

## ПРОБЛЕМАТИКА ЗДОРОВ'Я, ВІКУ, ТІЛЕСНОСТІ У ДЗЕРКАЛІ СОЦІОЛОГІЧНИХ ДОСЛІДЖЕНЬ

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### THE SITUATION OF FAMILIES WITH AUTISTIC CHILDREN

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The unpredictable and unusual nature of the development of autistic children makes the situation of their families extremely difficult. Research conducted on the issue has confirmed that parents of autistic children experience all kinds of problems, difficulties, tensions and stress. Available literary sources present a unanimous opinion - functioning of such families, as well as their ability to cope with care-related and educational problems depend upon various factors. This study analyses chosen socio-economic and cultural factors influencing how such families overcome difficulties connected to care and education of autistic children.

*Key words:* family, autism, functioning, problems, support

#### Introduction

*A considerable amount of both empirical and theoretical studies is focused on the subject of functioning of autistic persons. They primarily analyse the diagnostic criteria, developmental disorders, educational, social and communication difficulties, as well as pathomechanisms triggering the problem (Sekułowicz, 1994; Pisula, Noińska, 2011; Pisula, 2012). Depending on the researchers' area of focus, the available study results on families with disabled members take two approaches. In the first one, the emphasis is laid on the situation of the disabled person within the family, i.e. on all the issues that may influence the person's functioning (e.g.: Karwowska, 2008). The other approach focuses on the analysis of the whole family and its functioning (e.g.: M. Dudek, 2015). It is frequently the case that the two approaches concern partially the same research field. This paper is dedicated to the functioning of a family with a child suffering*

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from autism spectrum disorder.

Each and every disease, disability or disorder in a child's development has impact on its family system and triggers stress, fear and anxiety in each of its members. Having a child with health or developmental issues breaks the established structure of its family into pieces and decreases the notion of safety (Sekulowicz, 1994).

Once a disabled child is born into a family, a source of an enormous stress emerges as well. Such an issue concerns families with an autistic child, as the child's development is unpredictable and unusual in nature. The available research has confirmed that parents of autistic children suffer from various kinds of tension and stress (Pisula, 2005, 2012; M. Dudek, 2017).

Autistic children tend to suffer from sleep and nutrition disorders, frequently present symptoms of hyperactivity, auto-aggressive and aggressive behaviours. These problems require the parents to be constantly alert which leads to their constant exhaustion. Mothers of autistic children often claim that their mental and physical health is deteriorating. Moreover, constant concerns on their child's well-being and life provide the source of long-standing stress. Yet another difficult situation the parents face is the fact that their child is unable to communicate that it is ill or hurting (Obuchowska, 1991).

In some cases, the parents may feel rejected by their own child who seems not to recognise them despite the parents' enormous effort put into establishing a normal relationship with their son or daughter. Such a situation puts exceptionally considerable strain on mothers. When her child would not hug, look or smile at her, react to its name or to anything else, the mother must feel lost and doubt her maternal competences. She doesn't know how to communicate with her child, as it does not want to be held, screams but never sheds a tear and when it appears, and only appears, not to need any love.

Autistic child provides its loved ones and its parents' marital relationship with an enormous challenge. While some tend to think that such a child makes the relationship stronger, others are of the view that it becomes a source of marital conflicts (Twardowski, 1991). The parents are forced to restructure their relationship, learn how to help one another. This new situation may also pose a threat to their relationship as a couple. Conflicts may arise also in the case when the care over a child is left entirely to one parent.

Arguments are triggered by critical opinions concerning parenting methods as well. Frequently shocking behaviours presented by autistic children force the parents to listen to lectures on how they should encourage their children to play, talk or behave properly (Orlikowska, Bołtuć, 2018). Such parents are also accused of not being able to raise their own son or daughter.

Experts agree that the exceptionally difficult situation of autistic children's parents results from: disorders typical of autism, delayed and hard diagnosis, as well as poor access to proper forms of therapy. Each case of autism is different - from high-functioning children to those suffering from additional mental disabilities and other diseases. In consequence, caring and working with such

children automatically requires different amounts of effort and causes various levels of stress.

The available literature features a common statement that environmental factors may impact the development and education of a child in a positive or a negative way. The negative factors include: the lack of stimulation of the child's development, poor education of the parents, unfavourable mental qualities of the parents, place of residence, social isolation, defective family structure, unemployment, poor material conditions, no access to medical assistance, no access to other specialists and therapists, birth order of the autistic child, the number of children, living with other members of the family (grandfather, grandmother, aunt, etc.) (e.g.: Kościelska 1995; Karwowska 2008; Balcerzak-Paradowska, 2008).

