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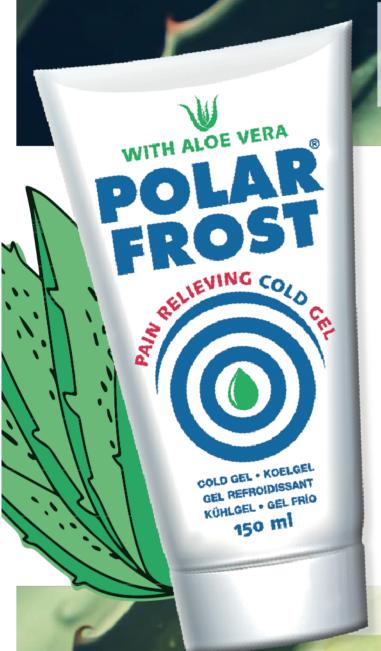
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The situation of mothers raising children with intellectual disabilities in relation to selected sociodemographic and clinical factors

Sytuacja matek wychowujących dzieci z niepełnosprawnością intelektualną w odniesieniu do wybranych czynników społeczno-demograficznych i klinicznych

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Abstract

Background. The diagnosis of a child's intellectual disability may trigger different emotions in parents, as a result of which the family may be strengthened, unified or weakened and destabilized. The aim of the study was to assess the situation of mothers raising children with disabilities depending on their age, living environment, education level and the degree of intellectual disability of the child.

Material and methods. The Chi-square test analyzed the results of 103 questionnaires from a diagnostic survey carried out in rehabilitation and educational facilities among mothers of children with intellectual disabilities.

Results. Statistically significant correlations between the age of mothers and the forms of education chosen for children (p = 0.021) and the type of extra classes (p = 0.015) were found. The level of education of mothers showed relationships with the type of sources of information about the specificity of child disorders (p = 0.043), and the degree of disability of the child with the frequency of receiving support from loved ones (p = 0.038), using institutional material help (p = 0.002), the type of factors that are most difficult to accept (p = 0.021), and feelings about the future of children (p = 0.002).

Conclusions. The mothers' age determines the forms of education and the type of extra-curricular activities. The living environment does not determine the situation of families raising a child with intellectual disability. The mothers' level of education determines the frequency of using sources of information about the specificity of a child's disorder. The degree of intellectual disability of a child determines the frequency with which mothers can count on the support of the loved ones, the frequency of using material assistance provided by institutions, as well as the most difficult to accept factors and feelings about the future.

Key words:

disability, support, acceptance, education

Streszczenie

Wstęp. Diagnoza niepełnosprawności intelektualnej dziecka może wyzwalać u rodziców różne emocje, w konsekwencji których rodzina może ulec wzmocnieniu i zjednoczeniu lub osłabieniu i destabilizacji. Cel pracy stanowiła ocena sytuacji matek wychowujących dzieci z niepełnosprawnością w zależności od ich wieku, środowiska zamieszkania, poziomu wykształcenia oraz stopnia niepełnosprawności intelektualnej dziecka.

Materiał i metody. Analizie testem chi-kwadrat poddano wyniki 103 ankiet pochodzących z sondażu diagnostycznego, wykonanego w placówkach rewalidacyjno-wychowawczych wśród matek dzieci z niepełnosprawnością intelektualną. Wyniki. Stwierdzono statystycznie istotne zależności między wiekiem matek a wybieranymi dla dzieci formami edukacji (p = 0,021) i rodzajem zajęć dodatkowych (p = 0,015). Poziom wykształcenia matek wykazywał zależności z rodzajem źródeł informacji o specyfice zaburzeń dziecka (p = 0,043), a stopień niepełnosprawności dziecka z częstością otrzymywania wsparcia od bliskich (p = 0,038), korzystania z instytucjonalnej pomocy materialnej (p = 0,002), rodzajem czynników, które najtrudniej zaakceptować (p = 0,021) i uczuciami na temat przyszłości dzieci (p = 0,002). Wnioski. Wiek matek determinuje formy edukacji i rodzaj zajęć dodatkowych. Środowisko zamieszkania nie warunkuje sytuacji rodzin wychowujących dziecko z niepełnosprawnością intelektualną. Poziom wykształcenia matek determinuje częstość korzystania ze źródeł informacji o specyfice zaburzeń dziecka. Stopień niepełnosprawności intelektualnej dziecka determinuje częstość, z jaką matki mogą liczyć na wsparcie bliskich, częstość korzystania z pomocy materialnej świadczonej przez instytucje, jak również najtrudniejsze do zaakceptowania czynniki oraz uczucia na temat przyszłości.

