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ASSESSMENT OF SOCIAL SUPPORT FOR A MOTHER RAISING A CHILD DIAGNOSED WITH ASPERGER SYNDROME, AS EXPERIENCED BY HER FAMILY. A CASE STUDY

OCENA WSPARCIA SPOŁECZNEGO PRZEZ
MATKĘ DZIECKA Z ZESPOŁEM ASPERGERA
DOŚWIADCZANEGO PRZEZ JEGO RODZINĘ.
STUDIUM PRZYPADKU

Keywords:

Asperger syndrome,
autism spectrum
disorders, adulthood,
family, social network,
social support

Summary: The article discusses a variety of issues related to social support given to Polish families raising a child with Asperger syndrome. The questions regarding the position of Asperger syndrome in the current ICD-10 classification are presented along with the full spectrum of problems faced by people with this type of disorder. The article also discusses selected issues related to the functioning of the whole family. Theoretical considerations focus on social support understood as a special kind of assistance provided to a family in a difficult situation. The paper analyzes the features of the social network, including social support networks, along with the changes that have taken place in these structures. The article also discusses the sources and types of social support experienced by the family in a 10-year period.

Słowa kluczowe:
zespół Aspergera,
zaburzenia ze spek-
trum autyzmu, do-
rosłość, rodzina, sieć
społeczna, wsparcie
społeczne

Streszczenie: W artykule omówiono kwestie związane ze wsparciem społecznym doświadczanym przez rodziny z dzieckiem z zespołem Aspergera. Zagadnienia dotyczące pozycji zespołu Aspergera w aktualnej klasyfikacji ICD-10 zostały przedstawione wraz z pełnym spektrum problemów, z którymi borykają się osoby z tego typu zaburzeniami. W artykule omówiono wybrane zagadnienia związane z funkcjonowaniem rodziny. Teoretyczne rozważania koncentrują się na wsparciu społecznym rozumianym jako szczególny rodzaj pomocy udzielanej rodzinie w trudnej sytuacji. Przedstawiono cechy sieci społecznościowej, w tym sieci wsparcia społecznego, wraz z prezentacją zmian, które zaszły w tych strukturach. W artykule omówiono również źródła i rodzaje wsparcia społecznego doświadczanego przez rodzinę w ciągu 10 lat.

Introduction

According to the ICD-10 classification, Asperger syndrome¹ (F84.5) belongs to the category of overall developmental disorders (F84) and is characterized by qualitative deviations from the norm in terms of social interactions, communication patterns and a limited and stereotypical repertoire of interests and activities. The absence of a general delay or impairment of speech development and cognition distinguishes this syndrome from childhood autism. At the beginning of adulthood, psychotic episodes occur sporadically (International Statistical Classification of Diseases and Health Problems – X Revision, pp. 248–249). The latest DSM 5 classification of the American Psychiatric Association introduced the general category of “Autism Spectrum Disorders” (ASD) (DSM 5, 2013) which includes the following entities: autistic disorder, Asperger disorder, childhood disintegrative disorder and overall developmental disorder not otherwise diagnosed (Chojnicka & Płoski, 2012, pp. 249–250).²

¹ Due to the specificity of the case described, the article uses the term Asperger syndrome, with the exception of the cited fragments containing the term “autism spectrum disorder,” i.e., ASD or HF – ASD (meaning high functioning ASD) (see: Ozonoff, Dawson & McPortland, 2015).

² DSM 5 criteria allow for the designation of subgroups that are distinguished by three levels of symptom severity and three levels of required support. The classification also takes into account the presence of unusual sensory reactions to the environment.