The objective of this paper is to determine the situation of families with children suffering from autism spectrum disorder. The goals are connected to answers to the following questions:

- 1) Are there any differences in terms of specific family functioning indicators in mothers and fathers of autistic children?
- 2) Does the place of residence enable the differentiation between the examined groups in terms of specific family functioning indicators?
- 3) What is the structure of the examined families?
- 4) What is the education level of the examined parents?
- 5) What is the socio-economic condition of the examined families?
- 6) Who would provide the examined parents with the primary support?

### **Methodology**

The research incorporates the diagnostic survey method. The author's own interview questionnaire served as the research technique. It included closed, half-open and open questions concerning the socio-economic and care-related situation of the family, etc.

### **Participants**

The presented research results constitute a part of a large academic project conducted between January 2016 and August 2017 within three provinces: Mazowieckie, Lubelskie and Podkarpackie. From the total of 315 parents of children with disabilities or developmental disorders, 132 were the parents of children with autism spectrum disorder (children of 32 parents suffer from the Asperger syndrome). The group of 132 parents of autistic children included 105 mothers and 27 fathers. The average age of parents was 40.3; 38.7 for mothers and 41.9 for fathers. The proportion of participants coming from the three backgrounds: rural areas, town and city (comp. table 1) was fairly equal.

### **Research results**

The available literature features a common statement that environmental factors may impact the development and education of a child in a positive or a negative way. The negative factors include: the lack of stimulation of the child's development, poor education of the parents, unfavourable mental qualities of the parents, place of residence, social isolation, defective family structure, unem-

ployment, poor material conditions, no access to medical assistance, no access to other specialists and therapists, birth order of the autistic child (e.g.: Balcerzak-Paradowska, 2008).

The place of residence of the parents constitutes a vital predictor in the manner they cope with challenges connected to raising an autistic child (e.g.: Obuchowska 1991). Considering the above, the researchers attempted to provide comparable groups of parents from different places of residence. Table 1 includes basic information concerning the place of residence of the participants.

Table 1. Place of residence of the examined persons (Group 1 - a city; Group 2 - a town; Group 3 - rural areas)

Sex	Place of residence							
	Group 1		Group 2		Group 3		Total	
	N	%	N	%	N	%	N	%
Women	38	36.2	30	28.6	37	35.2	105	79.5
Men	14	51.9	6	22.2	7	25.9	27	20.5
Total	52	39.4	36	27.3	44	33.3	132	100.0

Source: own research

Table 1 indicates that the quantity of participants in each group was comparable. The sex of the participants was, however, a vital differentiating factor within the groups. Men constituted only 1/5 of the participants, which tends to prove the theory that fathers are less willing to give interviews.

The analysis of the education level indicates that, among the mothers, persons representing higher education (41.7%), secondary education (31.8%) and vocational education (15.2%) are in majority. The lowest percentage of mothers obtained post-secondary education (8.0%), vocational education (15.2%), primary education (2.3%) and incomplete primary education (0.8%). The structure varies from the researched group of fathers (figure 2). It appears that among fathers the percentage of those with vocational education (28.8%), secondary education (28.8%) and higher education (29.5%) is comparable. Among the remaining part, 6.1% of the fathers represent post-secondary education and 7.6% - primary education.

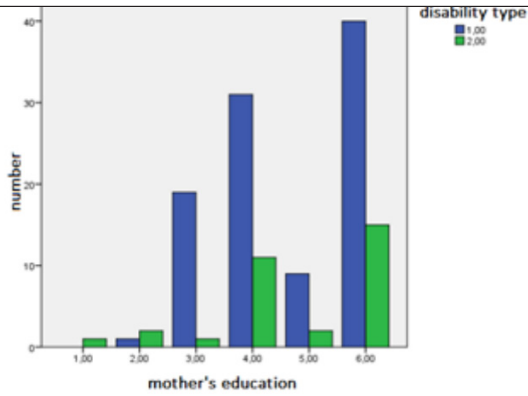


Figure 1. Education level among mothers of children with full autism spectrum disorder and with Asperger syndrome (1-incomplete primary; 2-primary; 3-vocational; 4-secondary; 5-post-secondary; 6-higher  
Source: own research

