in the development of

¹² J. Morrison, *DSM-V® bez tajemnic. Praktyczny przewodnik dla klinicystów*. Wyd. UJ, Kraków 2016.

¹³ S. Pużyński, J. Wciórka (ed). *Klasyfikacja zaburzeń psychicznych i zaburzeń zachowania w ICD-10. Badawcze kryteria diagnostyczne*. Uniwersyteckie Wyd. Medyczne „Vesalius”. Institute of Psychiatry and Neurology, Warsaw 2007; *Diagnostic and statistical manual of mental disorders*, 4th Ed, rev. (DSM-IV), Washington 1994, DC: American Psychiatric Association; A. Maciarz, M. Biedasiewicz, *Dziecko autystyczne z zespołem Aspergera. Studium przypadku*, Impuls, Kraków 2000; J. Urbaniak, „*Mali profesorowie czy inteligentni autystycy. Wczesna diagnoza dziecka z zespołem Aspergera*”, [in:] red. B. Cytowska, B. Winczura, *Wczesna interwencja i wspomaganie rozwoju małego dziecka*, Oficyna Wydawnicza Impuls, Kraków 2006, pp. 399–428; B. Winczura, *Autyzm, autyzm atypowy a schizofrenia wczesnodziecięca*, [in:] ed. Dzieci z zaburzeniami łączonymi. Trudne ścieżki rozwoju, Oficyna Wydawnicza Impuls, Warsaw 2012, pp. 63–118; J.J. Bleszyński, *Autyzm a niepełnosprawność intelektualna i opóźnienie w rozwoju. Skala oceny zachowań autystycznych*. Harmonia Universalis, Gdańsk 2016.

¹⁴ G. Gilberg, C. Gillberg, *Asperger syndrome – Some epidemiological considerations: A research note*, “Journal of Child Psychology and Psychiatry”, Vol. 30, pp. 631–633; T. Attwood, *Zespół Aspergera*, Wyd. Zysk i S-ka, Poznań 2006; M. Korendo, *Językowa interpretacja świata w wypowiedziach osób z zespołem Aspergera*, Omega Stage Systems, Kraków 2013; J. Cieszyńska-Rożek, *Metoda Krakowska wobec zaburzeń rozwoju dzieci. Z perspektywy fenomenologii, neurobiologii i językoznawstwa*, Omega Stage Systems, Kraków 2013; Błaszczyk, S. Kowalska, E. Gacka, *Rozwój komunikacji językowej u dzieci z zespołem Aspergera*, „*Problemy opiekuńczo-Wychowawcze*” 2015, No 10, pp. 3–13.

speech included in the medical diagnostic criteria for AS (DSM-IV, ICD-10): "...it is a paradox that, due to the delay in the development of language, Temple Grandin would not meet the criteria for this diagnosis (Asperger syndrome – annotation by EG) according to DSM-IV, although he remains a model example of this disorder"¹⁵.

The author of this article supports the viewpoint which differentiates two models of speech development in persons with AS: with a delay in speech development and without delay in the formation of speech. In the case of some children with this diagnosis (as confirmed by many years of speech therapy practice of the author of these words), speech develops with a certain shift in time. Patients begin to speak their first words and utter their first sentences later than the majority of typically developing peers, and their linguistic utterances, which are delayed, include characteristic irregularities. In the second model, speech develops without delay, i.e. children begin to utter first words and first sentences in due time, but their communication (verbal and non-verbal) includes the specific characteristic of AS.

The diagnostic features of the Asperger syndrome include:¹⁶

- an immature and unilateral type of social interaction,
- empathy disorder,
- inadequate expression and recognition of other people's emotions,
- pedantic, encyclopaedic language
- schematic speech,

¹⁵ J. Morrison, *DSM-V® bez tajemnic. Praktyczny przewodnik dla klinicystów*. Wyd. UJ, Kraków 2016, p. 47.

¹⁶ ICD-10; DSM-IV; T. Attwood, *Zespół Aspergera*, Wyd. Zysk i S-ka, Poznań 2006; A. Bryńska, *Deficyty językowe w zespole Aspergera jako możliwy wyraz dysfunkcji prawopótkulowej*. „*Psychiatria i psychologia kliniczna*” 2010, 10(4), pp. 247–253; M. Korendo, *Językowa interpretacja świata w wypowiedziach osób z zespołem Aspergera*, Omega Stage Systems, Kraków 2013; J. Panasiuk, M.M. Kaczyńska-Haładyj, *Po-stępowanie logopedyczne w przypadku osób dorosłych z zespołem Aspergera*, [in:] ed. S. Grabiś, J. Panasiuk, T. Woźniak, *Logopedia. Standardy postępowania logopedycznego. Podręcznik akademicki*. Wyd. UMCS, Lublin 2015, pp. 517–549.

- literality of language reception,
- poor non-verbal communication,
- impulsiveness,
- intonation and accentuation disorders,
- focus on one's own interests, persistency in certain topics,
- difficulties with maintaining the communication rhythm,
- clumsy moves, "a strange attitude"

Characteristics of communication of children with Asperger syndrome

The analysis of the diagnostic criteria makes it possible to distinguish between verbal (based on words) and non-verbal communication. In the case of Polish children with Asperger syndrome, there are difficulties with the use of inflectional forms, and thus the difficulty in building the text. The lack of such problems in the case of English-speaking children can be explained by the specificity of English, which, unlike Polish, is not an inflectional language. Children with Asperger syndrome have difficulty in understanding and expressing spatial, temporal, causal relationships. For example, during a therapeutic session, a child with Asperger syndrome, when asked "*Why should you wash your hands before eating?*", answers "*To wipe them with a towel*", and when asked "*Why is the boy supposed to sit quietly?*", answers "*To say nothing*"¹⁷. The narrative of a person with AS is inconsistent, multifaceted, chaotic, which makes it difficult to communicate with classmates, but it can also interfere with communication with the teacher, because "jumping" from one subject to another disrupts the reception of speech by the environment.

Children with AS do not understand metaphors or jokes, therefore they have problems with interpreting poems and understanding the moral of a fairy-tale. Literal and schematic language reception mean that they do not realize the ambiguity of words, the so-called homonyms. Therefore, a patient asked to indicate the difference between the pictures, looks at the speech therapist in a surprised way and says: "*But Ms Ewa, there is no difference here, difference*

¹⁷ The examples come from the speech therapy practice of the author of the article.

is... (a moment of thought - annotation by E.G) *the result of subtraction, and there is no subtraction here*"¹⁸.

Lack of understanding of jokes, metaphors, sayings become the cause of conflicts with peers. Peer-to-peer interaction is also disturbed by stereotype statements, e. g. using the same form of greeting no matter who it is directed to or addressing classmates using their full name, e. g. "Jan Nowak". The pedantic, formal, and "adult" language of a child with Asperger syndrome is often the reason that he/she is considered "big-headed" or "weird".

A narrow range of interests involves persistency in certain topics (those that are exciting for the child). Marta Korendo emphasizes the uneven development of vocabulary in children with AS, associated with their specific interests and the existence of the so-called language passages, i.e. excessive development of vocabulary from a particular semantic category accompanied by difficulties in areas with which most typically developing children have no difficulty e. g. names of colours or meals¹⁹.

The communication process of children with Asperger syndrome may be disturbed by echolalia: open and hidden. Hidden echolalia is the repetition of heard fragments of speech (e. g. from commercials), adequate to the given circumstances, but without understanding the meaning of the words, only by grasping the context of the situation²⁰. Another kind of hidden echolalia is forcing parents or other people to say a word or phrase they used before always in the given circumstances. If a child liked a phrase used by an adult, he or she asks the parent to repeat it in a similar situation, for example, while shopping or cooking dinner. A student with Asperger syndrome may expect the teacher to always address

¹⁸ The examples come from the speech therapy practice of the author of the article.

¹⁹ M. Korendo, *Językowa interpretacja świata w wypowiedziach osób z zespołem Aspergera*, Omega Stage Systems, Kraków 2013.

²⁰ J. Cieszyńska-Rożek, *Metoda Krakowska wobec zaburzeń rozwoju dzieci. Z perspektywy fenomenologii, neurobiologii i językoznawstwa*, Omega Stage Systems, Kraków 2013.

him/her in a certain way, e. g. while checking the attendance list or asking him/her to do a certain exercise. Open echolalia is the repetition of fragments of heard speech regardless of the context of the situation.

Children with AS have a problem with observing the rule of alternation in communication (the rhythm of communication). Behaviour contrary to the principle of alternation, i.e. the inability to conduct a dialogue or discussion, often ends with their exclusion from the peer group, the admonition from the teacher or comments of other adults about the lack of proper "upbringing".

Conversation (dialogue) requires the knowledge of certain conventions associated with, for example, initiating or continuing conversation, and "[...] asking questions relevant in a given context"²¹, and this is an area of significant deficits in the case of people with Asperger syndrome. Children find it difficult to make statements that are relevant to the recipient, the situation, the place, the purpose of the communication, and therefore in the area of communication skills, resulting from schematic language, impaired empathy, one-sided type of social interaction characteristic for AS.

Non-verbal communication of people with this diagnosis is characterized by supra-segmental disorders, concerning the melody, the accent of the rhythm of expression. Patients use abnormal intonation, their voice can be squeaky, unnatural²². They also show difficulties in expressing and receiving communication based on a non-language code. They have difficulty in making eye contact, which is an important part of conversation, a signal that says, e. g. that we want to initiate conversation, a sign of interest in the interlocutor and the topic of conversation. They exhibit difficulties in expressing and receiving gestures and facial expressions, therefore they may not register non-language manifestations, such as impatience, weariness or nervousness.

²¹ T. Attwood, *Zespół Aspergera*, Wyd. Zysk i S-ka, Poznań 2006, p. 61.

²² D. Graaisma, *Rozstrojone umysły. Dzieje chorób i historie chorób*. PIW, Warsaw 2009.

The aforementioned deficiencies, especially the lack of communication skills, failure to observe the communication rhythm, schematic language, difficulties with understanding jokes, persistency in certain topics make it difficult to fulfil the role of a school colleague. A "strange" voice, the use of too sophisticated, adult language, incomprehensible for other children, can be the cause of ridicule, teasing on the part of the other students. Research confirms the correlation between communication skills and peer acceptance²³. Also, the study conducted by the author of this article on the school situation of children with communication difficulties – Polish children affected by stuttering – showed that most of the respondents experience harassment from their peers due to communication difficulties²⁴.

Literal language reception, difficulty in understanding metaphors, narrative abnormalities manifested by problems with understanding causal, temporal, spatial dependencies or inflectional mistakes and failure to observe the rhythm of communication in the classroom may make it difficult to succeed as a learner. It sometimes happens that a child with Asperger syndrome unintentionally violates the school rules that prohibit the use of words that are considered vulgar, "ugly", inappropriate. The reason for breaking the rules in this regard is the failure of the student to take into account the cultural aspect of using certain words²⁵. School rules may also be violated intentionally, by using "these" words for manipulation purposes to control and influence adult responses. Therefore, know-

²³ P.A. Hadley, Rice M., *Conversational responsiveness of speech and language impaired pre-schoolers*. "Journal of Speech and Hearing Research" 1991, no 34, pp. 1308–1317; T.M. Gallagher, *Language skill and the development of social competence in school-age children*. "Language, Speech and Hearing Services in the Schools" 1993, no 24, pp. 199–205.

²⁴ K. Węsierska, E. Gacka, M. Langevin, M. Węsierska, *Sytuacja szkolna dzieci jakujących się w Polsce – wstępne wyniki badań i strategie pomocy*, [in:] ed. K. Węsierska, *Zaburzenia płynności mowy. Teoria i praktyka*. Vol. 1, Wyd. Komlogo, Katowice 2015, pp. 221–235.

²⁵ M. Korendo, *Językowa interpretacja świata w wypowiedziach osób z zespołem Aspergera*, Omega Stage Systems, Kraków 2013.

ing and understanding the specific behaviour of children with AS helps parents and teachers in appropriate treatment and sets the desired direction of therapeutic effects.

Helping a child with AS

A child with Asperger syndrome needs treatment that takes into account abnormalities in the linguistic, social and emotional areas. All these areas are relevant and related. When organizing help, it is important to emphasize the importance of speech therapy focusing on language and communication deficits, as we develop social and emotional attitudes through language. Language allows us to get to know the reality, it is [...] a path leading to human emotions and desires, and also the determinant [...] of the possibility of human existence in the social group"²⁶.

Support measures for children with Asperger syndrome should include:

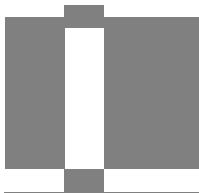
- early diagnosis and early care (psychiatric, psychological, speech therapy, pedagogical),
- providing assistance to both the child and the family; parents need professional knowledge, as well as psychological support, due to the emerging complaints about lack of educational competency (the environment explains the behaviour of children with AS in terms of "bad upbringing"),
- information about the disorder among teachers (in kindergartens, primary schools, lower-secondary schools, secondary schools),
- preventing isolation, social exclusion of children with AS, preventing all forms of bullying, ridiculing, harassment (prevention of bullying), education of the entire school community in terms of anti-bullying activities,
- promoting openness, tolerance and acceptance for others.

²⁶ S. Grabias, *O ostrość refleksji naukowej. Przedmiot logopedii i procedury logopedycznego postępowania*, [in:] *Logopedia. Wybrane aspekty historii, teorii i praktyki*, ed. S. Milewski, K. Kaczorowska-Bray, Harmonia Universalis, Gdańsk 2012, p. 61.

References

- Attwood T., *Zespół Aspergera*, Wyd. Zysk i S-ka, Poznań 2006.
- Błaszczyk-Kowalska S., Gacka E., *Rozwój komunikacji językowej u dzieci z zespołem Aspergera*, „Problemy opiekuńczo-wychowawcze” 2015, no 10, pp. 3–13.
- Błeszyński J.J., *Autyzm a niepełnosprawność intelektualna i opóźnienie w rozwoju. Skala oceny zachowań autystycznych*. Harmonia Universalis, Gdańsk 2016.
- Bryńska A., *Deficyty językowe w zespole Aspergera jako możliwy wyraz dysfunkcji prawopółkowej*. „Psychiatria i psychologia kliniczna” 2010, 10(4), pp. 247–253;
- Cieszyńska-Rożek J., *Metoda Krakowska wobec zaburzeń rozwoju dzieci. Z perspektywy fenomenologii, neurobiologii i językoznawstwa*, Omega Stage Systems, Kraków 2013
- Diagnostic and statistical manual of mental disorders*, 4th Ed, rev. (DSM-IV), Washington 1994, DC: American Psychiatric Association.
- Gajda S., *Wprowadzenie*, [in:] *Logopedia. Pytania i odpowiedzi. Podręcznik akademicki. Interdyscyplinarne podstawy logopedii*. Vol. I, ed. T. Gałkowski, G. Jastrzębowska, Wyd. UO, Opole 2003, pp. 11–18.
- Gajda S., *Jak się porozumiewamy?* [in:] *Logopedia. Pytania i odpowiedzi. Podręcznik akademicki. Interdyscyplinarne podstawy logopedii*. Vol. I, ed. T. Gałkowski, G. Jastrzębowska, Wyd. UO, Opole 2003, pp. 19–26.
- Gallagher T.M., *Language skill and the development of social competence in school-age children*. “Language, Speech and Hearing Services in the Schools” 1993, no 24, pp. 199–205.
- Gillberg C., Gillberg C., *Asperger syndrome – Some epidemiological considerations: A research note*, “Journal of Child Psychology and Psychiatry”, Vol. 30, pp. 631–63.
- Graaisma D., *Rozstrojone umysły. Dzieje chorób i historie chorób*. PIW, Warsaw 2009.
- Grabias S., *O ostrość refleksji naukowej. Przedmiot logopedii i procedury logopedycznego postępowania*, [in:] *Logopedia. Wybrane aspekty historii, teorii i praktyki*, ed. S. Milewski, K. Kaczorowska-Bray, Harmonia Universalis, Gdańsk 2012, pp. 56–69.
- Grabias S., *Postępowanie logopedyczne. Diagnoza, programowanie terapii, terapia, „Logopedia”* 2008, Vol. 28, pp. 13–37.
- Grabias S., *Interakcja językowa i jej uwarunkowania. Perspektywa lingwistyczna*, [in:] *Bariery i pomosty w komunikacji językowej Polaków*, ed. J. Bartmiński, U. Majer-Baranowska, Wyd. UMCS, Lublin 2005, pp. 19–44.
- Grice H.P., *Logic and conversation*, [in:] *Syntax and semantics*, ed. P. Cole, J.L. Morgan, V/3, New York 1975: Academic Press, pp. 41–58; translated by J. Wajszczuk H.P., Grice H.P., *Logika i konwersacja*, „Przegląd Humanistyczny” 1977, no 6, pp. 85–99.
- Hadley P.A., Rice M., *Conversational responsiveness of speech and language impaired preschoolers*. “Journal of Speech and Hearing Research” 1991, no 34, pp. 1308–1317.
- Kaczmarek B., *Misterne gry w komunikację*, Wyd. UMCS, Lublin 2010.