Słowa kluczowe:

niepełnosprawność, wsparcie, akceptacja, edukacja



Introduction

The issue of disability is broadly outlined in literature, however its definition is very contractual and cannot be clearly defined. The term 'disability' was first used in an official document in 1981, while in the native lexicography it appeared in 1994, in the 'Polish Dictionary' edited by Mieczysław Szymczak. The adjective 'disabled' stood there for failure to achieve full physical fitness due to mental impairment or handicaption [1]. According to the definition formulated by the World Health Organization, a disabled person is a person, whose significant damage and a decrease in the functioning of the body cause difficulties, prevention or limiting of the efficient functioning in society, taking into account such factors as age, gender and external factors [2]. Intellectual disability (mental retardation, mental impairment, oligophrenia) manifests itself during the developmental period and is characterized by a clearly lower intellectual ability than the average for a given age - which is associated with impaired ability to social functioning, and often also disorders of learning and maturing processes [3]. The degree of mental retardation is expressed in some sense quantitatively, using the Intelligence Quotient IQ and mental age. Adopting the established ranges of these parameters, the following degrees of mental retardation are distinguished: mild (IQ = 50-69; mental age: 9-12 years), moderate (IQ = 35-49; mental age: 6-9 years), severe (IQ = 20-34; mental age: 3-6 years), profound (IQ < 20; mental age below 3 years [4, 5].

Disabled children demonstrate various deficits, personality disorders, hyperactivity, emotional inhibition and therefore require special treatment in the field of upbringing and care. Each of them, regardless of degree or type of disability, needs understanding, support and love. Undoubtedly, this is facilitated by environment that welcomes them with willingness to help, openness and tolerance [6, 7].

Learning about a child's disability can be a source of change in various spheres of family life, and as a consequence trigger both positive and negative emotions. A child's disability creates difficult situations. Internal, emotional problems are accompanied by inconveniences related to child care, treatment and rehabilitation [8]. Handling parental tasks requires overcoming limitations, obstacles, social and architectural barriers, but also acquiring knowledge about developmental disorders and methods of therapy [9].

A child with a disability determines the family life, violates the current order and organizational peace, assigning each member new functions, tasks and responsibilities, which may disrupt parental and marital relationships [10]. Daily child care, as well as disability itself, can be stressors promoting burnout. Mothers are more exposed to this phenomenon than fathers because of their nursing, cleaning, caring and pedagogical activities [11].

Parental attitudes are repeatedly modeled by a social environment that can support or show indifference and lack of kindness. Such attitude may result from a widely promoted model of modern man who is successful, physically fit, educated and mobile [12]. Depending on the reaction of society, the family may be weakened and destabilized or, on the contrary, there may be an increase in internal cohesion and



an improvement in its organization [13]. Parents can adopt two types of attitudes: isolation, consisting of withdrawing from social life, limiting contact with the family, breaking up existing relationships and consequently internal isolation, or integrative, based on the quest for maintenance and expansion of social connections by joining the activities of the organization and associations for the disabled [9].

The parents' attitude towards the child's deficits, the range of their support and work on the child have an undoubted impact on the child's perception of itself and its own imperfections and the ability to adapt to the environment where they function. A disabled child besides specialist rehabilitation and therapy, needs a psychological presence of parents to be able to develop as much as possible. Therefore, close and good relationships with its parents provide it with a sense of security and emotional stability. In a normal family system, a disabled child can reveal and develop the potential of its capabilities and skills [14].