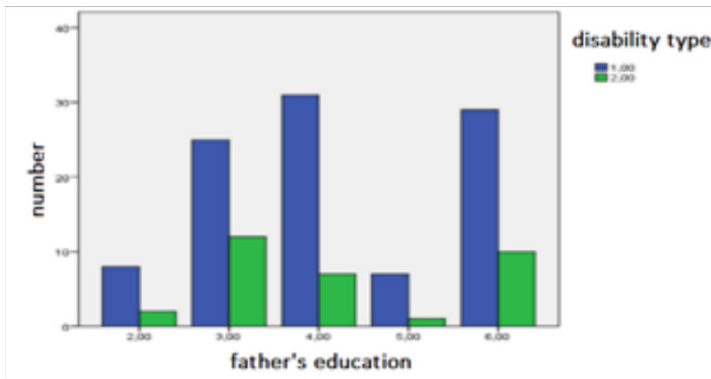


Figure 2. Education level among fathers of children with full autism spectrum disorder and with Asperger syndrome (1-incomplete primary; 2-primary; 3-vocational; 4-secondary; 5-post-secondary; 6-higher)  
Source: own research

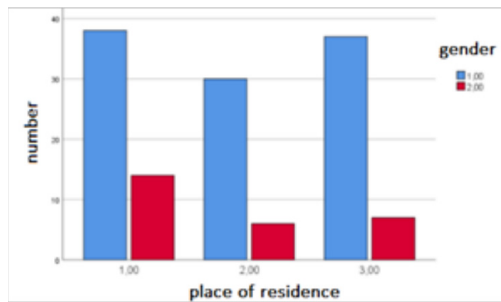


Figure 3. Sex of children from the examined families  
Source: own research

Figure 3 shows that the majority of examined children are girls (79.5%) and that boys constitute only 20.5%. The examined parents provided care for their children from the pre-school age until the end of school age. The average age of the examined children from each background group was: city - 10.8, town - 11.2, rural areas - 11.8. Figure 4 presents the results profile. The available literature strongly highlights the importance of the mother's age upon giving birth to a disabled child. Authors frequently emphasise that too early or too late age of mothers may have a negative impact on their children's development. The results profile concerning mother's age upon giving birth to an autistic child is shown in figure 5.

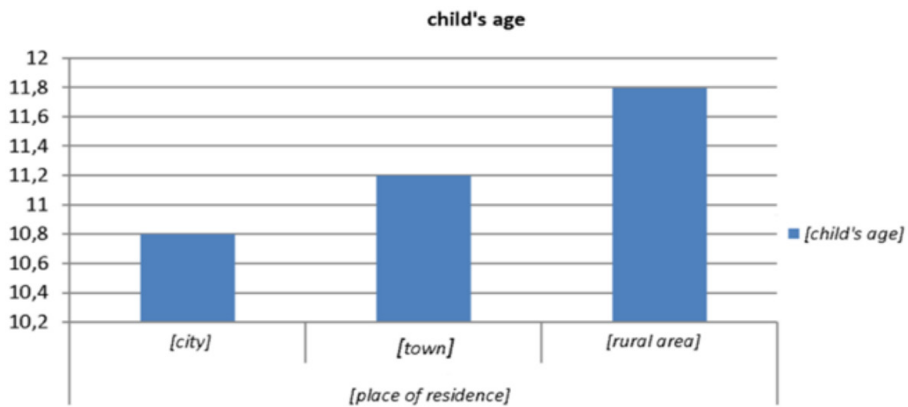


Figure 4. The age of examined children

Most mothers - 65.8%, were between 21 and 24 years of age upon giving birth to an autistic child. Such an age range is commonly accepted as the best one for having children. Hence, the collected data seem to contradict researchers' suspicions concerning the impact of mothers' age on the emergence of autism in their children.

The next step was to compare the average age among groups distinguished based on the place of residence. The variance analysis shows differences of statistical significance ( $F=4,737$ ;  $p<0,01$ ). The implementation of the NIR post test enables closer localisation of the existing differences (table 2). It appears that women from rural areas had their autistic children much earlier than women from cities ( $p<0,01$ ).