- Korendo M., *Językowa interpretacja świata w wypowiedziach osób z zespołem Aspergera*, Omega Stage Systems, Kraków 2013.
- Maciarz A., Biedasiewicz M., *Dziecko autystyczne z zespołem Aspergera. Studium przypadku*, Impuls, Kraków 2000.
- Morrison J., *DSM-V® bez tajemnic. Praktyczny przewodnik dla klinicystów*. Wyd. UJ, Kraków 2016.
- Panasiuk J., Kaczyńska-Haładyj M.M., *Postępowanie logopedyczne w przypadku osób dorosłych z zespołem Aspergera*, [in:] *Logopedia. Standardy postępowania logopedycznego. Podręcznik akademicki*, ed. S. Grabias, J. Panasiuk, T. Woźniak, Wyd. UMCS, Lublin 2015, pp. 517–549.
- Pużyński S., Wciórka J. (ed). *Klasyfikacja zaburzeń psychicznych i zaburzeń zachowania w ICD-10. Badawcze kryteria diagnostyczne*. Uniwersyteckie Wyd. Medyczne „Vesalius”. Institute of Psychiatry and Neurology, Warsaw 2007.
- Szacka B., *Wprowadzenie do socjologii*, Oficyna naukowa, Warsaw 2008.
- Urbaniak J., „*Mali profesorowie czy inteligentni autyści. Wczesna diagnoza dziecka z zespołem Aspergera*”, [in:] *Wczesna interwencja i wspomaganie rozwoju małego dziecka*, ed. B. Cytowska, B. Winczura, Oficyna Wydawnicza Impuls, Kraków 2006, pp. 399–428.
- Węsierska K., Gacka E., Langevin M., M. Węsierska, *Sytuacja szkolna dzieci jąkających się w Polsce – wstępne wyniki badań i strategie pomocy*, [in:] *Zaburzenia płynności mowy. Teoria i praktyka*. Vol. 1, ed. K. Węsierska, Wyd. Komlogo, Katowice 2015, pp. 221–235.
- Winczura B., *Autyzm, autyzm atypowy a schizofrenia wcześniodziecięca*, [in:] *Dzieci z zaburzeniami łączonymi. Trudne ścieżki rozwoju*, ed. B. Winczura, Oficyna Wydawnicza Impuls, Warsaw 2012, pp. 63–118.



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School environment in the Asperger Syndrome students narration, research conclusions

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The article addresses the subject of social functioning of a student diagnosed with Asperger Syndrome in the environment of a mass education school, in his subjective opinion. Methodologically speaking it is based on qualitative studies and the aim of the research was to reach subjective significance given by the students with Asperger Syndrome to this institution and understanding the role it plays for them.

KEY WORDS: Asperger Syndrome, mass education of disabled students, narration of students with Asperger Syndrome

Transformations of the contemporary world, ever-present civilisation progress, the surrounding reality changing at a breathtaking pace and the change taking place in front of our eyes, for instance with regard to approach to disabilities, has become the basis for investigating the thoughts and feelings of the disabled. The studies covered the students diagnosed with Asperger Syndrome, and the material for research was their own narration devoted to functioning in the environment most crucial for them – peer environment of

the mainstream school. The problem of constantly growing epidemiology of Autism Spectrum Disorders is not without considerable significance here. Despite the growing number of students with Asperger Syndrome in the mainstream schools, it is still difficult to detect the source which would provide a complete picture of the condition and the model of procedure. Asperger Syndrome is a fairly new nosologic condition included in the list of International Statistical Classification of Diseases and Related Health Problems, ICD-10¹ in the 1990s, therefore the literature on the subject is still scarce. What makes the matters even more difficult, we lack diagnostics criteria, in result of which some publications consider Asperger Syndrome a form of autism. Also contemporary classification tendencies seem to be seeking to liquidate both autism and Asperger Syndrome as separate diseases in order to create one single disease entity: ASD – Autistic Spectrum Disorder (*Autystyczne Spektrum Zaburzeń*)². It entails the risk of repeating in Poland the situation which took place in the 1980s. Then in the education process both students with high-functioning autism, and students with Asperger Syndrome were mainly educated as part of special education. The changes described above, taking place also in the organisation of education for the disabled people in Poland covered also the researched group of students with the diagnosed Asperger Syndrome, within the cognitive parameters standards, able to function in the world around them as its fully legitimate participants. It is difficult to find in the theme publications any answers to the questions concerning functioning of the people with Asperger Syndrome as seen from their perspective, since the explanations are mostly supplied by diagnostic criteria or from the perspective of standards, or criteria for the functioning of the disabled people.³ The perspec-

¹ *Klasifikacja zaburzeń psychicznych i zaburzeń zachowania ICD 10, Badawcze kryteria diagnostyczne*, Wyd. Vesalius, Kraków – Warszawa 1998.

² *Klasifikacja Diagnostic and Statistical Manual of Mental Disorders, fife edition DSM-5, American Psychiatric Association*, American Psychiatric Association, 2013

³ Galkowski T., *Dziecko autystyczne w środowisku rodzinnym i szkolnym*, WSiP, Warszawa 1997; Gralińska M., *Jak dokonać wyboru właściwej drogi edukacyjnej dziecka*

tive of the parties concerned is rarely a subject of studies in the special education. Also the search for some educational or integration solutions lacks such perspective. Thus the opinions of the very beneficiaries of those transformations and systemic adaptations was quite intriguing. If these action correspond to their needs in their subjective opinion? Clinical experience and initial analysis of literature revealed that the students under the studies act as a quite conscious subject with well-defined plans and environmental activity. Questions asked during the studies were connected with perception of one of the most significant environment for children, namely the school they attend. Therefore the meaning given to school and events taking place at school by students with Asperger Syndrome became the subject of the studies. The research process was supposed to make us understand the sense and essence given to such experience by us – the observers – the way those students interpret it, and not the way we think they do.

The subject of the research was the school environment and the relationship between it and a student with Asperger Syndrome, the way the student perceives the school through this relation and the final significance given to the school environment by the student with Asperger Syndrome. In the conducted research it was quite interesting to reach the senses and meanings given by students with Asperger Syndrome to their functioning at school as the socialising area of multilayer relations, reconstructing and reaching the subjective meanings given to this institution by the students with Asperger Syndrome and understanding what school is form them.

niepełnosprawnego?, [in:] Twardowski A. (ed), *Wspomaganie rozwoju dzieci ze złożonymi zespołami zaburzeń*, Wydawnictwo Naukowe Polskiego Towarzystwa Psychologicznego, Poznań 2005; Jagielska G, *Dziecko z autyzmem i Zespołem Aspergera w szkole i przedszkolu*, Wydawnictwo Ośrodka Rozwoju Edukacji, Warszawa 2010; Jaklewicz H. ed., *Edukacja osób autystycznych w praktyce i badaniach naukowych*, SPOA, Gdańsk 1997, materiały pokonferencyjne; Komender J., Jagielska G., Bryńska A., *Autyzm i Zespół Aspergera*, PZWL, Warszawa 2009; Pisula E., *Jak matki postrzegają swoje dzieci z autyzmem – jakościowa analiza wypowiedzi matek*, [in:] Pisula E., Mazur A., *Rodzina z dzieckiem z niepełnosprawnością*, Harmonia, Gdańsk 2007.

Searching for the way to show the perspective of respondents, qualitative research turned out to be the best perspective. Qualitative methodology seemed the most appropriate research form for subjective feelings connected with functioning within social interactions of the people with disability like Asperger Syndrome. Research carried out according to a qualitative method, in a natural environment create a holistic picture of the experience shared by the boys. The phenomenon under research is difficult to explore applying the objective method, since the aim of the research process was mainly to deepen the significance and emphasizing an individual character of every respondent, and not merely learning the reality in an objective sense. The criteria for choosing the research sample enumerated in the research were: clinical diagnosis of the Asperger Syndrome, category student, critical period of development which is growing up and maturing (this category is particularly important because of the type of the research dealing with social interactions established by people with Asperger Syndrome, which become predominant in a teenage group), possibility of communication and involvement in the narration.

The research was carried out between December 2011 and July 2012 in an office in Autism Advice Centre at Mental Health Outpatient Clinic for Children and Adolescents in Voivodeship Psychiatric Health Centre in Olsztyn. The procedure lasted from sixty to ninety minutes. The interviews were recorded with the use of a recorder, thanks to which repeated returning to the recording and going through the recorded material was possible. In order to ensure some comfort during the research, each student was informed about the confidential character of personal data of the participants. The group consisted of eleven boys with diagnosed Asperger Syndrome aged between 13 and 18, namely: four thirteen-year-olds, four fifteen-year-olds, one seventeen-year-old and two eighteen-year-olds. The research group was homogenous in terms of sex. Selection of age between 13 and 18 was crucial due to critical phase of development of the respondents. The group was homogeneous in terms of sex. The students under the research realised their compul-

sory education on the basis of the evaluation for special education, attending 11 mass education schools in Warmia-Mazuria Voivodeship. In the course of the studies the subject of the analysis was the issue of how the students with Asperger Syndrome experience their functioning in school environment and what meaning do they apply to it? In the research they told about their experience and the accompanying emotions and feelings. The respondents, even those – as indicated in their answers – clearly alienated from the school society of their peers, like school and like spending time in it, also willing to spend their free time within its premises taking part in extra-curricular activities, observing their mates at play, taking advantage of the quiet comfort and book collections of the school reading. Also the boys who have finished their school education, seem to be returning to the school vicinity, to pay a visit. The analysis of the respondents' replies indicates that their experience in establishing relations both with their peers, and their teachers, as well as the course of such relations, determine their opinion of school to a considerable extent. Difficulties in establishing relationships with other people by the students with Asperger Syndrome can be recognised in their replies indicating isolation of such students at school. Surprisingly enough, subjective reception of such difficulties determine the perception of the school environment by such student only to a small extent. Of course, the relation between the quality of interpersonal relationships experienced by the surveyed students and their approach to school as such is quite noticeable, yet, even those respondents with extremely negative experience of peer contact, explicitly claim that school is an important place for them. Experiencing "being different" in the out-of-school environment may be transferred in the form of fear of "the other" mass school environment, where such "otherness" is even more noticeable. The research conducted failed to prove it. The surveyed students with Asperger Syndrome did not signal in their replies that leaving the protective family environment and functioning in the school environment would be problematic for them. Answering the question about the significance given to the mainstream (mass) school environment by

people with the diagnosed Asperger Syndrome we should indicate that the respondents, despite functioning on the periphery of the peer group declare that they like school, like being in it and like spending time at school, both while learning, and in their free time. The analysis of the interview states that, just like in case of all students, school institution is given a prominent place in the life of a student with Asperger Syndrome. When asked to talk about their lives, the surveyed students devoted a considerable part of their remark to school or even started their statement with a tale of school. The research has shown that for a student with Asperger syndrome and problems connected with establishing a relationship, school is nevertheless a place of establishing contacts. During the interview the respondents talk about distress experienced at school, derision, violence from the peers, nonetheless they seem to emphasize that they feel "cool" at school and know that they can seek help from teachers. Most importantly, the narration of the respondents suggests that they start to create defensive mechanisms, learn to adapt to certain situations, and thus they socialize. The content of the narration indicates that they perceive school as fulfilling its educational, and also partly integration and social function. Another interesting issue that appeared was the way the surveyed students with the diagnosed Asperger Syndrome experience their functioning in school environment and what meaning do they assign to this environment? Special talents and interests typical of Asperger Syndrome translate into the results at school. For students with Asperger Syndrome school acts as not only the sphere of functioning with their peers, but also creates the possibility of confirming their own competences. Many surveyed people emphasize their significant achievements in terms of science. Their encyclopaedic knowledge enables them to improve their own self-esteem and most importantly – impress a teacher. Feeling no need for competition is characteristic of functioning of people with Asperger Syndrome.⁴ Therefore

⁴ Komender J., Jagielska G., Bryńska A., *Autyzm i Zespół Aspergera*, PZWL, Warszawa 2009.

their achievements against the rest of the population are not so meaningful in the subjective assessment of the respondents. Whereas a praise addressed directly at them has significant meaning. A positive assessment aspect is mainly visible with regard to educational role of the school. The respondents become clearly frustrated when talking about the PE lessons. These are the classes which require physical skills and teamwork, whereas a student with Asperger Syndrome struggles not only with motor dysfunctions, but has a huge problem with team games and understanding the their rules. The interview clearly indicate a negative assessment with regard to failures experienced during PE classes. These failures influence the way in which such student is treated by his peers. Negative assessment is characteristic of the first years of education. The respondents explicitly emphasize that it was extremely difficult for them in the beginning, being taken advantage of by their mates e. g. as a person to copy their homework from or to laugh at. The surveyed students declared that functioning "on the margin of school social life" is not a big problem for them and does not influence their assessment of school, which they like attending, and even a shallow character of the relationship with peers is valued by them higher than total lack of it.