Psychiatric comorbidity is an important problem in ASD, which can affect 70% of patients in childhood, and up to 100% throughout their lives (Rosenberg, Kaufman, Law & Law, 2011). On the basis of their thorough review of the scientific research completed so far, Rybakowski et al. (2014) indicate that the most common comorbid disorders in people with ASD are anxiety disorders (30–50%), OCD (17%) and social anxiety disorder with agoraphobia (17%). The incidence of depression ranges from 1.5 to 38%, bipolar disorder from 2.5 to 3.3%, and ADHD from 30 to 50%. Sleep disorders affect 40–83% of patients with ASD (see: Płatos, 2016, pp. 38–40, 77–79). Sensory disorders are also a serious problem which, according to some adults with Asperger syndrome, have a greater impact on their lives than the common problems in social and emotional functioning (Attwood, 2013, p. 299). The occurrence of mental disorders in people with Asperger syndrome may be the result of a combination of both genetic and environmental factors. Therefore, it is important to recognize their living environment and the needs of the people affected in order to prevent low self-esteem, suffering and difficult and socially inappropriate behaviors (Mazzone, Ruta & Reale, 2012), as well as to secure social assistance and support.

E. Pisula and D. Porębowicz-Dörsmann (2017) emphasize that people with ASD are a very diverse group and suggest the need to conduct research in more homogeneous groups. Research on families raising a child with Asperger syndrome is undoubtedly a response to this postulate.

Parental stress is particularly often pointed out in studies devoted to the functioning of families raising children with ASD. Although the list of stressors is long (see: Pisula, 2015, pp. 26–41), behavioral problems of children with ASD, including children with Asperger syndrome where the severity of the problems is relatively low, are a serious challenge for families (Pisula, 2015, pp. 31–32). P.A. Rao and D.C. Beidel (2009, after: Grootsholten, van Wijngaarden & Kan, 2018) examined parents of children with HF – ASD and asserted that a higher intellectual level of children does not lower the stress level in parents. In fact, although the children had fewer externalization (behavioral) problems, they had more internalization problems, such as anxiety and depression, which may greatly contribute to parental stress. Although the type of stressors changes with the child's age (Pisula, 2015, p. 35), behavioral problems may still be present in adulthood, constituting a barrier to independent living (after: Smith, Greenberg & Mailick, 2012). The functioning of adults with Asperger Syndrome can be further complicated

by psychological symptoms in comorbidities (after: Mazone et al., 2012). Numerous studies show that parenting children with ASD causes significant stress even when the child reaches adolescence and adulthood (e.g., Smith, Greenberg & Mailick, 2012). Studying their daily experience for eight days, L.E. Smith and colleagues found that mothers of teenagers with ASD were three times more likely to experience stress on a given day than mothers of children with other disabilities. These stressful experiences were related to the emotional well-being of mothers; the researchers speculate that stressors accumulate over years of care and hence have a cumulative effect on the mothers' well-being (Smith et al., 2010).

In fact, when people with ASD reach adulthood, the burden on their carers increases, which is caused by the unmet needs of young people with the disorder (after: Grootcholten et al., 2018). It should be added that for most adults with ASD, parents, especially mothers, remain the primary carers and the main source of support (Howlin et al., 2004, after: Van Bourgondien, Dawkin & Marcus, 2014, p. 18). Their stress is most often dictated by the fear for their child's future, lack of employment and other serious limitations, including the lack of independent living opportunities, the child's experience of loneliness, and lack of specialized services (Van Bourgondien et al., 2014, pp. 18–22). E. Pisula also accentuates the experiences of violence and emotional harassment reported by parents (Pisula, 2015, p. 36; see: Płatos, 2016, pp. 42–44). The results of Polish research likewise indicate a great sense of fear and helplessness in parents of adults with ASD (Autism – Situation of Adults, 2014, p. 259).

Parental stress, therefore, depends on many factors whose impact is so complex that its detailed analysis goes beyond the scope of this article. J. Prata, N. Lawson and R. Coelho (2019) have developed an integrative model of factors affecting parental stress, in which, in addition to factors related to parents and children, they listed those related to social support, including professional support, support within the family system and social assistance, and the socioeconomic status of the family.

Support for the family should be understood as assistance available in its environment provided by institutions and associations, as well as by individual people and other families with whom it forms interpersonal relationships. The family relationship with the surrounding social network is considered to be the main determinant of social support. Assistance and support provided to families with a disabled child is tantamount to helping the disabled child

(Radochański, 1991, p. 7). For parents of adults with ASD, social support can be a particularly important resource due to the additional burden associated with, among others, aging parents, as well as a reduction in formal services (Shattuck et al. in: Smith, Greenberg & Seltzer, 2012). In many studies, social assistance has been recognized as a key factor in reducing the negative psychological effects of raising a child with ASD and other disabilities (after: Ekas, Lickenbrock & Whitman, 2010).