Table 2. Differences in arithmetic averages and standard deviation of mothers' age upon giving birth to children in connection to their place of residence (1-city; 2-town, 3-rural areas)

Residence	N	Average	Std. dev.	F	df	p<	Post test			
							NIR Comp. groups	Average of	p<	
A City	52	28.23	5.69	4,73*	2	0.010	A-B	2.03		
B Town	36	26.19	4.22				A-C			3,18*
CRural	44	25.04	5.13				B-C			1.14
Total	132	26.61	5.28							

\*p<0,01

Source: own research

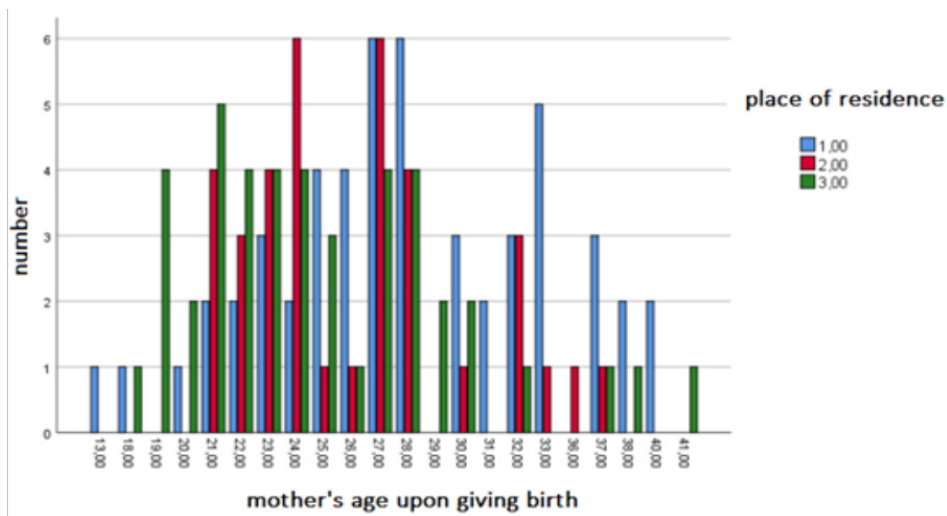


Figure 5. Mother's age upon giving birth to autistic child  
Source: own research

One of the most significant factors in terms of family structure is the birth order of the autistic child. It is crucial for the aetiology of the disorder. Moreover, it is possible that part of the parents rejects the possibility of having more children as the care over the autistic one is too much of a challenge. The result profile presented in figure 6 clearly shows that the majority of autistic children, 44.7% (59), were born as the first ones, slightly less of them, i.e. 32.6% (43), were born as the second child, 15.2% were born as the third child, 6.1% (8) were born as the fourth and only 0.8% (1) was born as the fifth or the sixth child in the family.

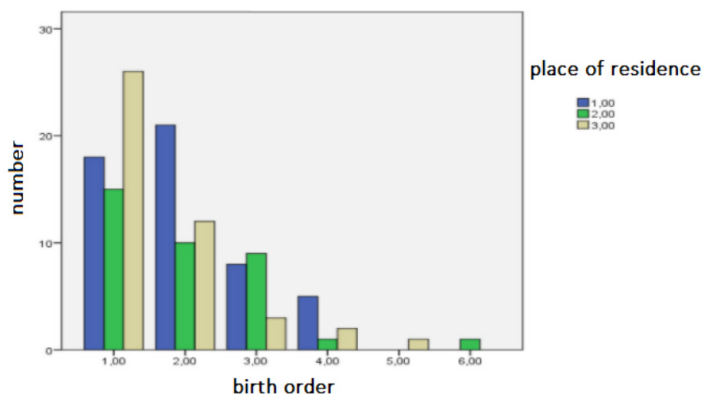


Figure 6. Birth order of autistic child in the family

Source: own research

The previous question led to the other one, concerning the number of children in a family. It seems that almost a half of the examined families, i.e. 49.2% (65) raises two children, 27.3% (36) have one child and 15.2% (20) families have three children. Families with more children clearly constitute a minority (figure 7)

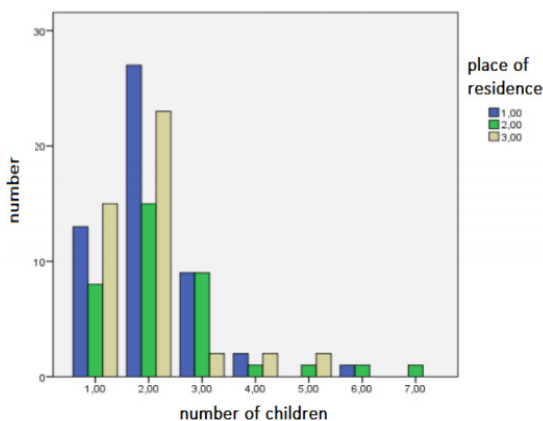


Figure 7. Number of children in examined families

Source: own research

According to many papers focused on family as a family environment the type of family is of crucial importance. The majority of the examined families (82.6%) are complete. Only 9.8% of them are incomplete. Half-orphans constitute only 3.8% of the examined group, single parents make up 2.3% and only 1.5% is represented by a reconstituted family (figure 8).