Investigating the issue of how the surveyed students with Asperger Syndrome interpret their social relationships at school showed that relationships with peers do not determine the meaning assigned to school environment by the respondents. It is conditioned by the specific functioning of the student with Asperger Syndrome. Such specificity makes the conclusions drawn while investigating the picture of school in the narration of a student with Asperger Syndrome completely different from those drawn from the research on peer relationships among non-disabled students. In the case of the latter aged 13–18, peer relationships play a significant part not only in a social development of a young man, but also influence the assessment of school. It does not mean, however, that relationships with peers are insignificant for students with Asperger Syndrome. The respondents tend to characterise the category of

friendship differently declaring that there is nobody they would call a friend. In fact, they declare to feel no particular need to establish such relationship. They do not mind sitting alone during breaks or passively observing their peers at play. In the descriptions of social relationships formulated by the surveyed students with Asperger Syndrome within the school premises, we can clearly notice their attempt at explaining and somehow justifying their peers approach to them. Due to the difficulties in establishing contacts with peers, a student with Asperger Syndrome naturally turns to people who, in their opinion, pose no threat, namely to teachers and pedagogues. The students gave positive assessment to teachers conducting classes in subjects related to selective interests of particular respondents and those intervening in situations threatening the student. In their narrations students with Asperger Syndrome describe their functioning in the school environment in an inconclusive way with a visible inner contradiction – they clearly emphasize how much distress they experienced at school from their peers. However it does not entail the domination of negative feelings in their subjective approach to school environment. From the respondents' remarks it follows that school environment and social relationships within its premises are significantly predominant over the family environment. The analysis of the interview in terms of aspirations and expectations of student with Asperger Syndrome with regard to school showed that the students with Asperger Syndrome are close to the concept of "full integration", with their effective participation in educational activities carried out in schools of mass education. What is more, their subjective assessment of school as an institution and their experience gained through earlier stages of education make them plan to continue such education in the longer perspective. Awareness of their own limitations is no obstacle for the respondents in formulating long-term plans. The combination of the aspirations of the surveyed students with Asperger Syndrome with their individual dysfunctions and talents indicated that they accurately defined their own predispositions. The analysis and conclusions drawn from the research show that the question about the

aspirations of the students with Asperger Syndrome one should reply that they boil down to normal peaceful living and that their plan does not assume vegetation and passive submission to the course of events, but an active conscious participation and fully fledged functioning in the society. Thus the assumptions of a significant theoretical conception of special education, namely standardisation of the environment with a basic aim in transformation of the environment so as to make a normal life possible are fully confirmed. This kind of purposeful legislative action with regard to integration will contribute to full participation of students with disabilities covered by Autistic Spectrum Disorders in the mass education system. Thus current legislative trends aiming at involving the legislators in creating legal regulations providing solutions for integrating disabled people, including students with Asperger Syndrome, within the mass education system are all the more important. Such process was caused by, e. g. ratification by the Polish government in 2012 *Convention on the Rights of Persons with Disabilities* (2006), aiming at the protection and ensuring full and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities on an equal basis with all other citizens. Provision of article 24 of the Convention guarantees the persons with disabilities the right to education without discrimination on the basis of equal opportunity, is reflected in the amendment to the Polish provisions on education system and social security. Currently we can state that the binding legal regulations in Poland provide conditions for implementation of the rights of the disabled persons to education. As the studies showed – it is not particular provisions on the access to education that entail problems, but lack of more precise executive provisions which would provide for their implementation.⁵

Slow character of changes taking place in the Polish mass education schools, resistance of the teaching staff to the necessity to im-

⁵ Błaszczał A., Kurowski K., Mazurczak A. i in. (ed), *Realizacja przez Polskę zobowiązań wynikających z Konwencji o prawach osób niepełnosprawnych – sprawozdanie Rzecznika Praw Obywatelskich*, Warszawa 2015.

prove their qualifications, slowness in adjusting teacher training programme to a new situation, duration of the process of changes in the approach of non-disabled members of the society, the cost of implementing changes – all this cannot become an excuse for limiting or cancelling the opportunity of students with Asperger Syndrome to fulfil their humanity.

Bibliography

- Attwood T., *Zespół Aspergera, Zysk i S-ka wydawnictwo, Poznań 1998.*
- Błaszcak A., Kurowski K., Mazurczak A. i in. (ed.), *Realizacja przez Polskę zobowiązań wynikających z Konwencji o prawach osób niepełnosprawnych-sprawozdanie Rzecznika Praw Obywatelskich, Warszawa 2015,*
- Charwicka M., *Dziecko z Zespołem Aspergera, wydawnictwo Difin, Warszawa 2015.*
- Chrzanowska I., *Edukacja włączająca – nowa jakość? Czy dotąd byliśmy pedagogicznie zacofani, [in:] Świat pełen znaczeń – kultura i niepełnosprawność, (ed.) Baran. J., Olszewski S., Kraków 2006, p. 659.*
- Frith U., *Autyzm i zespół Aspergera, PZWL, Warszawa 2005.*
- Gałkowski T., *Dziecko autystyczne w środowisku rodzinnym i szkolnym, WSiP, Warszawa 1997.*
- Gralińska M., *Jak dokonać wyboru właściwej drogi edukacyjnej dziecka niepełnosprawnego?, [in:] Twardowski A. (red), Wspomaganie rozwoju dzieci ze złożonymi zespołami zaburzeń, Wydawnictwo Naukowe Polskiego Towarzystwa Psychologicznego, Poznań 2005.*
- Jagielska G., *Dziecko z autyzmem i Zespołem Aspergera w szkole i przedszkolu, Wydawnictwo Ośrodka Rozwoju Edukacji, Warszawa 2010.*
- Jaklewicz H. (ed.), *Edukacja osób autystycznych w praktyce i badaniach naukowych, SPOA, Gdańsk 1997, post-conference materials.*
- Komender J., Jagielska G., Bryńska A., *Autyzm i Zespół Aspergera, PZWL, Warszawa 2009.*
- Pisula E., *Jak matki postrzegają swoje dzieci z autyzmem – jakościowa analiza wypowiedzi matek, [in:] Pisula E, Mazur A., Rodzina z dzieckiem z niepełnosprawnością, Harmonia, Gdańsk 2007.*
- Harpur J., Lawlor M., Fitzgerald M. (ed.), *Interwencje społeczne dla nastolatków z Zespołem Aspergera, Fraszka Edukacyjna, Warszawa 2012.*



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Mothers of children with Tourette's syndrome

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The purpose of this study was to gather data from the mothers of children with Tourette Syndrome (TS), in order to examine the extent to which the existence of a child with TS in the family affected mothers' Quality of Life (QOL). The research was conducted according to the qualitative methods. Data was collected from semi-structures interviews with 50 mothers of children with TS. The interviews were analyzed using a content analysis method. Conclusions derived from the research findings found that lack of accurate diagnosis and information leaded mothers to a state of imbalance and great stress. When they were given accurate information, they seemed to be more able to advocate for the child with TS and thus prevent misunderstandings, and consequent unpleasant situations and confusion.

KEY WORDS: Mothers, Quality of Life, Tourette syndrome.

Introduction

Tourette syndrome is a neuropsychiatric disorder named after Dr. Georges Gilles de la Tourette (1857-1904). It is an inherited, neurological disorder characterized by repeated involuntary movements and uncontrollable vocal (phonic) sounds called tics. Most tics occur at the level of the shoulders and above: eye tics were the most frequent, followed by facial/cervical tics, and those involving

the arms and legs¹. In some cases, such tics can include inappropriate words and phrases². The symptoms of TS generally appear before the individual is 18 years old and usually at the age of six to seven years old³. TS can affect people of all ethnic groups, and it appears to be familial (i.e. it 'runs' in families). Recent information appears to indicate that there is likely to be a significant genetic factor responsible for its genesis. Research by Abelson et al.⁴, reviewed some of the genetic research and identified a new candidate gene. Gender is also linked to the incidence of TS: boys are significantly more likely to develop TS than girls; males are affected three to four times more than females⁵. Most people with TS experience additional problems such as *Obsessive-Compulsive Disorder* (OCD)⁶. Additional problems may include Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)⁷; *learning disabilities* (LD), which include reading, writing, arithmetic, and perceptual difficulties; problems with impulse control, which can result in overly aggressive behavior and socially inappropriate acts; or sleep disorders, which include frequent awakenings or talking in one's sleep⁸. Study examined the association between tic suppress-

¹ C. Ganos, J. Bongert, L. Asmuss, et al., *The Somatotopy Of Tic Inhibition: Where and How Much?* Mov Disord. 2015, 5(9), p. 1184–1189.

² N. Dreher, *What is Tourette Syndrome?* Current Health, 1997, 23, p. 21.

³ Ibidem, p. 21, J.F Abelson et al., *Sequence Variants in Slitrk1 are Associated with Tourette's Syndrome*, Science, 2005, 310(5746), p. 317–320, J. Swain, L. Scabill, P. Lombroso, R. King, J. Leckman, *Tourette Syndrome and Tic Disorders: A Decade of Progress*, Journal of the American Academy of Child and Adolescent Psychiatry, 2007, 46(8), p. 947–968.

⁴ J.F. Abelson et al., (2005). *Sequence Variants in Slitrk1 are Associated with Tourette's Syndrome*, Science, 2005, 310, (5746), p. 317–320.

⁵ N. Dreher, What is Tourette Syndrome? Current Health, 1997, 23, p. 21, J.F. Abelson et al., (2005). *Sequence Variants in Slitrk1 are Associated with Tourette's Syndrome*, Science, 2005, 310(5746), p. 317–320.

⁶ M. Robertson, *Tourette Syndrome, Associated Conditions and the Complexity of Treatment*, Brain, 2002, 123, p. 425–462.

⁷ Ibidem, p. 425–462.

⁸ R.L. Albin, J.W. Mink, *Recent Advances in TS research*. Trends Neuroscience, 2006, 293, p. 175–182.

sion and quality of life. Although most tic patients frequently try to suppress tics, they find suppressing them uncomfortable and distracting. However, those patients who are more satisfied with their ability to suppress their tics also report a higher quality of life⁹.

Having a child with Tourette Syndrome (TS) seriously challenges parents who aspire to raise a 'normal' family, because of the stresses and strains engendered by the unusual behavior of the child with TS¹⁰. As mentioned above, children with TS may experience a wide range of psychological, behavioral and psychiatric problems in addition to vocal and motor tics. These difficulties also lead to interpersonal communication problems, feelings of anxiety and mood-changes, and may be accompanied by difficulty in concentrating, hyperactivity and obsessive behaviors¹¹. These children usually find it hard to adapt their behavior to their environment and their particular characteristics may have a negative impact on the child's functioning at school. In addition to their difficulties in daily functioning in school, children with TS exhibit significant problems with labile emotions, impulsivity, and aggression directed at others¹². Usually, this situation engenders confusion, helplessness and sometimes an inability to maintain 'normal' family life.

Parents' perceptions on the nature of a disability are determined to some degree, in line with their cultural values. This is also true for their views about the nature of a disability. Common perceptions include envisaging that their children as developing normally,

⁹ N. Matsuda et al., *Self-Initiated Coping with Tourette's Syndrome: Effect of Tic Suppression on QOL*. *Brain Development*, 2016, 38(2), p. 233–41.

¹⁰ R.W. Greene (1996). *The explosive child: A new approach for understanding and parenting easily frustrated chronically inflexible children*. New York, NY, 1997. Available from the Tourette Syndrome Association, Inc. 42–40 Bell Blvd., Suite 205 Bayside, NY, 11361–2820.

¹¹ D.A. Carter et al., *Social and Emotional Adjustment in Children Affected with Gilles De La Tourette's Syndrome: Associations with ADHD and Family Functioning*. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 2000, 41, p. 215–223.

¹² J. Piacentini, R.L. Bergman, M. Keller, J.T. McCracken, *Functional Impairment in Children and Adolescents with Obsessive-Compulsive Disorder*. *Journal of Child and Adolescent Psychopharmacology*, 2003, 13, Supplement 1, p. 61–69.

identifying their children's condition as a temporary or passing condition, and perceiving a disability as God's punishment or, conversely, as God's special gift¹³.

Mexican American mothers of children with disabilities believe their child's development to be normal¹⁴. Some mothers defined their child as having a disability and yet developing normally. Mexican American mothers of children with language disabilities were not concerned about their children's language difficulties. Although they accepted that their children were developing at a different rate, they had expectations that their children would have better communication skills after age three and the mothers believed that as their children grew older, they would 'catch up' with their peers. On the other hand, Mexican American mothers of children with disabilities clearly distinguished between being disabled and being normal. Believing that each child with a disability was unique, they perceived their child's condition as a disability, and not an illness or disease¹⁵.

Mothers of children with intellectual disability experience more depression than those of children who develop normally¹⁶. When the parental experience was examined across diagnoses, differences were noted. Parents of children with Down syndrome have been found to experience less stress,¹⁷ depression,¹⁸ than parents of children with other diagnoses, particularly autism. Parents of children with disabilities were found to have poorer parenting efficacy and

¹³ S.B. Garcia, A.M. Perez, A.A. Ortiz, *Mexican-American Mothers' Beliefs about Disabilities: Implications for Early Childhood Intervention*. Remedial and Special Education, 2000, 21, p. 90-102.

¹⁴ Ibidem, p. 90-102.

¹⁵ Ibidem, p. 90-102.

¹⁶ M.B. Olsson, C.P. Hwang, *Depression in Mothers and Fathers of Children with Intellectual Disability*. Journal of Intellectual Disability Research, 2001, 45, p. 535-543.

¹⁷ L.A. Ricci, R.M. Hodapp, *Fathers of Children with Down's Syndrome Versus Other Types of Intellectual Disability: Perceptions, Stress, and Involvement*. Journal of Intellectual Disability Research, 2003, 47, p. 273-284.

¹⁸ L. Abbeduto et al., *Psychological Well-Being and Coping in Mothers of Youths with Autism, Down Syndrome, or Fragile X Syndrome*. American Journal on Mental Retardation, 2004, 109, p. 237-254.

poorer parental mental health¹⁹, and poorer marital adjustment. It seems that since Down syndrome can be diagnosed either during pregnancy or at birth, rather than at an older age - as is the case of TS, which is diagnosed at the age of 6-7; this can explain the differences in parents' reactions to their child's disability²⁰.

Studies regarding the impact of the birth of a child with TS on the family life pattern²¹ found two central aspects regarding the processes that occur in the family of a child diagnosed with TS: 1) the various stages of the parents' responses; 2) consequences for siblings of the child. The model offered by Wanless and Fortier²², which describes the passage of the family of the child with disability through a number of stages from the time of discovery of the disability, reflects similar stages noticed in families of a child with TS, but with a unique emphasis on the syndrome itself and its attributes. The stages indicated are: 'clash', 'denial' and 'sadness', 'focus on the external world' and eventually 'acceptance'²³.

According to this multi-stage model, the *Clash Stage* is characterised by shock, mourning and fear Haerle²⁴ developed a seven-stage model of coping with TS) argues that the initial response of many parents to a diagnosis of TS in their children is 'shock'. This response is very common, particularly in cases in which the syndrome appears suddenly, or when parents had not perceived their child's disability as so severe. Nevertheless, even when parents did sense

¹⁹ J. Kersh, T.T. Hedvat, P. Hauser-Cram, M.E. Warfield, *The Contribution of Marital Quality to The Well-Being of Parents of Children with Developmental Disabilities*. Journal of Intellectual Disability Research, 2006, 50, p. 883-893.

²⁰ Ibidem, p. 883-893.

²¹ A. Duvdevani, M. Hovav, A. Rimmerman, A. Ramot, *Parenting and developmental disability in Israel*, Jerusalem, 1997.

²² R.L. Wanless, L.M. Fortier, Family Crisis Following the Diagnosis of a Handicapped Child, [in:] *Parenting and developmental disability in Israel*, eds. A. Duvdevani, M. Hovav, A. Rimmerman & A. Ramot, *Parenting and developmental disability in Israel*. Jerusalem: Y.L. Magness Pres, 1997.

²³ A. Duvdevani, M. Hovav, A. Rimmerman, A. Ramot, *Parenting and developmental disability in Israel*, Jerusalem, 1997.

²⁴ T. Haerle, ed., *Children with TS: A parent's guide*. Rockville, MD, 1992.

that something was not right for many years previously, hearing the words 'TS' often causes feelings of shock. TS, unlike many other chronic disorders, is a syndrome that is not well known to many people and therefore most parents have difficulty understanding the nature of their child's disorder. A lack of sensation which often arises as a result of discovering that the child has TS, may help parents avoid being swallowed up by feelings of distress and sadness²⁵. It also apparently prevents parents from accepting the full meaning of the syndrome and its attributes. At this stage, parents have difficulty absorbing new information provided to them, and therefore during this stage, many neurologists tend to transmit test results and information in a short and simple fashion²⁶.

In contrast to these responses of shock, sometimes, as a result of the unique nature of development of the syndrome, the initial response of parents to discovering their children's condition is a sense of profound 'relief'²⁷. Because of the unique characteristics of the syndrome, parents have often been aware that something was not right with their child, for many years before diagnosis²⁸. Since, in most cases, TS is not diagnosed until the child is seven to eight years old; this means that parents have often already become concerned about the child's early development before they approach a neurologist, they become worried that something is not right and consequently the eventual diagnosis of TS may be less menacing than their most terrible imaginings²⁹.

Thus, raising a child with TS has significant implications for the family's everyday life. Like other families who deal with a child with a disability, families of children with TS also undergo crises

²⁵ M.M. Robertson, M.R. Trimble, A.J. Lees, *The Psychopathology of the Gilles De La Tourette Syndrome*. British Journal of Psychiatry, 1988, 152, pp. 383-390.

²⁶ W. Pavot, E. Diener, E., *Review of Satisfaction with Life*. Psychological Assessment, 1993, 5(2), p. 164-172.

²⁷ E.F. Shimberg, *Living with Tourette Syndrome*. N.Y., 1995.