Social support is very important for parents because it enables them to be heard, share their experiences, find hope and gain information on various strategies for working with their children (after: Heiman & Berger, 2007). For families of children with severe developmental disorders, it is important to have larger social networks. For example, L.E. Smith, J.S. Greenberg and M.M. Seltzer (2012), who assessed the impact of social support on the well-being of mothers, came to the conclusion that mothers with larger social networks reported a decrease in symptoms of depression.

A. Axer (1983) lists three basic ways of understanding social support systems. These are institutions and networks of institutions, as well as assistance programs that meet the needs of their clients; assistance organizations inspired by professionals and spontaneous organizations; natural systems, which include people from the immediate environment whose feelings, attitudes and behavior favorably affect the subject. The natural system is the most durable and reliable source of family support (Axer, 1983, pp. 200, 207–208). Ekas and colleagues have found that informal sources of support, including partners, other family members and friends, are particularly important for mothers of children with ASD. These sources of support are associated with lower levels of parental stress and lower levels of depression. Support received from partners and friends was associated with an increase in life satisfaction and better mental well-being. Support from other family members increased mental well-being, too (Ekas et al., 2010). T. Heiman and O. Berger (2007) indicate the need for effective intervention programs for parents that would focus on developing coping skills to better respond to their own changing needs as well as those of their children. Because the needs of the people with developmental disorders change when they enter adulthood, the demands regarding social support for the family also change. In fact, however, this is often when the family becomes the sole care provider for the adult with ASD.

Organization of research and method used

Based on the above assumptions, a qualitative study was conducted, i.e., a case study of a family with a child diagnosed with Asperger syndrome and comorbid mental disorders. The analysis aims to draw attention to the difficult and complex situation of the family of an adult with ASD, in which problems accumulate due to the lack of help from social services. The purpose of the case study is to provide a comprehensive description and understanding of the case along with the surrounding context (Strumińska-Kutra & Kołodkiewicz, 2012, p. 4). The goal of the study is also to assess the social support received by the family, with a focus on the changes in the social network and the support granted by it, as well as other sources and types of social support. Material, informational, instrumental, unconditional (spiritual) and emotional support are all assessed (Sęk & Cieślak, 2004, pp. 18–20), as well as support in care.³ I conducted the study ten years after the first interview, which allowed me to capture the changes in the family system, social network and social support network. The study used document analysis and individual in-depth structured interview (Gutkova, 2012, p. 113). The interview was conducted using the Social Network and Social Support Network questionnaire. The tool was prepared based on the interview questionnaire Assessment of Surroundings and Social Support (OOiOS) (Bizoń et al., 2001, pp. 617–634).⁴ Prior to the interview, the medical documentation and record of the interview conducted in 2006 were reviewed. The obtained information was subject to qualitative analysis.

Analysis of own research results

Characteristics of the Family. As of 2006, Barbara's⁵ was a two-parent family with two daughters: 14-year-old Marta, who was diagnosed with Asperger syndrome, and 21-year-old Iwona – a student. The health status of the family members was good. Barbara assessed the family's financial situation and housing

³ Support in care should be understood as replacing the mother in caring activities for the child, in order to enable her rest, regeneration and mobilization of strength.

⁴ The authors state that this tool was created on the basis of clinical experience and can be used in cognitive research (Bizoń et al., 2001, p. 627). The tool is used to collect data about people who perform support functions for the examined person and to develop an adequate support system.

⁵ Names have been changed for the purposes of this research.

conditions as good, too. She took care of Marta together with her mother (the girl's grandmother). Sometimes her older daughter also helped her. According to Barbara, the relations between the sisters were appropriate. Barbara, a teacher by profession, worked in an elementary school, while her husband worked abroad. They usually spent their free time outdoors – at a swimming pool, horseback riding, hiking in the countryside and walking. Barbara emphasized that their “life revolved around Marta,” and that the above-mentioned forms of family activity were selected mainly taking into account the interests, needs and capabilities of the younger daughter. Marta also enjoyed spending time with her grandmother, with whom she felt particularly connected. Barbara did not report any upbringing problems regarding her older daughter, whom she tried to devote her free time to.