Parents with disabled children, especially those suffering from autism spectrum disorder, face an extremely difficult reality. It is due to the characteristic nature of this disorder as well as the necessity to provide the child with constant care. Almost half of the participants (49.2%) declare that their autistic child is under the mother's care, 29.5% claims that the role is played by grandparents and only 7.6% point to fathers as the primary care-givers. Hence, it is vital whether parents receive help from their relatives. In the case when the household includes grandparents or the parents' siblings, mothers and fathers may count on



support in some exceptional circumstances.

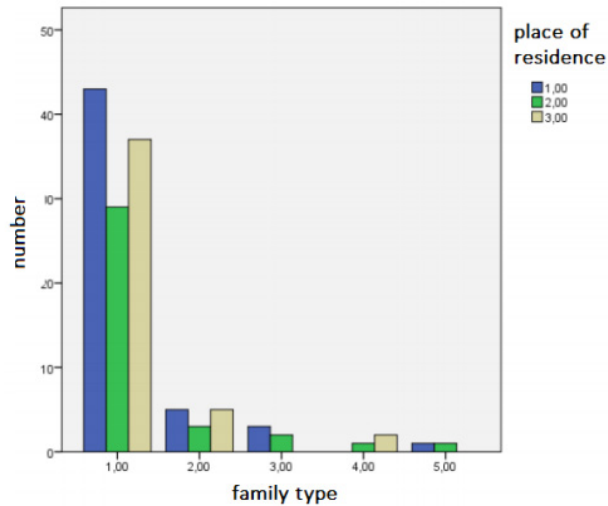


Figure 8. Family type: 1-complete family, 2-incomplete family, 3-family incomplete due to the death of a spouse, 4-incomplete family, single parent, 5-reconstituted family.

Source: own research

Such situations should be understood as a natural need to rest, shopping, attending to some official matters, seeing a doctor, pursuing career possibilities, etc. As it is presented in figure 9, the majority of the examined families, i.e. 68.2% declare that they live separately from their relatives. One in every 5 participants (22.0%) admits that he/she lives with a grandmother or a grandfather and only 9.1% live with siblings. Only 0.8% declare living with other relatives (e.g. aunts or uncles).

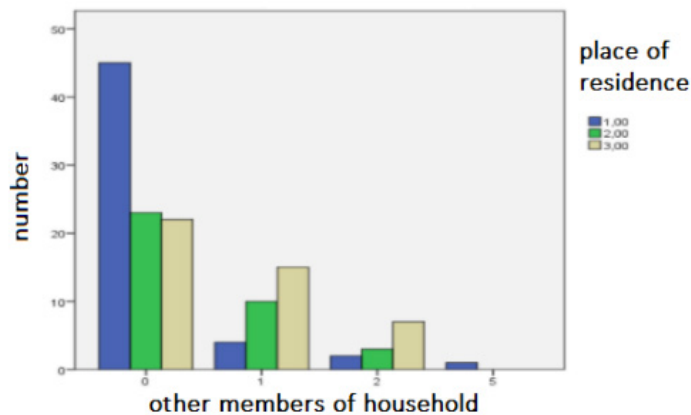


Figure 9. Other persons living with the examined family

Source: own research

For one of the parents (usually the mother) having a disabled child very frequently equals the end or limitation of one of the parents' professional activity. Such a tendency is confirmed by the examined persons.

Upon the research being conducted, one third of the mothers was employed as a white-collar employee (31.8%) and one fifth of the mothers declared working as a qualified employee (22.7%). Approximately 12.9% of them worked as an unqualified worker. 8.3% of the mothers were unemployed and the same number of them worked abroad (figure 10).

As far as the fathers' employment is concerned, 36.4% worked as a white-collar employee. Almost the same percentage, i.e. 34.1%, declared to be unemployed (figure 11).