²⁸ W. Pavot, E. Diener, *Review of Satisfaction with Life*. Psychological Assessment, 1993, 5(2), p. 164-172.

²⁹ E.F. Shimberg, *Living with Tourette Syndrome*. N.Y., 1995.

and changes in various areas of family life. Those changes may appear in the family when viewed as an organization and a system, changes in systems of relations between parents and children and also within the parental relationship. Studies indicate that the family is an important mediating factor in the emotional and social adjustment of the child. For this reason, information regarding the manner in which parents and siblings of children with TS tend to respond to this crisis situation and their coping strategies can help professionals in the mental health field, as well as the doctors and neurologists who may encounter such families in the future. It can also help the families, especially the mothers, to better understand how the birth of a child with TS affects the family, and help them learn better ways of dealing with the many difficulties that arise while raising a child with TS together with their other children in the family. The next section discusses conceptions of QOL in relation to mothers who have a child with TS.

Any discussion of QOL usually refers to how 'good' life is. If human beings are seen as organisms with 'potential', capable of mental and social self-realization, then the purpose of life is the ability to allow this 'potential' to develop in both an individual and ecological context. Therefore, QOL, or in other words, 'a good life', means the ability to maximize life's 'potential' in a particular social and ecological context.

QOL is shaped by a variety of life conditions that interact in complex ways. What is considered to be a 'good' life is different for different people. People in various parts of the world have defined quality in their lives in rather distinct ways. Different groups and individuals often think of QOL in ways that are specific to their own life situations and their own characteristics. But a slightly more profound examination of this issue reveals that it is not always a simple task to determine how 'good' life is or what the meaning or purpose of life is. QOL relates to the person's general expectations of life, therefore, its conceptualization varies according to individual perceptions³⁰.

³⁰ I. Brown et al., *FQOL: Canadian Results from an International Study*. Journal of Developmental and Physical Disabilities, 2003, 153, p. 209-230.

In many cases, QOL relates to a cognitive judgment regarding satisfaction with life and an affective assessment of emotions and moods. It relates to individuals' overall assessment of their internal experiences, including thoughts, attitudes, motives, dreams, and emotions³¹, and their subjective and intuitive assessment of the quality of their experience as they are able to rationally and responsibly report. QOL may not be explainable solely on the basis of objective situations that the individual experiences, as it is affected by the individual's personal perceptions and attitudes³², and therefore, different people will not necessarily assess the same life circumstances in the same way.

From a historical perspective, the definitions of QOL have changed over the last decades, and the term has been defined differently by different researchers. Thus, QOL has been defined as the difference between the hopes and expectations of the individual and their present experience³³, while others see QOL as a sense of personal satisfaction that is more than contentment and happiness but less than fulfillment. It is experienced when a person's basic needs are met and when he or she has the opportunity to pursue and achieve goals in definitive life settings, namely, work, school, home, and community³⁴.

Although QOL is defined in different ways, researchers have agreed on two fundamental concepts: QOL is multi-dimensional, and it includes both subjective and objective dimensions³⁵. Thus, in QOL research, a distinction is often made between subjective and objective³⁶.

³¹ E. Diener, R.E. Lucas, Personality and Subjective Wellbeing, [in:] *Hedonic psychology: Scientific perspectives on enjoyment. Suffering and well-being*. Eds D. Kahne-man, E. Diener, N. Schearz, New York 1997.

³² Ibidem.

³³ K.C. Calman, *Quality of Life in Cancer Patients: An Hypothesis*. Journal of Medical Ethics, 1984, 10, p. 124– 127.

³⁴ Ibidem, p.124– 127.

³⁵ A.S. Halpern, *Quality of Life and Conceptual Framework for Evaluating Transition Outcomes*. Exceptional Children, 1993, 596, pp. 486–498.

³⁶ Quality of Life Research Unit, *An overview of the Quality of Life Research Unit, University of Toronto*. Department of Occupational Therapy Centre for Function and Well-Being, University of Toronto., 2001, Available at: <http://www.utoronto.ca/qol/unit.htm> (accessed: 1.6.2010).

Subjective QOL is about feeling good and being satisfied with things in general. Objective QOL is about fulfilling the societal and cultural demands for material wealth, social status and physical well-being.

QOL is also the degree to which people enjoy the important possibilities in their lives³⁷. Possibilities result from the opportunities and limitations that people are offered in their lives and reflect the interaction of personal and environmental factors. QOL includes, but is not limited to, the social, physical and emotional functioning of the child and the adolescent, and when indicated, the family members, and it necessarily alters according to changes that occur throughout the child's development. QOL is measured by the difference, at a particular period of time, between the hopes and expectations of the individual and the individual's present experience. It is influenced by the individual's past experience, present lifestyle and personal hopes and ambitions for the future³⁸.

As mentioned earlier, this research seeks to explore the QOL of mothers who have a child with TS, with the hope that this exploration and the insights gained from this process might inform best practice and assist policy makers who treat and determine policy for these families especially the mothers.

The conceptual framework of this research

Systems Theory and the *Ecological Model* were selected to explain how mothers of children with TS operates and functions in the family. Systems Theory was the name used by early investigators to describe the organization and interdependence of relationships³⁹,

³⁷ H. Ouellette-Kuntz, B. McCreary, Quality of Life Assessment for Persons with Severe Developmental Disabilities. [in] *Quality of Life in Health Promotion and Rehabilitation*. eds. R. Renwick, I. Brown & M. Nagler Thousand Oaks, CA, 1996, p. 268-278.

³⁸ K.C. Calman, *Quality of Life in Cancer Patients: An Hypothesis*. Journal of Medical Ethics, 1984, 10, p. 124-127.

³⁹ R. Rapoport, R.N. Rapoport, *The Dual Career Family: A Variant Pattern and Social Change*. Human Relations, 1969, 22(1), pp. 3-30.

and was defined as a set of objects or elements in interaction to achieve a specific goal⁴⁰. Systems theory considers the way relationships within the family and between the family and the social environment influence individual development and family functioning, and provides guiding principles for family systems⁴¹. Thus, Systems Theory explains how family members interact and what personal and interpersonal processes occur inside the family.

The Ecological Model views human development from a person-in-environment context, and emphasizes the reciprocal connections between the person and the environment⁴². Thus, the ecological model delineates how mothers interact with the environment outside the family. Use of the two theories (Systems Theory and the Ecological Model) enables a holistic depiction of the mother functioning inside and outside the family system.

Methodology

Since the research sought to examine the QOL of mothers who have a child with TS, and with no pre-determined hypotheses available, a qualitative approach⁴³ was used to address related issues and deepen the understanding of the mothers' perceptions of their QOL. Interviews were conducted with the mothers to ascertain their views, opinions, and feelings⁴⁴.

⁴⁰ S.D. Ryan, M.S. Gates, *Inclusion of Social Subsystem Issues in IT Investment Decisions: An Empirical Assessment*. Information Resources Management Journal, 2004, 17(1), p. 1-18.

⁴¹ M. Bowen, *Family Therapy in Clinical Practice*. Northvale, NJ, 1978.

⁴² K. Kreppner, R. Lerner, Family systems and the Life Span Development: Issues and Perspectives. [in] *Family Systems and Life-Span Development*, eds. K. Kreppner, R. Lerner, Hillsdale, New Jersey 1989.

⁴³ Daniel Ortiz, Jennifer Greene, *Research Design: Qualitative, Quantitative and Mixed Methods Approaches Book Review on line*. Qualitative Research Journal, 2007, 6(2), p. 205-207.

⁴⁴ A. Oppenheim, *Questionnaire Design, Interviewing and Attitude Measurement*, London 1992.

The research interview was a recorded, open interview that was conducted with the mothers of children with TS. The interviewer presented one initial descriptive question aimed at eliciting as much information as possible: '*Describe what it is like to live with a child with TS at home*'. A single open question was used so that the researcher could provide the mothers with the opportunity to continue to develop the discussion as they desired, and to indicate what they felt was important, without any intervention or direction on the part of the researcher. The goal was to understand their personal experience as they felt it and the meaning that they attributed to this experience. Both the researcher and the mothers contributed to and were affected by this process of re-constructing reality⁴⁵. This allowed better and deeper understanding of the impact that the child with TS has on the QOL of the mothers.

The research population included 50 mothers in Israel at the time of the research that had a child with TS living in the family home, who were registered with the TS Organisation in Israel (TSOI). The participants were identified with the help of the TSOI. The TSOI staff mailed letters to the mothers requesting their agreement to participate in the research. All the mothers who agreed to participate in the research were included as participants (50 mothers). At this stage, it is noted that the mothers who consented to participate in the research were homogenous in ethnic origin although the population from which they were drawn (all those families registered with the TSOI) is not so homogenous from this aspect.

Findings and discussion

In accordance with the research programme, data were gathered from interviews of mothers who have children with TS. Fifty interviews were conducted and recorded in the families' homes. The aim of these interviews was to capture the perceptions and feelings of

⁴⁵ Ibidem.

mothers regarding their experiences in raising a child with TS, in order to understand their QOL more deeply and how they coped with raising a child having TS on a daily basis. This chapter presents the findings that emerged from the content analysis of the interviews with those mothers.

The fact that a family has a child with TS affects family dynamics and relationships among the mothers and family members. Even though positive relationships between and among family members are very necessary for a good QOL, for some mothers, their relationships apparently undergo significant changes because of the pressure they experience: 'The many pressures i faced made my life impossible'.

For some mothers, they expressed that dealing with the situation caused almost total dissolution of the family:

The stress of our lives tore my husband and me apart, not an uncommon story in the life of a child with TS. We could not understand and we needed guidance to go through all this. We couldn't function as a family.

When the father could not function, and separated himself from the situation, this could cause much frustration the mother:

My husband detached himself... it was his way of coping with the new situation. He didn't want to talk and couldn't help and I felt frustrated.

And when the entire burden fell on the mother, it caused a lot of tension:

As if the family almost disintegrated. There were a lot of problems. In the house my husband and I are very close to one another, we have a very good relationship, but we were so tense and the tension was so hard on me. These were the nights that I cried and cried and my husband couldn't help.

Most of the mothers indicated that they needed guidance and some activities to maintain good relationships within the family:

I wanted to talk to my husband but I didn't know how to do so, I wish I could get some help.

Families expressed a need to share their feelings in order to function in daily life, as one mother said:

At first my husband and I had difficult times. We did not know what to do, and this created tension between us. But now I feel that it brought us closer. My husband also has TS. We found it out only after we understood that our son has Toilette. Now we speak about it between us a lot and it helps us and makes us closer.

One of the mothers said:

It was most difficult for me because all the time, almost all the time, it was only me who was with him [the child with TS], I slept with him on the couch, because there was a period when he tried to bite himself all the time, he would cause himself injury with his teeth, and I would perform reflexology, and that calmed him down, and I would lie with him on the couch, and I would caress him until he fell asleep. Those were the nights we slept on the couch. In the morning, I was tired and could not function and take care of the other family members.

When a parent could not function, stress was apparently engendered, '*I wanted to talk to my husband but I didn't know how to do so, I wish I could get some help.*'

Good cooperation between the parents seemed to help alleviate pressure:

Twice a week I go to exercise class and yoga and my husband puts the children to bed. It also helps. I am with myself and it is very important to me, and I relax from the stresses of the day.

Thus, according to the evidence it seems that when the father isolates himself, the mother apparently takes the responsibility for the care of the child with TS. Sharing feelings and open discussions apparently help to decrease stress. It seems also that Information about TS might help the mothers deal with the situation in a better way, yet this will not necessarily remove all social difficulties.

My son did not invite his friends to his home because he did not want his friends to see his sister, because he thought he would get teased.

In another case a brother's inability to communicate with the sibling with TS led the brother to isolate himself in his room:

The most difficult episode was when his brother tried to create contact and speak to him [the child with TS]; he would repeat the words that his brother said and would not stop. It annoyed his brother and sometimes he would get so angry that he shut himself in his room.

Some siblings of children with TS showed concern regarding the future of their TS siblings. One of the brothers was afraid that his brother was going to die. When his mother asked him why he felt so, he answered:

Because at first you would go off and discuss with my father, my brother's situation in whispers, and no one told me anything, which caused me to think that something horrible was about to happen.

Siblings apparently do not understand that there are so many problems to deal with and it seems to be difficult for them to accept the fact that the child with TS needs more care.

Thus, it seems that open communication within the family initiated and guided by the mother helped to clarify the feelings of the siblings of the child with TS, and helped the family to understand the needs of all family members.

Thus too, from the evidence gathered from the interviews it appears that there are two critical elements for mothers QOL: The role of the mother within family interaction and provision of accurate and relevant information. And, it seems that openness, and airing and sharing of family members' feelings guided by the mothers, can positively affect the mothers QOL.

Taking care of a child with TS was perceived as an opportunity to do good deeds and thus gain innate satisfaction from helping the child and the family. The findings seem to indicate that in families of children with TS, in order to maintain a 'normal' family interac-

tion, family members need to talk with each other about their feelings and the ways they are dealing with the situation.

This apparently enables them to feel competent and comfortable. They need to talk about their feelings of safety and fear, and what it takes to improve the sense of security in the family. The mothers' interviews revealed that when they were able to talk openly with each other this helped to prevent stress and generate options for problem solving.

Thus, in sum, the evidence seems to indicate that the mother emerges as a critical figure within the family as a catalyst creating an atmosphere of openness, sharing and airing of feelings, and helping to improve the morale and mood of the family.

It is common assumption that mothers expect to have a perfect, healthy child. Disappointment can be acute when one has a child with TS. mothers may experience feelings of denial, anxiety, guilt, depression, or even anger when they are unable to help their child. One mother said:

After he [child with TS] was expelled from school in Year 9, he spoke about the fact that he had been considering suicide and all kinds of things, and I felt hopeless. How can I make him happy again? Whenever I remember that feeling, I cry. I cried and simply asked the doctor to help me, to find a way for my child to be happy. I had no one to turn to ... and the doctor did not know how to help.

The fact that mothers needed to watch their child all the time exhausted them:

I always had to watch him to ensure that he wouldn't go into the bathroom alone, so i had to go in with him and make sure he wouldn't put his hands in'.

I had to prevent him from having the opportunity to be alone and to hurt himself. I would follow him everywhere. It was as though he was hospitalised, and all the time he couldn't leave the house. I had to be with him all the time until he stopped the behaviour once and for all, and every time he had an attack, obsessions, I would give him medication, and then stop when he calmed down.

The need for continual supervision and worrying about the child with TS and the need for intensive care often meant that the mothers neglected the other children in the family:

He was unable to wash himself, he could not dress himself. I had to do everything. He was not able. He was in such a state that if he spoke to me, you couldn't be sure if you were communicating with him, it was as though you were talking to him and then didn't know if he was receiving what you said. He was in his own world. At the end of the day I was weak and nervous and couldn't help the other children.'

Thus, mothers often felt that they did not invest enough in their other children, and that they could not protect them and this caused them much sorrow:

Attention and energy are too focused on the child with TS, and I feel that I am not sensitive to the other children. I feel that this is not fair, but I do nothing about it.

Others feared that they might lose control of their child with TS, particularly fearing adolescence and fear for the child's future. With tears in her eyes, one mother said that:

I am really afraid that a day will come and I will not be able to catch him and calm him down. I am particularly afraid of adolescence. He will grow up, continue to swear, and I won't be able to control him. This really scares me. Now he is little, but, what is going to happen when he grows up? [Almost choking with tears, the mother continued saying:] Sometimes I am afraid that he will be a criminal, I don't want to even think about it.

Families apparently need to maintain good relations in order to be strong enough and have the strength to help their other children. One mother said:

I try to maintain a strong relationship with my husband and my other children, because this gives me the ability to help my child with TS.

Lack of information about the syndrome sometimes led mothers to act violently:

At home, he would go crazy and not stop yelling and cursing. Sometimes it would drive me crazy. I would put him in the room and hit him hard and ask him not to come out. I didn't know he couldn't control his behaviour.