Diagnosis of Developmental Disorders and Health Condition. Marta was born healthy and initially developed properly. According to Barbara's report, she noticed the first alarming symptoms in the form of delayed motor development in her daughter at the age of several months. There were behavioral problems in the preschool period, including hyperactivity and tantrums, lack of interest in contact with peers and lack of tolerance for strangers. During this period, the child was diagnosed with a “slight delay in motor development,” followed by “attention deficit hyperactivity disorder,” “autistic traits” and “high-functioning autism.” The final diagnosis of Asperger syndrome (F84.5) based on the ICD-10 classification was issued when Marta turned 10. Intellectual development was described as “within the norm.” Barbara described the diagnosis period as “long and burdensome for the family and the child.” At the age of 22, Marta had her first episode of psychosis with loss of consciousness; 20 months later, she also experienced an epileptic seizure. In both cases, she was treated in a psychiatric hospital. Finally, she was diagnosed with acute and transient psychotic disorders (F23) and other epilepsies (G 40.8). Marta has a certificate of moderate disability.

Marta's Education and Therapy. Marta received individual and group therapy for children with autism spectrum disorder since her diagnosis. She carried out her education in generally accessible, public institutions. She also obtained a statement of special education needs. In junior high school and high school, she was eligible for an individualized education program. Her parents chose this form of education because of the child's difficult behavior: tantrums, verbal aggression, hyperactivity, anxiety and attention deficit disorder. Even though Marta's teachers had no previous experience working with students

with autism spectrum disorders, Marta's parents were satisfied with this form of schooling. The girl attended additional English classes, achieving significant successes in this subject. Due to difficulties in learning mathematics, however, she did not take the *matura* exam, which, according to Barbara, was a wrong decision influenced by the teacher's suggestions. Marta has been at home since graduating from high school. For a few months she participated in occupational therapy workshops but, in Barbara's view, was not satisfied with this form of activity; the facility was intended for people with intellectual disabilities and thus did not meet her daughter's need for social contacts.

All in all, Barbara positively assessed Marta's education period. First of all, her daughter's functioning improved gradually under the influence of educational and therapeutic activities: "It was a good time in Marta's life and in the family's life [...] she liked English, she was eager to learn [...], we went to therapy for some time and Marta liked to be there [...], she studied, although she had problems, she was nervous, but she finally managed." The implementation of the compulsory schooling in the form of individualized instruction created the right conditions to meet Marta's need for security and offered her appropriate educational support: "at home she was calmer and remained active; she was not worried about what would happen at school, what the children would say."

The subject of education often appears in Barbara's narrative, which may suggest that this type of support is, in her opinion, particularly important. Barbara drew attention to the noticeable progress in her daughter's development and the hopes associated with it: "we saw progress in her development, she went ahead, we were very happy, everything started to fall into place, [...] after junior high school there was high school, language competitions that she won [...] hopes for studying at a university [...], we were very happy [...]. She had private lessons in mathematics because she had a problem with it, but she did quite well with other subjects [...]. I was hoping that maybe she would make money doing translations [...] and Marta thought so too. And now all is lost." The present situation, as Barbara points out, is caused by her daughter's loneliness, lack of contact with peers and the resulting sense of exclusion.

Current Family Situation. In the course of 10 years, the family situation has changed significantly.⁶ The older daughter became independent and started her own family. Barbara divorced her husband. She believes that the main reason for the breakup of the marriage was the separation resulting from his

⁶ As of 2016.

employment outside the country. Although the father sends money to Marta, he contacts his daughters only occasionally. The material situation of the family deteriorated. Barbara believes that Marta does not understand the new circumstances, and that the departure of her father undermined her sense of security, deteriorated her functioning and became a source of suffering: "I think she does not understand what happened; I explain to her that her dad will not be with us anymore, that he has a new wife, but she doesn't understand; she asks again and gets nervous [...]. At other times, I think she understands more, because when I told her that her dad would not come back, she started watching movies from her baptism and communion in which he carried her and kept her on his lap."