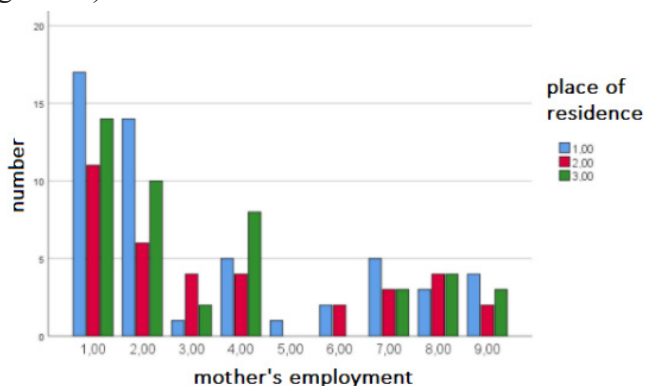


Figure 10. Employment structure of mothers: 1- white-collar employee; 2-qualified worker; 3-farmer; 4-unqualified blue-collar employee; 5-pensioner; 6-retired; 7-unemployed; 8-working abroad; 9-other.

Source: own research

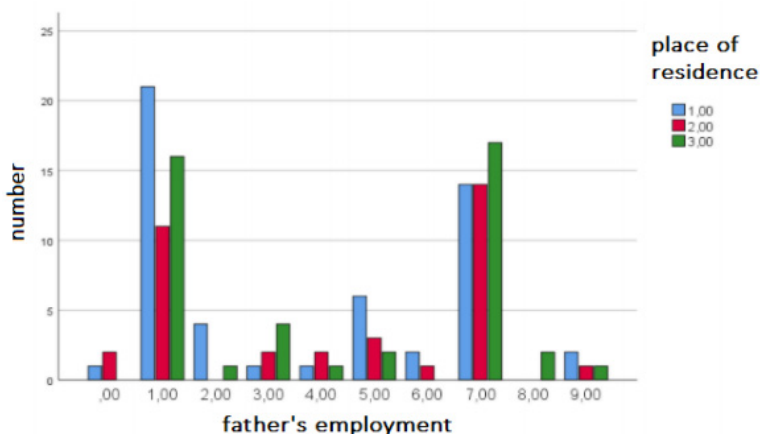


Figure 11. Employment structure of fathers: 0- no father; 1- white-collar employee; 2-qualified worker; 3-farmer; 4-unqualified blue-collar employee;

5-pensioner; 6-retired; 7-unemployed; 8-working abroad; 9-other.

Source: own research

All kinds of social studies include the establishment of the financial condition of the family. It is strongly connected to the family's quality of life and the ability to fulfil its basic needs. The financial condition is especially crucial in the context of families facing disability, as in such a case the needs connected to providing treatment and therapy are vast. Results obtained through the author's own research show that almost three quarters of the participants coming from the three different backgrounds evaluate their financial condition as good. 22.7% of the examined persons claim that their financial condition is poor. Only 3.8% of the participants evaluate their condition as particularly good. None of the examined persons declared that the financial condition of their family is extremely poor. Obviously, there are many kinds of professionals working with children in kindergartens and schools. They may be divided into 8 categories. A parent encounters each of them in the institution his/her child attends. Basic qualifications and tasks of these people make them perfect for working with the family tackling disability or developmental disorders of a child.

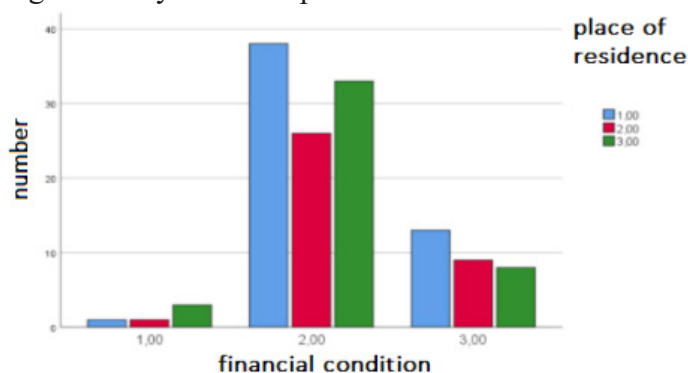


Figure 12. Financial condition of the examined families within groups distinguished according to their places of residence: 1-rural areas; 2-town; 3-city (financial condition: 1- particularly good, 2- good, 3- poor, 4- very poor).

Source: own research

Such a support is vital for the identification of the child's developmental problems (i.e. diagnosis) or for the joint composition of an individualised education and therapeutic programme [Polish: IPET]. The author's own research indicates that, in terms of professional support, parents of children with autism spectrum disorder could count only on teachers working with their child and pedagogues (figure 13).