Most of the mothers indicated that if they had been given information about the syndrome they would know how to deal with it:

Knowing that my child could not control himself because he has a neurological problem tore me apart, for years I blamed him for his behaviour and punished him I even sometimes used physical force to control him.

It is commonly assumed that parents feel that part of their role is to protect their children and they expect others to support their children in order to improve their quality of services. Mothers indicated that they had to develop good decision-making strategies and advocacy to help their child with TS:

I always feel that I have to speak up with teachers, doctors and specialists to make sure my child gets good care.

They apparently needed the help of professionals to take care of their children's emotional difficulties:

I cried and simply asked the doctor to help me, to find a way for my child to be happy. I had no one to turn.'

They expressed a need to stand up for the child with TS in the environment in order to protect them from the environment:

People don't understand that he has a disorder and look at him strangely. They think he isn't disciplined. I don't have the strength to explain it to everyone, but I know that I have to do so for his sake.

Thus, according to the evidence, the mothers apparently find it difficult to take care of all of their children as they would like to, as an integral part of their parenting, and simultaneously to advocate for and provide intensive care for the child with TS. Mothers seem

to be forced to cope with their difficulties alone, and in most cases, do not receive any assistance from the extended family.

My parents did not want to help because they thought I didn't know how to raise my children and they weren't able to cope. My mother and father very rarely come to visit us. They claim that I don't know how to educate my children.

My mother in law is an elderly woman so she does not intervene with the TS'.

Friends stopped visiting us, for some the swearing was very difficult so they stopped coming (for a visit)'.

Inability of friends to help and understand also made the mother feel guilty:

One of our friends constantly accused me of giving my son too much medication, and medications are not good. What, doesn't she understand that I have no choice? She used to aggravate me with her comments, so I told her not to come any more. She made me feel guilty.

These circumstances apparently led to the isolation and exclusion of the family:

The feeling that the environment blames me for not knowing how to raise my child and the conclusion that I am not a successful mother is very difficult, in particular, when it comes from the people who are the closest to you.

Some mothers felt that they neglected their children and did not provide sufficient care for the other children in the family:

Sometimes I would take the little sister to therapy at the psychologist because she starting hitting and biting children in kindergarten and this was new behaviour.

Inability of mothers to help and support all the siblings led to much tension:

The children in the family needed a lot of encouragement and I didn't give it to them. Sometime I would hear the brother say that he wanted to kill himself.

Mothers didn't see the pain of the other siblings because they were so worried about the child with TS:

My daughter once wanted to run away from home. She couldn't deal with him. She couldn't speak to us about it. She felt tension. He bothered her. She couldn't do her homework because of the noise and yelling. He hit her and she couldn't manage and tried to run away. Only later, when we talked about what happened we understood how much she was suffering.

Thus, the evidence seems to indicate that due to the inability of the mothers to provide sufficient care for all the children and the inability of the extended family or friends to understand the difficulty and to assist, the mothers often felt isolated and alone.

Some mothers reported that they did not trust the medical and psychiatric doctors' abilities to diagnose the problem. From their experience and in their opinion, most doctors did not know what was wrong with the child. One of the mothers said:

After I discovered that my child had almost stopped breathing, I decided to look for a more serious doctor who could explain what was going on with my child. Until then, no doctor had been able to tell us what was wrong with the child. Why hadn't anyone told us what the child has... all these problems all these years.

The mothers often did not receive answers from the public health system and were forced to look for a diagnosis in private health care:

I saw that the child was behaving in a strange way. My husband was out of the country, and I decided to look for a more serious doctor than the one I had. I made an appointment with Dr. S. in Zichron Yakov, because until then no one had told me what was wrong with my child.

Most of the mothers who were interviewed indicated that services provided to the child with TS were defective or inadequate especially during the diagnosis. Sometimes the diagnosis of the symptoms was a shock for the families:

After much suffering, my friend gave me an article to read. She studies psychology and she said she thought that she knew what my child has. The article exactly described the attacks and the ceremonies that he has, I was shocked. How come the doctor did not tell me what my child had? Then I asked the psychiatrist if this is what my son has, and he said he doesn't like to call it by that name, but that is what he has. It's a shame we had to wait so long to know what my son has. I feel a relief knowing that my son has a neurological problem and that his condition has a name.

Mothers turned to doctors for help in crisis situations and received no help:

He talked to me about the fact that he had considered suicide and all kinds of things that he wanted to do to himself, and I felt helpless. How can I help him and restore joy in his life? It is a feeling that I felt remembering that I cried. I simply asked the doctor to help me, as if he could find a way for me to give him back joy in life. The doctor didn't know and didn't help.

Even when mothers asked for answers when the child was at an early age, they were disappointed when the diagnosis was not sufficiently deep or professional:

At age 4 we went to a psychiatrist because he had temper tantrums, he would yell, he didn't stop repeating words over and over. The doctors diagnosed ADD and recommended Ritalin.

Lack of appropriate information or contradictory information apparently confused the mothers:

One psychologist recommended that I should leave him [the child with TS] alone and not tell him to stop all the time because he could not control his behaviour. But the other psychologist said we have to set limits and teach him that it isn't nice to act this way, and with time he'd learn to control himself.

Mothers reported that if the diagnosis had been given to them earlier, it would have averted unnecessary stress and tension. This

response was common among the families participating in the research. For example, one mother explained:

The knowledge that my child's disorder had a name and that they knew what was causing the behaviour led me to understand that both I and my son had done nothing wrong. It helped me to accept the fact that my son simply couldn't control his tics. Now I can tell people that my child has a neurological problem.

Another mother said that:

Knowing that my son's condition has a name brought some relief as we understood that there is situation here that needs to be treated, and it has nothing to do with the fact that we are or are not good parents. Knowing brought some relief.

In another family, the mother said:

When the psychiatrist said, your child has TS, I became dizzy. For years we had run from one doctor to another doctor and no one was able to explain what was wrong with my child.

The discovery (diagnosis) of TS and the acceptance of the diagnosis are difficult, and in many cases, it takes much time until the family receives assistance. The lack of appropriate services was repeatedly noted in the interviews as something that affected the mothers' QOL. Another claim that was made was that if the child could receive appropriate services, daily coping would be ameliorated and less complex. Mothers began to disintegrate when they were not able to diagnose the child's behaviour: 'it was as if the family almost fell apart.' The risk of family breakdown was especially noted during the initial period following diagnosis of the syndrome.

Thus, most of the mothers reported that the medical, psychological and psychiatric care that they received fell far below their needs. These services cost money, and the families with little means were unable to withstand the high expense. Often, the family's decision was to accept services from their medical insurance funds, but

they sometimes felt that these did not satisfy their needs. In certain cases, out of despair, some families decided to privately seek services and to pay the high cost, which forced them to change their financial priorities in the household. Seven of ten of the families who were interviewed had to change their family's financial priorities in order to finance medical services

An additional deficiency in services that the families noted related to the consideration of the child with TS by the education system. Most of the mothers reported that the education system failed to accept their child's situation and lacked knowledge concerning the child's difficulties and the ability to cope with these difficulties:

The difficult problem began in school, in Year 1. He didn't fit in, he left the classroom, yelled and cursed without end, talked and talked, didn't let the teacher teach. I knew that I had to fight for him.

A few mothers found a solution to the problem by turning to the Ministry of Education or to organisations that help families whose children have difficulties assimilating within the education system:

I asked the Israel TS Organisation to come to the school and lecture the teachers on the phenomenon. I turned to the Special Education Service and asked for a teaching assistant to be assigned to him.

The more severe the case, the more mothers reported on the authorities' inability to help them, despite their appeals to different associations. The education system very often asserted that they were unable to cope with the difficulties engendered by the TS condition:

At that time, he had a lot of temper tantrums, cursing fits and yelling, and talking incessantly. He kept repeating the word 'sex'. Every sentence and in every situation, he said 'sex'... Every time the teacher couldn't cope with him, she would ask the assistant to take him out into the yard. At the end of the year, they asked him to leave the school.

Despite the fact that some of the children were diagnosed as having behavioural problems and not as 'learning disabled', it was often reported that the school decided not to deal with the situation:

He doesn't have a learning disability. When he is calm he is very smart and fits in well. Because of his attention and hyperactivity problems, he couldn't learn and the school system just gave up.

Mothers reported that they could not trust the school because they would always call and ask them to come and take their child home or they would call to complain about the child: 'They call from school all the time. Sometimes I need to go and bring him home.'

For this reason, some mothers have to leave or change their place of work: 'I work here at home because I need to be available.' mothers spend time at school because they worry about their child being expelled from school: 'Most of the time either I or my husband was at school. It was very difficult.'

According to the evidence, the lack of appropriate services from the education system made it difficult for the family to function and in most cases, they ask the family to solve the problem by themselves:

They asked us to find another school for him, and said that he was not suited to stay in the school. With great difficulty, we found an open school and he was accepted, he cursed a child and called him 'dirty Ethiopian'. The child was the son of the therapist in the school, and they called and said they could not keep him because of his cursing [the mother began to cry]. We didn't know what to do.

Mothers felt that they need to advocate for the child opposite the education system:

I turned to the Regional and Town Support Centre which is a professional centre that provides care to children with academic difficulties in the regular education system, and asked for an assistant to stay with him. If I had not gone directly to the supervisors in the education system and the support centre, the school would have thrown him out, and he'd be in special education in a school for disturbed children.

According to the evidence, the research indicated that the main need for mothers is to receive truthful, accurate and comprehensive

information from professionals concerning the nature of TS and its implications. Accurate information about the syndrome at the early stages of diagnosis can apparently prevent mothers from acting inappropriately or even violently towards their children with TS in order to 'discipline' them, and allow better understanding of the child's situation. Mothers blamed themselves for many years for their violent behavior towards their children with TS, and felt that they were 'not good' Mothers. However, when parents received accurate information about the syndrome, it helped them to organize their priorities correctly, and understand that what was really important was to provide the help that the child with TS needs. Additionally, having accurate information apparently helped the parents to stand up more forcefully to their extended family and friends when they needed to deal with prejudices regarding their child with TS. If explanations did not help and grandparents and aunts and uncles did not change their attitude concerning the behavior of the child with TS, the parents at least felt more comfortable after they knew the facts about the syndrome and what should be done to help the child, even if it meant distancing themselves from extended family and friends.

Once they had accurate information about the syndrome, most mothers seemed able to maintain a balance in the family and could provide explanation and support to the other children. Mothers felt that they would also be able to plan their child's treatment at the early stages of the emergence of the symptoms if they had the proper information.

Knowledge of the symptoms of the syndrome at an earlier stage could guide the mothers' reactions towards their children, and if this were successful they would be able to perceive themselves as successful mothers, and this would help them serve as a better and more positive example to their other children.

As it was, the mothers often lacked sufficient information and support, and it was found that mothers felt that they neglected their other children and were unable to fix this. They were often not sensitive enough towards the other siblings, and did not share their

emotions or information with them. When they were given accurate information, they seemed to be more able to explain the syndrome to their other children and thus prevent misunderstandings, and consequent unpleasant situations and confusion among their children in all areas relating to the syndrome. Siblings did not have to speculate regarding the nature of the problem their brother or sister had. They did not feel so ashamed when facing their friends, and they did not unnecessarily fear that the difficulties of their sibling with TS indicated that the child was going to die. Transmission of accurate information to siblings opens channels for better communication and cooperation and thus decreases unnecessary stress.

It appeared that mothers who have a child with TS, cooperation between the parents seems to be critical. A child with TS needs much attention, as well as medical and psychiatric treatment. Most of the time, he or she needs to be accompanied at school and outside the house. Mothers of children with TS face many challenges in raising a child with TS. Therefore, cooperation between them could decrease stress and tension, employing open conversations that could prevent feelings of isolation. Cooperation between family members, meant that there was an effective division of roles between them and that the burden did not fall only mothers. Such a relationship apparently sustained mothers and enabled them to deal with the day-to-day stresses, providing tools to decrease tension. It seems that when there is adequate cooperation, mothers do not feel so exhausted and have more time and energy to give attention to the other children in the family, and siblings do not feel neglected.

In addition, it seems to be essential for mothers to have accurate information about the syndrome so that they can act as advocates for their children when facing teachers and other professionals who work in the educational system and have relations with their child with TS. In order that these professionals can help the child with TS to integrate and function within the education system, they need to be sensitive to the difficulties of the child. The findings of the present research show that in most cases the professional functionaries

of the education system give up and send the child with TS home, leaving him or her without any educational solution. When advocating for their child with TS, it appears that the mothers must be equipped with relevant knowledge so that professionals and decision makers in the educational system can also understand the problem better and be more willing to deal with the difficulties. In this case, it would be easier if the professional bodies involved could see the child with TS as a child who needs emotional, behavioral and sometimes academic support.

The educational framework was found to be the most influential variable affecting mothers' QOL of children with TS. Mothers expressed their dissatisfaction with the educational framework, but also expressed hope that if the educational system could learn to deal with the child with TS, then there would be an improvement in their QOL.

Recommendations

The conclusions that emerged from this study seem to allow the advancement of several recommendations that can serve as a framework OR model to help mothers, educators and therapists cope more effectively with the difficulties of a child with TS. Lack of accurate diagnosis and information may lead to a state of imbalance and great stress for mothers. Professionals should understand that their role is very critical to these and that inaccurate diagnoses or the lack of any diagnosis at all leaves mothers, with a feeling of helplessness when dealing with the misunderstood behavior of their child with TS.

Additionally, the educational framework seems to avoid and reject any attempt to understand the important role it plays in the lives of these families. In the Israeli reality, children with TS are not defined as children with special needs. This research indicates that children diagnosed as having TS need to be included within this special group in order to receive appropriate educational and ther-

apeutic assistance. Inclusion within this definition would help to improve the Mothers' QOL of those. This research offers this knowledge as a recommendation for government education policy in Israel.

The results that emerged from this research also have implications for the policy of the Ministry of Health. It is recommended that family doctors and pediatricians receive training to raise their awareness and knowledge regarding children with TS in order to avoid parents' exhausting searches for accurate diagnoses and advice and medical treatment with the consequent saving of the family's financial resources. Evidently, the need to constantly supervise the child with TS in order to prevent unsafe behavior meant that mothers often neglected the child's siblings. Families ceased their activities outside the home because they did not want to hear the comments of neighbors and friends. It is recommended that awareness towards TS should be raised amongst the community through the social services in order to avoid ignorance regarding this syndrome. Advocacy should not be the exclusive realm of the mothers, but should also be employed by professionals, who can explain the syndrome and assist the education system in its work with children with TS.

References

- Abbeduto L. et al., *Psychological Well-Being and Coping in Mothers of Youths with Autism, Down Syndrome, or Fragile X Syndrome*. American Journal on Mental Retardation, 2004, 109, p. 237-254.
- Abelson J.F. et al., *Sequence Variants in Slitrk1 are Associated with Tourette's Syndrome*, Science, 2005, 310(5746), p. 317-320.
- Albin R.L., Mink J.W., *Recent Advances in TS research*. Trends Neuroscience, 2006, 293, p. 175-182.
- Bowen, M., *Family Therapy in Clinical Practice*. Jason Ahronson, Northvale, NJ, 1978.
- Brown I. et al., *FQOL: Canadian Results from an International Study*. Journal of Developmental and Physical Disabilities, 2003, 153, p. 209-230.
- Calman K.C., *Quality of Life in Cancer Patients: An Hypothesis*. Journal of Medical Ethics, 1984, 10, p. 124-127.