Currently, the most serious problem is Marta's health. For the family, this is a particularly difficult situation to come to terms with. During the interview Barbara did not hide her regret: "I have already gotten used to autism, we learned to live with it, we sorted out our lives, and here's another blow [...]. This disease takes everything from her and us [...]. Why did this happen to her? [...] and what awaits her?" Particularly strong emotions were aroused by reference to recent events, including the severity of disease symptoms and adverse prognosis: "the last attack was terrible, she lost consciousness, she was out of touch, my mother thought that Marta was dying [...]. I am very worried because doctors say that these attacks will happen again; it is not known when, but they will definitely happen again, and this uncertainty is the worst." Marta's stays in a psychiatric hospital, which the young woman could not accept, were an exceptionally difficult experience for the family.

Social Network and Social Support Network. The family's social network, and the social support network inscribed within it, was formed during the period when Barbara and her mother first sought help and remained unchanged for several years. The social network of 42 people was made up of close and distant family members, neighbors and a large group of friends, mainly from Barbara's work. Barbara maintained close contacts with other parents from the Association of Intervention and Therapy for Children with Autistic Disorders and Their Families. Among the people helping with Marta's treatment were doctors and psychologists from the Child and Adolescent Mental Health Clinic. Barbara also had the support of therapists and teachers, riding and swimming instructors, and a psychologist running a parent support group.

The social support network numbered 40 people and was dispersed. Sources of support were present in different areas, with the exception of the closest

neighborhood. The immediate family, friends from the Association and professionals constituted the strongest support system, with Barbara's mother being the primary source of support. The family also received all types of social support, including emotional, and, to a lesser degree, material support, care support and unconditional support. Informational and instrumental support were also well secured.

Over the past 10 years, the social network and social support network have changed. Currently, these structures have 18 and 12 people, respectively. The family group decreased by only one person, but the number of friends from work definitely decreased. Barbara broke off contacts with the parents from the Association and with the staff of the facility. She justified her decision by the nuisance of traveling to meetings and the lack of the need to maintain relationships with parents of children with autism: "The Association and parents were very good at the beginning; we went there with Marta and my mother [...]. Commuting took a long time; it was especially difficult in winter. We gave up because these meetings did not bring anything new to our lives."

Experienced Social Support. Barbara enumerated the many people who have supported her. Doctors, psychologists and therapists from specialist clinics, and parents of children with autism were sources of information and instrumental support. Barbara benefited from their experience, as they willingly shared their insights. Through participation in individual and group classes, she learned various techniques for working with her child and the procedures for dealing with difficult behavior. She was emotionally supported by family, friends from work, parents of children with autism, doctors, psychologists, therapists and teachers. As she says: "We have been shown a lot of heart and kindness. Marta's relations with extended family members were particularly valuable. My daughter, despite her behavior problems, was accepted and liked."

The most important person for Barbara has been her mother, who has engaged in helping her daughter and has been happy to help in the care, upbringing and education of her granddaughter: "Mom quickly began to work, she established and kept in touch with parents of disabled children, completed specialist training, told me what to do, taught me how to deal with Marta." Barbara's narrative, therefore, shows much gratitude for her mother's help and commitment: "Without her support it would be hard for us; thanks to my mother I could devote more time to my older daughter and we avoided major problems of adolescence." Barbara's parents were also a source of material

support. Barbara knew that in the most difficult moments she would be able to count on the support of her mother and older daughter.

Evaluation of Received Social Support. As indicated above, Barbara's parents have been a source of material support. Marta is completely looked after by her mother and grandmother. Barbara believes that her daughter will remain dependent on other people's care, a thought which fills her with sadness. Support in care has been particularly important since she noticed her daughter's first alarming symptoms. Because of her parents' professional work, her father's absence and the implementation of individual education, Marta spent a significant part of her time at her grandmother's home. They currently live together. Barbara believes that thanks to her mother's help she was able to work, train, improve the financial situation of the family and help her older daughter take care of her child: "I owe my mother a lot, actually everything, studies, work [...]. If it wasn't for her, I couldn't do it, all the more so, now." Currently, because of the new diagnosis, caring for Marta is of particular importance. Barbara's mother has remained the only source of support in care and of unconditional support (besides Barbara's older daughter): "Who will help me, who will help Marta? It is difficult to talk about it [...], but there is mother and Iwona, although she has her own life, but we can count on her with Marta."