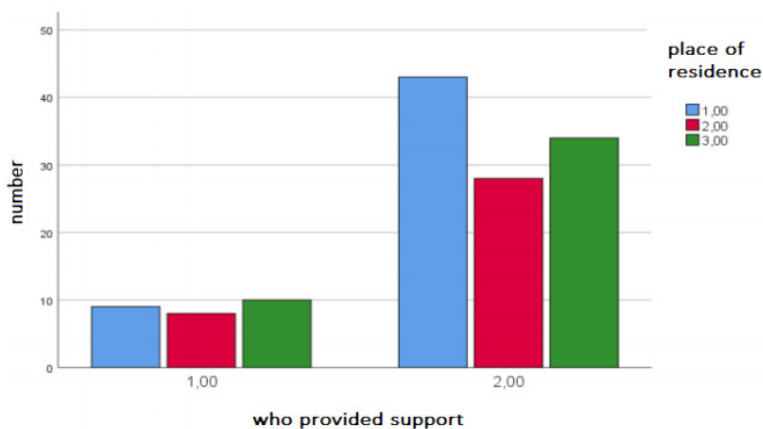


Figure 13. Who provided support for parents of autistic children from different backgrounds? (1- form teacher, 2- pedagogue, 3- principal, 4- teacher, 5- parents, 6- other parents, 7- no one, 8- therapist).

Source: own research

## Conclusions

- The majority of the examined parents represent a higher, secondary or vocational level of education.
- Most of the examined mothers had their autistic child between the ages of 24 and 28.
- Mothers from rural areas gave birth to their autistic child earlier than those from cities.
- Among the examined parents, half of them raise two children, almost one third raise three children and only one out of four families raise one child.
- Most of the examined families (82.6%) represent complete families. One out of ten families are incomplete.
- Almost half of the participants declare that the mother is the direct and primary care-giver for the autistic child, in one third of the families the role is played by grandparents.
- 68.2% of the examined families are nuclear. One out of five participants admits that he/she lives with a grandparent, while one in ten declares living with a sibling (i.e. the child's aunt or uncle).
- Vast majority of mothers work professionally. Only 8.3% of them are unemployed and the same number declares working abroad. One out of three fathers (34.1%) is unemployed.
- Vast majority of the participants consider their financial condition to be good.
- Most parents point to teachers directly working with their children and pedagogues as those who provided them with primary support.

### Discussion

Available results of research on functioning of families with autistic children are unequivocal. On one hand, it is claimed that welcoming a disabled child into the family (or learning about a child's disability) destroys the established structure of the family and completely disorganises its functioning. It has been common for researchers to believe that greater number of cases of developmental problems in children and adolescents from the rural background characterised by poorer socio-economic status. As far as parents from the rural background are concerned, they were perceived as less skilful in terms of raising their children and representing lower level of education comparing to those from cities. Poorer competences of parents and limited access to specialists and institutions dedicated to supporting children and their families were believed to cause raised susceptibility to parental stress and crisis of the whole family system (Dudek, 2015;2017). Some of these assumptions may now be considered invalid. They have been verified by the latest research results.

As a disabled child is born, the life of its entire family is limited and transformed in terms of emotional and social functioning (Sekulowicz 2010: 47). On the other hand, a child's disability is believed to bring the family some benefits (e.g.: Tomkiewicz, 1975; Orlikowska, Bołtuć, 2018). While investigating the needs of families raising disabled children, Tomkiewicz (1975) concluded that in some cases the child may itself become the source of satisfying these needs. The author points to the situation in which the disabled child provides its parents with the notion of responsibility for somebody else's well-being. A disabled child will never start the process of weakening the bond with its parents.

In their research on family situation, Magdalena Orlikowska and Iwona Bołtuć (2018) claim that roles performed by mothers and fathers of disabled children are conditioned by the culture the family lives in. The authors conclude that the role we play is determined by the environment and it governs our choices, these concerning raising a child as well. Hence, the cultural background of a family with an autistic child is of great importance for multiple research. Specialists recognise both positive and negative consequences of living in rural areas. On one hand, such a specificity of place of residence impedes family functioning and stress-management processes due to poor access to services dedicated for autistic children (negative consequence) (Obuchowska, 1991). Literary sources on the subject frequently highlight the fact that environments created by rural areas and small towns facilitate closer and more direct relationships between members of communities. Moreover, they are characterised by homogeneous views and interests (positive consequence). In such a context, the process of accepting the disability or disease of a child by adults and peers is easier. As far as big cities are concerned, the situation appears to be different due to the decreasing importance of establishing relationships with neighbours and scarce or no interest in other people's lives. Obviously, living in a large metropolis is also beneficial to some extent. Families from such backgrounds enjoy easier access to all kinds of specialists, rehabilitation and therapy facilities (Sekulowicz,

1994; Dudek, 2018). They have the opportunity to choose the best place for their child. Such a chance is practically taken away from those living in rural areas and small towns, as the number of facilities and specialists qualified to work with autistic children is limited.