- Carter D.A. et al., *Social and Emotional Adjustment in Children Affected with Gilles De La Tourette's Syndrome: Associations with ADHD and Family Functioning*. Journal of Child Psychology and Psychiatry and Allied Disciplines, 2000, 41, p. 215–223.
- Diener E., Lucas R.E. (1997), Personality and Subjective Wellbeing, [in:] *Hedonic psychology: Scientific perspectives on enjoyment, suffering and well-being*. eds D. Kahneman, E. Diener, N. Schearz, Russell Sage Foundations, New York, 1997.
- Dreher N. *What is Tourette Syndrome?* Current Health, 1997, 23, p. 21.
- Duvdevani A., Hovav M., Rimmerman A., Ramot A., *Parenting and developmental disability in Israel*, Magnus Press, Jerusalem 1997.
- Ganos C., Bongert J., Asmuss L. et al., *The Somatotopy Of Tic Inhibition: Where and How Much?* Mov Disord. 2015, 5(9), p. 1184–1189.
- Garcia S.B., Perez A.M., Ortiz A.A., *Mexican-American Mothers' Beliefs about Disabilities: Implications for Early Childhood Intervention*. Remedial & Special Education, 2000, 21, p. 90–102.
- Greene R.W., *The explosive child: A new approach for understanding and parenting easily frustrated chronically inflexible children*. New York, NY, 1996. Available from the Tourette Syndrome Association, Inc. 42–40 Bell Blvd., Suite 205 Bayside, NY 11361–2820.
- Haerle T., ed. *Children with TS: A parent's guide*. Woodbine House, Rockville, MD, 1992.
- Halpern A.S., *Quality of Life and Conceptual Framework for Evaluating Transition Outcomes*. Exceptional Children, 1993, 596, pp. 486–498.
- Kersh J., Hedvat T.T., Hauser-Cram P., Warfield M.E., *The Contribution of Marital Quality to The Well-Being of Parents of Children with Developmental Disabilities*. Journal of Intellectual Disability Research, 2006, 50, p. 883–893.
- Kreppner K., Lerner R., Family systems and the Life Span Development: Issues and Perspectives, [in:] *Family Systems and Life-Span Development*. eds. K. Kreppner, R. Lerner, Laurence Erlbaum, Hillsdale, New Jersey, 1989.
- Matsuda N. et al. *Self-Initiated Coping with Tourette's Syndrome: Effect of Tic Suppression on QOL*. Brain Development, 2016, 38(2), p. 233–41.
- Pavot W., Diener E., *Review of Satisfaction with Life*. Psychological Assessment, 1993, 5(2), p. 164–172.
- Piacentini J., Bergman R.L., Keller M., McCracken J.T., *Functional Impairment in Children and Adolescents with Obsessive-Compulsive Disorder*. Journal of Child and Adolescent Psychopharmacology, 2003, 13, Supplement 1, p. 61–69.
- Olsson M.B., Hwang C.P. (2001) *Depression in Mothers and Fathers of Children with Intellectual Disability*. Journal of Intellectual Disability Research, 2001, 45, p. 535–543.
- Oppenheim A. (1992), *Questionnaire Design, Interviewing and Attitude Measurement*, Pinter, London 1992.

- Ouellette-Kuntz H., McCreary B., Quality of Life Assessment for Persons with Severe Developmental Disabilities, [in:] *Quality of Life in Health Promotion and Rehabilitation*. eds. R. Renwick, I. Brown, M. Nagler, Sage Publications, Thousand Oaks, CA, 1996, p. 268-278.
- Ortiz D., Greene J., *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. Book Review on line. Qualitative Research Journal, 2007, 6(2), p. 205-207.
- Quality of Life Research Unit, *An overview of the Quality of Life Research Unit, University of Toronto*. Department of Occupational Therapy Centre for Function and Well-Being, University of Toronto 2001. Available at: <http://www.utoronto.ca/qol/unit.htm> (accessed: 1.6.2010).
- Rapoport R., Rapoport R.N. (1969), *The Dual Career Family: A Variant Pattern and Social Change*. Human Relations, 1969, 22(1), pp. 3-30.
- Ricci L.A., Hodapp R.M. (2003), *Fathers of Children with Down's Syndrome Versus Other Types of Intellectual Disability: Perceptions, Stress, and Involvement*. Journal of Intellectual Disability Research, 2003, 47, p. 273-284.
- Robertson M., Baron-Cohen S. (1995), *Tourette syndrome: The facts*. Oxford University Press, Oxford 1995.
- Robertson M.M., Trimble M.R., Lees A.J., *The Psychopathology of the Gilles De La Tourette Syndrome*. British Journal of Psychiatry, 1988, 152, pp. 383-390.
- Robertson M.M., *Tourette Syndrome, Associated Conditions and the Complexity of Treatment*. Brain, 2002, 123, p. 425-462.
- Ryan S.D., Gates M.S., *Inclusion of Social Subsystem Issues in IT Investment Decisions: An Empirical Assessment*. Information Resources Management Journal, 2004, 17(1), p. 1-18.
- Shimberg E.F. (1995), *Living with Tourette Syndrome*. Simon and Shuster, N.Y., 1995.
- Swain J., Scahill L., Lombroso P., King R., Leckman J., *Tourette Syndrome and Tic Disorders: A Decade of Progress*. Journal of the American Academy of Child and Adolescent Psychiatry, 2007, 46(8), p. 947-968.
- Wanless R.L., Fortier L.M., Family Crisis Following the Diagnosis of a Handicapped Child, [in:] *Parenting and developmental disability in Israel*, eds. A. Duvdevani, M. Hovav, A. Rimmerman, Ramot, *Parenting and developmental disability in Israel*. Jerusalem: Y. L. Magness Pres, 1997.



CONFERENCE REPORT



**Report of the 19th National Scientific and educational
Conference ‘*Speech therapy.
Practices in Speech Disorders*,
30 June – 2 July 2017, Lublin, Poland**

The 19th National Scientific and Educational Conference ‘Speech Therapy. Practices in Speech Disorders’, combined with the General Meeting of Polish Logopaedic Society Members, was held from 30 June to 2 July in Lublin, Poland. The conference was organized by the General Board of the Polish Logopaedic Society and the Department of Logopaedics and Applied Linguistics of the Maria Curie-Skłodowska University in Lublin.

Honorary patronage was assumed by: the Mayor of Lublin City Krzysztof Żuk, the Marshall of the Lubelskie Voivodeship Sławomir Sosnowski and His Magnificence Rector of the Maria Curie-Skłodowska University Prof Stanisław Michałowski. Media patronage was held by TVP 3 Lublin, Polskie Radio Lublin and Radio Centrum.

The Scientific Committee of the conference included: Prof Stanisław Grabias DSc, (UMCS) (UMCS), Prof Jolanta Panasiuk, DSc (UMCS), Dr Katarzyna Kaczorowska-Bray (UG), Dr Barbara Kamińska (UG), Anita Lorenc, DSc (UW), Dr Olga Przybyla (UŚ), Dr Joanna Stasiak (UMCS), UMCS Prof Tomasz Woźniak, DSc (UMCS), UP Prof. Miroslaw Michalik, DSc (UP), UG Prof Stanisław Milewski, DSc (UG), US Prof Barbara Ostapiuk, DSc (US).

The topic of the conference was chosen in response to the long-standing demand for speech therapy standards in cases of various speech disorders. Speech therapists not only need strong theory and skilful craftsmanship, but also clear legal bases for their practice.

The aim of the conference was to present a coherent system of speech therapy based on well-established theoretical knowledge of speech disorders and on many years of practical experience. Currently developed models of the diagnostic and therapeutic process are to be used as the basis for determining speech therapy forms, especially in health care and education sectors. They are also meant to serve as the foundation for programme contents that are formulated for didactical purposes in teaching centres for speech therapists throughout Poland.

The issues of therapeutic treatment related to various disorders were presented in plenary sessions (21 lectures), while series of workshops were devoted to explication of selected stages of the programme (25 workshops). Apart from the lecture and the workshop sections, a poster session was also held. 23 scientific posters acquainted participants with the current state of reflection, the directions of the theory development and with interesting casuistry, which always brings new research problems into contemporary speech therapy.

The conference was interdisciplinary and its participants were subject matter experts specialising in theory and practice of speech therapy, in related disciplines (doctors, pedagogues) and students.

83 people participated in the conference, including many scientists representing the following academic institutions and institutes: Academia Ignatianum. Branch Faculty of Humanities and Social Sciences in Mysłowice, M. Grzegorzewska Academy of Special Education in Warsaw, Jerzy Kukuczka Academy of Physical Education in Katowice, John Paul II Catholic University of Lublin, University of Gdańsk, Jan Kochanowski University in Kielce, University of Łódź, Maria Curie-Skłodowska University in Lublin, Medical University of Lublin, Nicolaus Copernicus University in Toruń, Pedagogical University of Kraków, Siedlce University of Natural Sciences and Humanities, University of Silesia in Katowice, University of Warmia and Mazury in Olsztyn, University of Warsaw, as well as Maria Skłodowska-Curie Institute in Gliwice, the Institute of Occupational Medicine in Łódź and the Children's Memorial Health Institute in Warsaw.

After the welcome speech and the performance by the Jadwiga Czerwinska UMCS Academic Choir, the debates began in four plenary sessions.

The first lecture titled *Speech-language pathology concept of adaptation of school textbooks to special educational needs of different groups of students with speech delays and language deficits (Logopedyczna koncepcja dostosowania podręczników szkolnych do specjalnych potrzeb edukacyjnych różnych grup uczniów)*

*z opóźnieniami rozwoju mowy i deficytami języka) was delivered by Ms Kaziemiera Krakowiak, Ms Aleksandra Borowicz and Ms Renata Kołodziejczyk (John Paul II Catholic University of Lublin). The authors noted that an important way to provide support for students with special educational needs is to develop specialised textbooks, closely related to textbooks used by agile learners, i.e. textbooks with the same core contents, but tailored to specific reading and comprehension capabilities. Stanisław Milewski and Katarzyna Kaczorowska-Bray (University of Gdańsk) were next speakers. In their lecture, they emphasized the fact that demographic change caused by ageing of society, is being experienced by an increasing part of the population in developed countries. It is therefore important for speech therapists to be theoretically and practically prepared to work with elderly people. Zbigniew Tarkowski (Medical University of Lublin) in his lecture devoted to psychogenic speech disorders therapy, such as stuttering and mutism, presented assumptions and methods of their effective therapy. Next speaker, Andrzej Czernikiewicz (Maria Curie-Skłodowska University in Lublin), in his speech on psychopharmacology for speech therapists, stated that the current problem in psychotropic drugs is not their level of effectiveness, but the extent to which they create cooperation. At the same time, research on the mechanism of action of psychotropic drugs allowed to understand the background of many psychiatric disorders. In turn, Alina Maciejewska, representing the University of Natural Sciences and Humanities in Siedlce, in her lecture titled *Logical-linguistic competence and development of linguistic proficiency (Kompetencja logiczno-językowa a rozwój sprawności językowych)* presented the results of research indicating the role of natural logical-linguistic competence in the development of linguistic proficiency. Such competence can be relatively easily assessed on the basis of the ability to draw conclusions by analogy about form and content relationships between lexical and word-formation units.*

The second plenary session started with the lecture by David Larysz and Agnieszka Rożek ('Kangur' Centre for Treatment of CNS Disorders and Child Development in Katowice) '*Holistic approach to speech disorders in children with facial and cranial defects on the example of isolated and complex craniosynostoses*' (*Holistyczny model postępowania w zaburzeniach rozwoju mowy u dzieci z wadami twarzo-czaszkowymi na przykładzie izolowanych i zespołowych kraniosynostoz*), in which the authors presented neurological, neurosurgical, neuropsychological and physiotherapeutic aspects of facial and skull defects treatment, which constitute a modern interdisciplinary

model for diagnostic and therapeutic procedures. The next lecture was on speech therapy, mainly by touch stimulation, of children with cerebral palsy. Renata Marciniāk-Firadza from the University of Lodz discussed the method of massage in case of flaccid and spastic dysarthria. The author of the massage is Prof Elena Archipova. In the third lecture of this session, '*The specificity of speech therapy in children with SLI?*' (*Specyfika oddziaływań logopedycznych w przypadku dzieci z SLI*) Sofia Kamińska (Daily Center for Psychiatry and Speech Disorders for Children and Young People in Wrocław) identified some therapeutic strategies used in the treatment of SLI children. In the lecture about the development of communicative competence in play, the authors, Ewa Bielecka-Nowakowska (Academy of Special Education in Warsaw) and Anna Zajac (Jan Kochanowski University in Kielce) tried to explain why play-based strategies are most effective in the process of shaping children's communication competencies. In their considerations, they used pragmatic foundations of linguistics and the theory of mind. Next, the speakers from the Maria Curie-Skłodowska University in Lublin, Urszula Mirecka and Aneta Domagała, took the floor and, recognising that speech-language pathology standards deal with problems of written language disorders in a too limited scope, they presented possibilities of incorporating this problem into the diagnostic and therapeutic process in speech pathology. In their lecture, they focused on therapeutic aspects of speech-language pathology treatment in people with communication disorders in speech and writing. Joanna Trzaskalik (Academy of Ignatianum, Faculty of Humanities and Social Sciences in Mysłowice) delivered the last lecture in this session, in which she attempted to make a terminological alignment, based on the assumption that the uniqueness and precision of the terms used is crucial for professional exchange of information thus guaranteeing quality and effectiveness of therapeutic interventions.

Tomasz Woźniak (Maria Curie-Skłodowska University in Lublin) was the first speaker in the third plenary session. In his lecture '*The method of rhythmisation of speech in the treatment of stutterers in the light of evidence based practice*' (*Metody rytmizowania wypowiedzi w terapii osób jakających się w świetle*) he presented considerations on the effectiveness and limitations of speech therapy methods using rhythmisation of speech expression in the light of practice and the latest research. The conclusions were mainly of applicational nature. Next the floor was given to Danuta Pluta Wojciechowska and Barbara Sambor (University of Silesia in Katowice). In their

lecture devoted to the subject of Inter-Speech, the authors raised a problem, not yet described in the current speech-language literature in Poland and in the world, which pertains to the position of speech organs, a tongue in particular, during a pause in speaking in people with disorders in realisation of phonemes. They presented their own research findings concerning Inter-Speech positions in patients with peripheral dyslalia and those with normative realisation of phonemes. The presentation of Mirosław Michalik and Anna Cholewiak, representing the Pedagogical University in Cracow, was focused on the results of a research on speech rate of special school students affected by mild mental retardation based oligophasia. Students' speech analyses included selected quantitative and qualitative aspects of speech. In the lecture titled '*Evaluation of hypernasality using the method of acoustic beam shaping*' (*Ocena nosowości z zastosowaniem metody kształtowania wiązki akustycznej*) Anita Lorenc and Daniel Król (University of Warsaw) presented a contemporary clinical and instrumental techniques for assessing nasality in speech, both normative and impaired. In turn, Joanna Mąka summarized dependencies between central auditory processing disorders (CAPD) and specific language impairments (SLI). These dependencies were captured from the perspective of the theory of central nervous system functioning. The last lecture in this session was delivered by: Andrzej Senderski (Senso-Medical, Warsaw), Katarzyna Iwanicka-Pronicka (Children's Memorial Health Institute in Warsaw), Joanna Majak, Marzena Walkowiak (Institute of Occupational Medicine, Łódź), Zenobia Bogdanowska (Psychological and Pedagogical Counselling Centre No. 1 in Olsztyn) and Karolina Dajos (APD-Medical Ltd., Warsaw). The purpose of the speech '*Normative values in screening tests for higher auditory functions on the APD-Medical diagnostic and therapeutic platform*' (*Wartości normatywne przesiewowych testów wyższych funkcji słuchowych platformy diagnostyczno-terapeutycznej APD-Medical*) were the development and presentation of reference values for screening tests for central auditory functions on the APD-Medical diagnostic platform for pre-school and early school children. It was shown that age significantly affects the results achieved by children in all tests.