Barbara highly appreciates the informational and instrumental support she experienced over the past years, starting with the diagnosis she obtained when Marta turned 10. Marta's psychosis motivated her to contact the doctor who provided the original diagnosis – and whom she trusted. She positively assesses the activities of medical personnel, describing them as competent, committed and kind. The information she received in the hospital and during follow-up visits concerned the symptoms and expected course of the disease, methods of treatment and rehabilitation, as well as possibilities of getting help and support. Instrumental support, however, is considerably lower due to the absence of people who experience similar problems: "I don't know anyone who has a child with psychosis. In the hospital, I focused on Marta and did not talk to people [...] I did not know what to do, we were helpless. This type of support in the past was secured by a group of parents from the Association and therapists, but it only concerned the management of a child with Asperger syndrome."

In the past, emotional support was provided by both natural and professional sources. For Barbara, this was especially important because, as she says: "it helps

you survive difficult times [...], gives you strength and a sense of security.” It seems that the support received has helped the family adapt to Marta’s disability. Although in the family environment the number of people who emotionally supported Marta has decreased, in the social network there still are Barbara’s mother and older daughter, who are its most important elements.

Conclusion

In this study, I evaluated the social network, social support network and social support experienced by one family over the course of 10 years. My analysis of the collected research material shows that after a relatively stable period, the family now has to face a particularly serious problem, which is the further mental illness of one of its members. At present, the situation resembles that of a family with a small child, when, after receiving the diagnosis, parents seek help and support. The recent events have made the mother well aware of the difficult situation in which she and her family find themselves – the future of her daughter is uncertain due to the autism spectrum disorders, comorbid psychiatric disorders, unfavorable medical prognosis, the inability of an adult with Asperger syndrome to lead an independent life and the high dependence on care provided by the mother and relatives (Van Bourgondien et al., 2014). Regarding the change of stressors that correspond to the child’s age, the research findings are consistent with the findings described in the literature on the subject (Pisula, 2015). Social support should, therefore, be adapted to these changes. The formation of a social network, and social support networks, remains an open question. The new situation should contribute to the search for sources of support, e.g., groups of parents who experience similar problems and can support the family by providing information and can become a source of positive interpersonal reactions, social support or assistance behavior.

Barbara’s mother and her help were frequently mentioned in the interview. Due to the increased demand for this type of care and the restrictions related to the aging process and loss of strength of the strongest source of social support, i.e., Barbara’s mother, the family situation is difficult, and requires taking the steps necessary to strengthen social networks with people who can support the family in the future. This issue is important in the context of the family’s adapting to the new situation. Research confirms the importance of having larger social networks (Smith, Greenberg & Seltzer, 2012), including sources

of informal social support from family members, friends and acquaintances (after: Pisula, 2015, p. 39). The indication of the older daughter as a potential source of support for Marta when Barbara's mother will no longer be able to provide care is noteworthy. However, it seems that for adult siblings, maintaining their own family, their own personal and professional life and supporting a person with Asperger syndrome and co-occurring mental disorders may be difficult or even impossible (Van Bourgondien et al., 2014, p. 30). What could make it easier is the general better functioning of a person with ASD (after: Van Bourgondien et al., 2014, p. 30) which is why such improvement should be sought by securing information and instrumental support.

At this point, various programs addressed to families, including parents and people with ASD, (see: Smith, Greenberg & Mailick, 2012; Gryniuk-Toruń, 2017) and aimed at developing the skills of using new, effective ways of acting should be indicated. Currently, however, these types of support are very limited. Establishing direct contacts or using online networks to get in touch with parents experiencing similar problems, therefore, are the most available ways to master new strategies, to increase guardianship competences and to adapt to the new situation. The analysis of the collected research material shows a worrying phenomenon: only natural systems appear in the social support network when a person with ASD reaches adulthood. Although it is impossible to overestimate their importance in terms of improving the situation of a family with an adult with ASD (Ekas et al., 2010), specialist support institutions should be available in the family environment, as the remaining resources of natural systems may yet cease to be sufficient.

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