Konstantareas (1991) concluded that parental stress depends upon a set of factors, such as: age, sex and birth order of an autistic child. Other variables of considerable importance include: number of siblings, ages of siblings, age difference between the disabled child and its healthy siblings, as well as other intervening variables.

Research results obtained by Kościelska (1995) prove that most of the students of life skills education facilities/groups come from incomplete families. The reason for such a situation was found in the fact that fathers tend to distance themselves from challenges posed by providing care for the disabled child. The author claims that escaping from problems is their reaction to them. Results obtained from my own research tend to contradict the previously established assumptions. Vast majority of examined families are complete and parents appear to share responsibilities concerning care and education of their children to the possible extent. The fact that other relatives, such as grandparents or aunts, live with the family is also of great importance (pointed out by Balcerzak-Paradowska, 2008 as well). It provides the parents with a chance to relax and rest as well as to pursue their professional careers. This dimension of parents' activity is also crucial, apart from circumstances connected to raising their children. It was researched by Barnett and Hyde, 2001, Marchall and Barnett, 1993. According to these authors, satisfactory and regular professional activity greatly influences the overall functioning of an adult. It fosters a more optimistic perception of reality and more successful handling of everyday problems (such as raising a disabled child). The obtained research results clearly indicate that although a half of the examined mothers claim that they are the primary caregiver for their autistic children, the majority of them work professionally.

Results obtained through our own research appear not to confirm previous assumptions concerning parents' education (e.g.: Karwowska, 2008), persons living in one household, employment and financial condition. The situation of the examined families exemplified the reality within certain environments throughout a specific period. Dynamic changes (political and economic) observed recently in Poland and all over the world may act both ways - as a factor improving or deteriorating the situation of parents with autistic children. Financial condition of a household is founded on the amount of financial resources and affluence, although a subjective evaluation of the overall financial condition is also of importance. The growing number of facilities and specialists qualified for supporting the development of autistic children and their families should also be considered crucial. The modern approach towards therapy and support for children with autistic spectrum disorder focuses on the increased activation and involvement of the parents. It is assumed that taking care of their physical and mental well-being is necessary for the effectiveness of the undertaken therapy.

Various authors (e.g.: Twardowski, 1991. Dudek, 2015)

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## СОЦІАЛЬНА СИТУАЦІЯ СІМЕЙ З ДІТЬМИ З АУТИСТИЧНИМ РОЗЛАДОМ

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Нетиповий характер розвитку дітей-аутистів надзвичайно ускладнює становище їхніх сімей. Дослідження, проведені з цього приводу, підтвердили, що батьки дітей-аутистів стикаються з різними проблемами, труднощами, напругою та стресом. Доступні літературні джерела висловлюють однакову думку – функціонування таких сімей, а також їхня здатність радити собі з проблемами догляду та освіти залежать від різних чинників. Це дослідження аналізує окремі соціально-економічні та культурні чинники, що впливають на те, як такі сім'ї долають труднощі, пов'язані з доглядом та навчанням дітей-аутистів. Політичні та економічні зміни, що спостерігаються впродовж останнього часу у Польщі та у всьому світі, можуть діяти в обох напрямках – як чинник, що покращує або погіршує становище батьків з дітьми-аутистами. Фінансовий стан домогосподарств заснований на обсязі фінансових ресурсів та достатку, хоча суб'єктивна оцінка загального фінансового стану також має важливе значення. Зростаючу кількість закладів та кваліфікованих спеціалістів із підтримки розвитку дітей-аутистів та їхніх сімей, також слід вважати вирішальною. Сучасний підхід до терапії та підтримки дітей з аутистичним розладом зосереджений на підвищеній активності та залученні батьків. Передбачається, що турбота про їхнє фізичне та психічне благополуччя необхідна для ефективності проведеної терапії.

*Ключові слова:* сім'я, аутизм, функціонування, проблеми, підтримка

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