The last, fourth plenary session was opened by the paper of Barbara Kamińska from the University of Gdańsk. The author stated that media journalists are confronted with such kind of requirements that make the goal of speech therapist not only to teach (more often - to improve) the correct pronunciation of speech sounds and the use of healthy, properly

produced voice, but also to speak using a clear so-called 'radio' voice, with intonation and tempo adjusted to different types of radio speech. Olga Przybyla (University of Silesia in Katowice) in the lecture '*Levels of organisation of sensory information processing and the development of language skills' (Poziomy organizacji przetwarzania informacji sensorycznych a rozwój sprawności językowych)*' presented the results of research indicating the relationship between the levels of organisation of sensory information processing and the state of language development in children with learning difficulties. In turn, Ewa Gacka, representing the University of Lodz, in the lecture titled '*The parent-child interaction approach in therapy of delays in language development' (Podejście interakcyjne rodzic - dziecko w terapii opóźnień w rozwoju mowy)*' highlighted the fact that, regardless of the nature of language development delays, a child requires early speech therapy. Its purpose is to diagnose/recognise the problem and to stimulate language development. Since communication is interactive, the quality and quantity of parent-child interactions is important. The author presented the strategies for stimulation of language development that are based on interactive attitude. The last of the presenters, Anna Czernuszenko (Rehaklinik Bellikon, Switzerland) discussed basic treatment of dysphagia in the prevention of fatal complications, stressing that treatment of dysphagia is not complicated but requires cooperation of many disciplines.

Each session attracted a lot of interest and each was closed with a discussion, sometimes heated, about presented topics.

As far as scientific and education workshops are concerned, the participants of the conference were offered six series of these.

In the first series, the following workshops took place: *Psychoeducation (Psychoedukacja)* (held by Andrzej Czernikiewicz, Maria Curie-Skłodowska University in Lublin). During the workshop, the use of role playing technique in psychoeducation of people suffering from schizophrenia was presented; *Therapeutic cooking (Gotowanie terapeutyczne)* (conducted by Agata Jędraszek, Nutricia Polska Sp. z o.o.). In the workshop, change of consistency of foods using thickeners was discussed, as well as practical tips on preparing food for patients with dysphagia and their feeding; *Workshop on voice production – breathing-voice-diction training in motion* (held by Magdalena Zaorska and Magdalena Osowicka-Kondratowicz, University of Warmia and Mazury in Olsztyn). In the training, participants were shown exercises whose main purpose is to create the habit of energetic, rhythmic and smooth dynamic breathing. Apart from breathing exercises in motion,

there were also exercises on voice production, articulation and diction presented, which are aimed at correlation of physical activity, in a broad sense, with breath, voice, and word; '*Padovan Method of Neurofunctional Reorganisation in theory and practice of speech therapy*' (*Metoda Neurofunkcjonalnej Reorganizacji Padovan w teorii i w praktyce logopedycznej*) (conducted by Aleksandra Listwoń, 'Fundacja 21', Krosno). The workshop was devoted to the presentation of the assumptions of the Padovan Method of Neurofunctional Reorganization based on the example of its use in therapy of a child with trisomy 21. The presentation focused on the dynamics with which the child was acquiring successive skills over two years, that is, from the beginning of constant and systematic therapy using this method.

In the second series, there were the following workshops: *Swallowing dysfunctions* (*Zaburzenia połykania*) (led by Tatiana Lewicka, Nutricia Polska). In this workshop, aspects of physiology and anatomy of the swallowing process were discussed, phases of swallowing, methods for diagnosing dysphagia with emphasis on particular phases, symptoms of dysphagia, therapy methods, complications of dysphagia, nutritional treatment, alternative access to the gastrointestinal tract, preparation of meals; *Dysfunctions of respiration and swallowing in diagnosis and in speech therapy* (*Dysfunkcje oddychania i połykania w diagnozie i terapii logopedycznej*) (held by Izabela Malicka, International School of Krakow). In the workshop, the breathing function was described as one of the primary functions. The relationships between respiration, resting position of a tongue, swallowing and articulation disorders were indicated. The subject was discussed in the aspects of diagnosis and speech therapy; *Resonance disorders in diagnosis and speech therapy* (*Zaburzenia rezonansu w diagnozie i terapii logopedycznej*) (led by Danuta Pluta-Wojciechowska, University of Silesia in Katowice). The author presented issues related to disorders of nasal resonator in the production of speech sounds from the speech-language pathology and speech phoniatrics perspectives. She presented methods for diagnosing resonance disturbances, as well as ways of determining their causes, and defined directions of post-diagnostic treatment in case of nasality; *Stimulator of Polymodal Sensor Perception – a Polish innovative device for multi-sensory therapy in sensory based disorders* (*Stymulator Polimodalnej Percepcji Sensorycznej – polskie, innowacyjne urządzenie do prowadzenia wielozmysłowej terapii w grupach zaburzeń o podłożu sensorycznym*) (conducted by Bartłomiej Szylz, GNP Magnusson Aparatura Medyczna Sp. z o.o.). During the meeting, participants could familiarize themselves with the rules governing the function-

ing of the system, assumptions for therapy, and witness the process of therapy programming on demo devices.

In the next, third series, the participants could choose from among the following workshops: *New methods of diagnosis and therapy in central hearing disorders (Nowe metody diagnostyki i terapii centralnych zaburzeń słuchu)* (led by Zenobia Bogdanowska, Psychological and Pedagogical Counselling Centre No. 1 in Olsztyn and Olga Przybyla, University of Silesia in Katowice). The workshop focused on the following issues: central hearing disorders: definition, epidemiology, pathomechanisms and clinical subtypes; diagnostics – theoretical part – overview of tests evaluating higher hearing functions and practical presentation of the tool for CAPD diagnosis: APD-Medical Platform; therapeutic treatment: theoretical bases of hearing improvement and presentation of Neuroflow active hearing training; *Programming of the Polish language in bilingual children (Programowanie języka polskiego u dzieci dwujęzycznych)* (held by Urszula Ciszewska-Psujek, Maria Curie-Skłodowska University in Lublin). This workshop was a review of methods and techniques used in teaching Polish as a foreign language in case of children of foreigners or Polish bilingual children in pre-school and early school age, methods which can also be used in therapy of children with delayed language development. During the meeting, there were also examples presented of grammar exercises, designed by the author, for mastering nominal and verbal inflection; *Talk Tools Oral Position Therapy (Terapia Pozycji Oralnej Talk Tools)*(led by Piotr Jaworski, PJtherapeutic Piotr Jaworski). The workshop programme included, but was not limited to: OPT and other therapies based on the physiotherapy model; theoretical principles of OPT, definition of motor plan; conditions necessary for improvement of speech clarity; OPT targets; model of diagnosis with feeding included; tools for therapy and diagnosis including bite blocks, a hierarchy of horns, tools for verticalisation and lateralisation of a tongue in structural-functional hierarchy, mandible-lip-tongue model; feeding as part of the OPT programme; *Development of communication at the pre-symbolic level – the basis of speech therapy for children with autism (Rozwijanie komunikacji na poziomie przedsymbolicznym – podstawa terapii logopedycznej dziecka z autyzmem)* (held by Magdalena Tarnawska, Psychological and Pedagogical Counselling Centre, Specialised Counselling Centre for Autistic People in Świdnik). During the meeting, a strategy for working with a child with autism spectrum disorder was presented, based on the author's professional experience. The specificity of communication development in people with autism

was discussed, followed by therapeutic techniques that develop communication skills important for emergence of symbolic communication.

In the fourth series, the following workshops were held: *Innovative methods of neurorehabilitation in language functions and cognitive therapy (Innowacyjne metody neurorehabilitacji w terapii funkcji językowych i poznawczych)*(led by Bożena Duda, Katarzyna Broniec-Siekaniec, Dorota Pikla, Upper Silesia Rehabilitation Centre 'REPTY' in Tarnowskie Góry). This workshop presented innovative methods of neurorehabilitation: *C-Eye System, Rehacom and Biofeedback (System C-Eye, Rehacom i Biofeedback)*, used to diagnose and treat patients with brain damage who are on treatment in Upper Silesia Rehabilitation Centre 'Repty'; *How to create easy-to-read texts? Principles of creating and modifying texts adapted to perceptive abilities of people with special communication needs* (conducted by Renata Kolodziejczyk, Aleksandra Borowicz, John Paul II Catholic University in Lublin). The aim of the workshop was to familiarise participants with the principles of creating or modifying texts so that they could be understood by people with language disorders: hearing impairment, aphasia, autism, mild mental retardation and people with special communication needs: foreigners, Polish children returning from emigration, etc. Adaptation of texts may pertain to the logical layout, content, vocabulary, syntactic structures and the graphical form of the text. Participants in the workshop had the opportunity to apply the principles they learned in practice, by creating easy-to-read texts and making modifications to difficult texts; *Speech therapy of people with ASD based on verbal behaviour response (verbal operants) (Terapia mowy osób z ASD w oparciu o werbalne zachowania sprawcze)*(led by Wojciech Lipski, Maria Curie-Skłodowska University in Lublin). The workshop was devoted to the application of the verbal behaviour response theory (verbal operants) according to B.F. Skinner, in the therapy of people with ASD. Verbal behaviour responses may serve as the basis to conduct a large functional diagnosis and build a plan for therapy adapted to particular child's communication capabilities. Broadening of the verbal behaviours repertoire enables an ASD person to develop communication skills; *Use of the natural environment in speech therapy (Wykorzystanie środowiska naturalnego w terapii logopedycznej)* (led by Aleksandra Matyjasek and Rafał Matyjasek, Maria Curie-Skłodowska University in Lublin). The aim of the workshop was to present the significance of hortitherapy, explain the principles of sensory garden design with regard to vegetation and elements of small architecture, and to propose specific therapeutic interactions support-

ing cognitive and communication functions based on author's design concepts.

The fifth series consisted of the following workshops: *Social and communication skills development in children and adolescents with autism spectrum disorders* (*Kształtowanie umiejętności społecznych i komunikacyjnych u dzieci i młodzieży z zaburzeniami ze spektrum autyzmu*) (led by Aleksandra Matyjaszek, Maria Curie-Skłodowska University in Lublin). Workshop participants learned how to formulate therapeutic goals, use motivational systems, and became familiar with techniques used in therapeutic work; *Hand therapy and SHand® integrated writing training as a form of child development support* (*Terapia ręki oraz Zintegrowany trening pisania SHand® jako forma wspomagania rozwoju dziecka*) (conducted by Agnieszka Rosa, Orticus Center for Vision and Development). During the workshop, a set of optimally selected hand therapy exercises and an integrated SHand® writing practice were presented, including the development of correct motion patterns in the scope of gross and fine motor skills, development of a correct motion pattern in graphomotor skills, correction of improper pencil grasp; *Formation of prosodic qualities* (*Kształtowanie sprawności prozodycznych*) (led by Marta Wysocka, Maria Curie-Skłodowska University in Lublin). The aim of the workshop was to familiarise participants with techniques and methods used to improve the perception and implementation of prosodic features, which may be applied in the treatment of speech disorders, in speech therapy for performing artists and in stimulation of language development in children.

In the last, sixth series, participants of the conference could choose from among the following workshops: *Speech-language neuropathology intervention practices in neurogenic dysphagia with the use of VocaSTIM and IOPI apparatuses* (*Metody postępowania neurologopedycznego w dysfagii neurogennej z wykorzystaniem aparatów VocaSTIM i IOPI*) (led by Ewelina Abramowicz-Pakuła and Grażyna Kubacka, Upper Silesian Rehabilitation Centre 'REPTY' in Tarnowskie Góry). The workshop was aimed at presenting a variety of methods of treatment of dysphagia, depending on the location of the damaged area and the condition of the patient. Adaptive, compensatory and restorative methods were presented, as well as stimulation methods, including the use of VocaSTIM apparatus; *60 steps programme in therapy of speech disorders – level 3* (*Program 60 kroków w terapii zaburzeń mowy – poziom III*) (conducted by Katarzyna Ita Bierkowska, M. Grzegorzewska Academy of Special Education in Warsaw, Association of Parents and

Friends of Children with Hearing Impairments in Krosno). The author of the workshop wanted to share her experiences and thoughts related to work on level 3 – linguistic. During the workshop, principles of extending lexical, paradigmatic and associative resources were discussed with the participants, and synthesising both in a natural dialogue and during planned exercises in accordance with the auditory verbal method; *Breath-work in voice rehabilitation (Praca z oddechem w rehabilitacji głosu)* (Barbara Sambor, L. Solski PWST National Academy of Theatre Arts in Kraków, University of Silesia in Katowice). The aim of the workshop was to familiarize participants with respiratory problems in children and adults with various types of dysphonia. During the workshop, different methods of breathwork were analysed, in terms of their effectiveness and consistency with the latest knowledge in voice rehabilitation. Participants learned effective techniques for restoring physiological respiration and how to keep proper respiration-phonation-articulation coordination during voice therapy; *Speech therapy for children with epilepsy (Terapia logopedyczna dzieci z padaczką)* (led by Magdalena Kozłowska, Maria Curie-Skłodowska University in Lublin). The issues discussed during the workshop included: epilepsy as the most common neurological disorder of developmental age and developmental disorders in epilepsy: linguistic, communication, cognitive, motor, emotional disorders; diagnosis of disorders, programming of therapy and the standard for speech therapy within the framework of integration methods: stimulation of psychomotor development (assumptions of psychomotor methods on the example of Procus and Block therapy); elimination of neuromotor immaturity through exercise therapy focused on primary reflexes; stimulation of development and sensory integration in children with epilepsy; *Sensory integration as a method supporting speech-language therapy (Integracja sensoryczna jako metoda wspierająca terapię logopedyczną)* (led by Sylwia Filipczak, Maria Curie-Skłodowska University in Lublin). The workshop was aimed at presenting the method of sensory integration and principles of its use in speech therapy. *'I learn to speak, to pronounce, to tell' – the use of educational books in prevention and therapy of speech disorders in children („Uczę się mówić, wymawiać, opowiadać” – zastosowanie książki edukacyjnej w profilaktyce i terapii zaburzeń mowy dziecka)* (led by Marta Galewska-Kustra, Maria Grzegorzewska Academy of Special Education in Warsaw). During the workshop, the participants were presented the ways of consciously supporting child's developing speech with the use of educational literature for children from the series 'I learn: to speak, to pronounce, to tell.'

It is worth emphasizing that all workshops, thanks to the experience of the trainers, were a source of very valuable and practical information for their participants.

During the conference, scientific posters were also presented. This included the following works and their authors: Kamila Bigos (Maria Curie-Skłodowska University in Lublin), *Articulation disorders in cerebral palsy. Case study. (Zaburzenia artykulacji w mózgowym porażeniu dziecięcym. Studium przypadku.)* The author presented a case study of a seven-year-old boy with cerebral palsy. With the help of diagnostic techniques and tools, she evaluated the structure and efficiency of speech organs, phonemic hearing and articulation. She also specified therapeutic goals; Kamila Bigos, Karolina Gruszka (Maria Curie-Skłodowska University in Lublin), *Infant at the speech therapist's. Stimulation of psychomotor development in the first year of life. (Niemowlę u logopedy. Stymulacja rozwoju psychoruchowego dziecka w pierwszym roku życia.)* The poster drew attention to the importance of proper motor development and development of cognitive functions within the first year of a child's life; Urszula Ciszewska-Psujek (Maria Curie-Skłodowska University in Lublin), *Do alcoholics need speech therapy? (Czy alkoholikom potrzebna jest terapia logopedyczna?)* The author emphasizes that toxic effects of alcohol on the central nervous system lead to a permanent decrease in the number and size of neurons and neuronal connections, and consequently to cognitive disorders, including executive functions and memory, and disorders in processing of emotional information. Alcohol addicts may need a speech therapist to show them how a language can stimulate brain activity; Katarzyna Cygan (Maria Curie-Skłodowska University in Lublin), *Cohesion of narrative images in children with epilepsy. (Spójność obrazów narracyjnych u dzieci z padaczką.)* The idea of this poster is to show how children with epilepsy create narrative images in texts created based on picture stories and given topics; Ewa Dzieciol-Chlibiuk (University of Natural Sciences and Humanities in Siedlce), *Linguistic metaphor indicators in statements uttered by students with hearing impairment. (Językowe wykładniki metafor w wypowiedziach studentów z niepełnosprawnością słuchową.)* Based on collected interviews with students with hearing impairment, the author attempts to answer the following questions: how do hearing impaired people understand figurative expressions: common metaphors, idiomatic compounds and proverbs, if they treat them relevant to a specific situation, and if they use them in everyday interactions. What is the biggest problem in the acquisition of metaphorical meanings. Do figurative expressions exist in

the conceptual system of people with hearing dysfunction and how are they perceived and interpreted? How do they try to explain relationships they do not know? Karolina Gruszka (Maria Curie-Skłodowska University in Lublin), *Language and communication skills of a child with cerebral palsy. (Sprawności językowe i komunikacyjne dziecka z mózgowym porażeniem dziecięcym.)* The purpose of the presentation was to describe and analyse the language and communication skills of a child with cerebral palsy. The results of the study were based on the speech-language pathology diagnostic standard. Attention was also paid to therapeutic treatment; Ewa Hrycyna (University of Warmia and Mazury in Olsztyn), *Semantic and pragmatic disorders in pre-school children – suggestions for therapeutic interventions.* The poster presented proposed therapeutic interventions in the case of semantic-pragmatic disorders in pre-school children. It stressed the importance of the matter in the context of a child's daily functioning in various social groups (family, peers, preschool group); Aleksandra Jastrzębowska-Jasińska (The 'Mówię Dobrze' Speech Counselling Office in Warsaw), *Practices of stuttering therapy in adolescents and adults on the basis of case studies. (Metody terapii jąkania u młodzieży i osób dorosłych na podstawie studiów przypadków.)* The author presented three case studies illustrating how stuttering therapy was performed, and showing that the methods used (of more fluent stuttering or more fluent speaking) may be effective in the treatment of stuttering in adults and adolescents; Olga Jauer-Niworowska, Anna Lis (Warsaw University), *Speech therapy of people with post-stroke dysarthria (including swallowing disorders). (Terapia logopedyczna osób z dysartrią poudarową (z uwzględnieniem zaburzeń połykania).* The poster dealt with a comprehensive speech therapy for people with post-stroke dysarthria with differentiated symptoms depending on the location of the stroke. The authors also presented principles of therapy for patients with dysphagia accompanying dysarthria; Aldona Kocyla-Łukasiewicz (Siedlce University of Life Sciences and Humanities), *Central Auditory Processing Disorders as one of the causes of communication disorders. (Centralne Zaburzenia Przetwarzania Stuchoowego jako jedna z przyczyn zaburzeń komunikacji językowej.)* The author pointed out that correct diagnosis allows to plan and guide therapeutic work with a child. Properly conducted therapy of central auditory processing disorders improves the child's communication skills and its functioning at school. Therapeutic potential is high: from standard methods of therapy to modern rehabilitation techniques: listening training based on the Tomatis, Johansen or Warnke methods; Sylwia Krupa (Maria Curie-

Skłodowska University in Lublin), *Dialogue skills of patients with frontal lobe damage.* (*Sprawności dialogowe osób z uszkodzeniami płatów czołowych.*) The poster featured dialogue skills of people with frontal lobe damage. The assessment of dialogue efficiency, based on the collected research material, was presented by the author in three aspects: the structure of the dialogue, the consistency of responses, and the length of the speech. The result of the analysis was the statement of the most characteristic dialogues skills of the discussed patients; Natalia Kryszak (Maria Curie-Skłodowska University in Lublin), *Difficulties in reading and writing in twins with motor alalia.* (*Trudności w czytaniu i pisaniu u bliźniąt z alalią motoryczną.*) The author showed a connection between conjugated developmental problems, including alalia, and difficulty in reading and writing; Marlena Kurowska (Uniwersytet Warszawski), *Methods of updating the correct vocal-articulatory-grammatical structure of words in children with speech and language development disorders of cortical origin.* (*Sposoby aktualizowania prawidłowej struktury brzmieniowo-artykulacyjno-gramatycznej wyrazów u dzieci z zaburzeniami w rozwoju mowy i języka uwarunkowanymi korowo.*) On the poster, the author presented groups of exercises and techniques allowing to easier and faster recall the form of expression expected in a given context: semantic, vocal-articulatory and grammatical; Magdalena Kwaterkiewicz (Maria Curie-Skłodowska University), *The influence of musical and music-movement exercises on the development of prosodic skills in 5–6 years old children.* (*Wpływ ćwiczeń muzycznych i muzyczno-ruchowych na rozwój kompetencji prozodycznych dzieci 5–6 letnich.*) In the scientific poster, the author presented the results of her own research on the influence of music and music-movement exercises on the development of prosodic competencies in five and six-year-old children whose dynamic development of phonetic-phonological system almost complete; Hanna Owczarzak, Lidia Nawrocka, Anna Sinkiewicz (Collegium Medicum in Bydgoszcz, Nicolaus Copernicus University in Toruń), *Voice and speech rehabilitation in a patient after removal of larynx and esophagus.* A transcript of speech and phoniatic rehabilitation of a 78-year-old patient after complete removal of the larynx and esophagus with reconstruction by gastric transposition was presented on the poster. The rehabilitation programme utilised the experience gained with training of esophageal speech; Hanna Owczarzak, Adam Maciejewski, Krzysztof Oleś, Cezary Szymczak, Łukasz Krakowczyk, Maciej Grajek, Anna Sinkiewicz (Collegium Medicum in Bydgoszcz, Nicolaus Copernicus University in Toruń, M. Skłodowska-Curie Institute in Gliwice), *Rehabilitation of voice and swallowing in a patient*

after a larynx transplant. (*Rehabilitacja głosu i potykania u pacjenta po przeszczepie krtani.*) The authors of the poster presented speech and phoniatric rehabilitation process of a 39-year-old patient after laryngeal transplantation. Rehabilitation exercises included respiratory tract, articulation apparatus and phonation exercises, using the vocal-phonetic method. At the same time, swallowing exercises were introduced; Jolanta Panasiuk (Maria Curie-Skłodowska University in Lublin), *Diagnostic and therapeutic procedures in locked-in syndrome. (Procedury diagnostyczno-terapeutyczne w zespole zamknięcia.)* On the poster, the topic of speech-language neurorehabilitation needs of people with locked-in syndrome was presented. These needs are related both to improvement of clinical treatment standards and to dissemination of knowledge about the syndrome and the life situation of people affected by it. Jolanta Panasiuk (Maria Curie-Skłodowska University in Lublin), Maria M. Kaczyńska-Haładyj (Neuropsychiatric Hospital in Lublin), *Development of a child with Dravet Syndrome. Disintegration – neuroplasticity – neurocompensation. (Rozwój dziecka z zespołem Dravet. Dezintegracja – neuroplastyczność – neurokompenzacja.)* A multifaceted assessment of neuro-developmental disorders in a 6-year-old boy with Dravet syndrome was presented in the poster, taking into account changes resulting from the course of the disease and their effects on motor, social-emotional, cognitive and linguistic functioning. Multidisciplinary evaluation of the child, verified in subsequent stages of the disease, allowed to plan an optimal, effective therapy and rehabilitation of the described child; Jolanta Panasiuk (Maria Curie-Skłodowska University in Lublin), Maria M. Kaczyńska-Haładyj (Neuropsychiatric Hospital in Lublin), *Dissociation or neurodegeneration. Problems of diagnosis, treatment and rehabilitation. (Dysocjacja czy neurodegeneracja. Problemy diagnozy, leczenia i rehabilitacji.)* The authors have shown that the diagnosis of degenerative disorders must be performed in a multi-stage and comprehensive way. Due to the dynamic nature of dementia, attention should be paid to prodromal symptoms preceding the onset of developing age dementia. Rehabilitation procedures are differentiated at various stages of illness and recovery. As a result of rehabilitation and educational interventions, improvements may be achieved in the area of correctional functioning; Jolanta Panasiuk (Maria Curie-Skłodowska University in Lublin), Maria M. Kaczyńska-Haładyj (Neuropsychiatric Hospital in Lublin), *Neurodevelopmental disorders in epilepsy. Dynamics – treatment – therapy. (Zaburzenia neurorozwojowe w padaczce. Dynamika – leczenie – terapia.)* The poster presented the dynamics of neurodevelopment-

tal disorders in the course of a severe symptomatic epilepsy with occurrences of status epilepticus in a 7-year-old boy and the impact of multidisciplinary therapy on resolution of epilepsy symptoms and significant improvement in motor, social-emotional and cognitive-language functioning. Ewa Wolańska (University of Warsaw), *New forms of neurological rehabilitation as a response to new forms of pharmacotherapy in Alzheimer's disease.* (Nowe formy rehabilitacji neurologopedycznej jako odpowiedź na nowe formy farmakoterapii w chorobie Alzheimera). The author presented an opinion-forming poster on new forms of neurological rehabilitation as a response to new forms of pharmacotherapy used in Alzheimer's disease. The aim of such rehabilitation is to help patients to return to relative self-reliance by stimulating the natural restoration of damaged functions and teaching patients how to compensate for those deficits, which turn out to be persistent. Marta Wysocka (Maria Curie-Skłodowska University in Lublin), *Emotional prosody in the perception of children with normal hearing and children with hearing impairment.* (Prozodia emocjonalna w percepcji dzieci z uszkodzonym narządem słuchu i dzieci styszących.) The poster presented results of own research on the reception of prosodically expressed emotions by children with prelingual damage to the hearing system, and by children with normal hearing. These results suggested that, despite the use of hearing aid, which enables reception of speech, children with hearing organ damage have big difficulties in perceiving emotional prosody; Anna Zwierzchowska (Jerzy Kukuczka Academy of Physical Education in Katowice), Katarzyna Ita Bieńkowska (M. Grzegorzewska Academy of Special Education in Warsaw, Association of Parents and Friends of Children with Hearing Loss in Krośno), *Exercises for children with hearing impairment to compensate for sensory, body control and balance disorders.* (Ćwiczenia kompensujące zaburzenia czucia, kontroli ciała i równowagi dla dzieci z wadą słuchu.) There were a dozen or so simple exercises presented on the poster, that not only activate gross and fine motor skills, but also influence the effects of interdisciplinary interventions aimed at compensation of developmental deficits caused by hearing impairment in children.

The conference has undoubtedly fulfilled its purpose – for the participants it became the forum for discussion, exchange of views, experiences and skills. It also contributed to strengthening the scientific cooperation between different centres.



REVIEW



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**Review of the book *Niezwykli ludzie. Nowe spojrzenie na autyzm*
(Uniquely human. A Different Way of Seeing Autism).**
Barry M. Prizant, Tom Fields-Meyer,
Wydawnictwo Uniwersytetu Jagiellońskiego,
Kraków 2017

Autism Spectrum Disorders have attracted a lot of attention of scientists all over the world. Despite many interesting reports, researchers are still searching for answers to some burning questions in this field. Amongst them are Barry Prizant and his co-workers (among others, Amy Wetherby, Emily Robin and Amy Laurent) who developed SCERTS (Social Communication, Emotional Regulation and Transactional Support)¹ model. The abovementioned model comprises some guidelines for parents, educators and therapists concerning their work with children with autism spectrum disorders. What is more, Prizant has been carrying out long-term observations and studies on the phenomenon of echolalia as a way to learn a language. Due to the fact that he travels around the world with his lectures, workshops and trainings, his activity is universal and comprehensive for all cultural communities. The book *Uniquely human. A Different Way of Seeing Autism* is a result of forty years of the author's scientific activity. It was created with the participation of many people (among others, co-author Tom Fields-Meyer, a long-time associate and friend of Barry M. Prizant). Highly emotional and wise, it encourages to make a change in our percep-

¹ B.M. Prizant, T. Fields-Meyer, *Uniquely human. A Different Way of Seeing Autism*. Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2017, p. 243.

tion of people who suffer from autism spectrum disorders. Already in his short preface, Prizant puts a great emphasis on the role of therapeutic work with the people with the autism spectrum (social communication, emotional stability, interactions with others.)

According to the data provided by the American Centers for Disease Control, nowadays autism is one of the most frequently diagnosed developmental disorder. One in 50 schoolchildren suffers from it². However, I am critical of his words (referred to a number of times in the text, e. g. p. 14, p. 17) defining autism as a disease (?/!) which requires proper treatment. After all, the definition of autism (according to the binding, e. g. in Poland, International Statistical Classification of Diseases and Related Health Problems ICD-10 of 1993) makes it clear that: "*autism is an overall developmental disorder characterised by inadequate or impaired development, showing itself by the age of 3, which involves abnormalities in each of the three spheres: social interactions, communication and limited, repetitive repertoire of behaviours*".

Despite this inaccuracy (perhaps caused by incorrect translation from English into Polish), it is impossible to disagree with the author, that our perception of the people struggling with autism should be changed. Reading the book is supposed to bring up a new paradigm in special education: "*instead of classifying permitted functional behaviours as the symptoms of pathology, we shall study them as a part of many strategies helping to cope with, adapt to, communicate in and face the world, which overwhelms such people, arousing their fear.*" And further: "...*how to create a strategy for dealing with problems and offer support, that will prevent alarming behavioural patterns and will naturally lead to those more desired?*"⁴ Thus, instead of rejecting "autistic", "inappropriate" behaviours, we should rather ask: what function do they perform? The whole book is divided in two major parts. The first part: "Understanding autism" contains six chapters: "Ask why?", "Listen", "Fascinations", "Trust, fear and control", "Emotional memory", "Social understanding". Undoubtedly, the issues discussed there open up the

² B.M. Prizant, T. Fields-Meyer, *Uniquely human. A Different Way of Seeing Autism*. Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2017, p. 15.

³ E. Pisula, *Autism. Reasons. Symptoms. Therapy*, Wydawnictwo Harmonia, Gdańsk 2016 – 4th Edition, p. 33.

⁴ B.M. Prizant, T. Fields-Meyer, *Uniquely human. A Different Way of Seeing Autism*. Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2017, p. 17.

hearts of the readers and inspire them to delve deeper into autism and, most of all – understand it. Two issues addressed deserve special attention: the ability to listen and the phenomenon of echolalia. Listening is the basis for proper communication. If we are unable to listen, children, incapable of communicating verbally, become frustrated and angry, which is not the result of aggression, but an attempt at communication. Raun Kaufman (the first child of Son-Rise Programme)⁵ shows, that autistic children communicate in a “foreign” language (compared to Swedish), which is incomprehensible for us. Barry Prizant, observing autistic people, studied the phenomenon of echolalia. He proved that this type of speech (communication) is not just meaningless “parroting”, but a verbal speech that serves a purpose. However, therapists who fail to understand echolalia and thus encourage parents to interrupt it every time, cause a speech impediment. What is more, by doing it, they prevent every attempt at communication and obstruct their process of learning and bonding with the world. The second part – “Living with autism” – is divided into next six chapters: “What has to be done to have that something”, “Wisdom of the group of friends”, “True Experts”, “Perspective”, “Arouse a spirit” and “Important questions”. This part carries a very significant message: “There is no way to grow out of autism – as explains Dena Gassner, mother, who has an autism spectrum disorder herself – you grow into it”⁶. Stories of the families, who share the difficult experiences of common growing up of their children from the early childhood, through the preschool time, adolescence, until adulthood, are extremely valuable. This is an incredible paper about a power of love, understanding, acceptance and great respect. Parents, who find out that their child is autistic, at first become lonely and isolated. Suddenly people, who have always been for them, start to withdraw. Barry Prizant, through the prism of his forty-year experience, maps out new paths of therapeutic work, helps to achieve a successes conditioned by autistic children’s, and later adult’s abilities.

The language used by the author (despite the difficulty of the problem of autism) is accessible and comprehensive. It gets through to the broad

⁵ R.K. Kaufman, *“Autism, breakthrough in the mindset”* Vivante Publishing House, Białystok 2016.

⁶ B.M. Prizant, T. Fields-Meyer *Uniquely human. A Different Way of Seeing Autism*. Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2017, p. 190.

audience (teachers, therapists and parents). Reading the book gives a new perspective on autism, as a „unique dimension of humanity”.

I believe that the publication, by providing new content, enriched with the data from the author's proprietary research and his long-term observations, is a valuable contribution in the area.

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