The aim of the study was to assess the situation of mothers raising children with disabilities depending on their age, living environment, education level and the degree of intellectual disability of the child.

Material and methods

Diagnostic survey performed in 2019 in revalidation and educational units in the Ropczyce-Sędziszow poviat involved mothers of children with intellectual disabilities. In total 130 questionnaires were distributed. The return rate was 95%, and after checking the completeness and correctness of the questionnaires, 103 forms were subjected to final analysis. Based on the obtained data, it was found that 21 mothers (20% of the group) raised children with mild degree of intellectual disability, 48 mothers of children with moderate disability (47% of the group), 28 mothers of children with severe disability (27% of the group), and children of 6 mothers (6% of the group) were diagnosed with profound intellectual disability. There were 56 women (54% of the group) in the 20-40 age range, and 47 women (46% of the group) in the 41-60 age range. Among the total number of respondents there were 63 respondents (61% of the group) living in the countryside and 40 residents (39% of the group) of the city. The greatest number of all respondents declared primary or vocational education (43 people - 42% of the group). 36 women (35% of the group) had secondary education and 24 respondents (23% of the group) had higher education. Most of the respondents formed a full family (83 respondents -81% of the group).

Declaration of 41 respondents (40% of the group) shows that a child's disability was diagnosed in the first year of life, 33 mothers (32% of the group) learned about their child's disability at the age of 2-3, 18 mothers (17% of the group) obtained diagnosis with a child at 4-5 years of life and 11 mothers (11% of the group) received such information above child's 6 year old.

We noted that 25 mothers (24% of the group) gave prenatal factors as the cause of the child's disability, 20 mothers (19% of the group) – perinatal factors, 16 mothers (16% of the



group) - postnatal factors while 42 women (41% of the group) did not have knowledge in this area.

For the analysis of results, a non-parametric Pearson Chisquare independence test (χ^2) was used, assuming the level of statistical significance $\alpha=0.05$. Statistical analysis was made in Statistica 13.1. program made by Stat Soft.

Results

Most of the subjects (78 mothers – 76% of the group) learned about the specificity of child's disorders from a doctor, for 20 parents (19% of the group) get information with this respect from a physical therapist, and for 5 parents (5% of the group) it was data from scientific publications. The frequency of using sources of information about the specificity of child's disorders depended neither on the age (χ^2 (2) = 1.49; p = 0.476) nor place of residence of the respondents (χ^2 (2) = 1.07; p = 0.585), or the degree of intellectual disability of the child (χ^2 (4) = 2.28; p = 0.685). This frequency depended on the level of education of the respondents (χ^2 (4) = 9.87; p = 0.043*). The surveyed women with primary or vocational education more often obtained information from a physiotherapist and mothers with a higher level of education more often received information from a doctor (tab. 1).

Table 1. Sources of information about the specificity of child's disorders obtained by mothers with different levels of education

Source of information	Primary o	vocational	Seco	ondary	Hiç	jher	Total		
	n	%	n	%	n	%	n	%	
Doctor	30	70.0	28	78.0	20	83.0	78	76.0	
Physiotherapist	13	30.0	4	11.0	3	13.0	20	19.0	
Scientific publications	0	0.0	4	11.0	1	4.0	5	5.0	
Total	43	100.0	36	100.0	24	100.0	103	100.0	

According to 36 respondents (35% of the group), the first response to news about a child's disability was fear of the future, and according to 25 mothers (24% of the group), the decision to rehabilitate the child. The respondents also indicated a feeling of shock and breakdown (18 people – 17% of the group), anger and regret (15 people - 15% of the group), and fear of social rejection (9 people - 9% of the group). These reactions did not depend on the age (χ^2 (4) = 4.94; p = 0.293), place of residence (χ^2 (4) = 3.59; p = 0.463), education of the respondents (χ^2 (8) = 8.88; p = 0.352) and the degree of intellectual disability of the child (χ^2 (8) = 10.14; p = 0.256). The majority, because 61 respondents (59% of the group) said that the material situation of the family after diagnosing the child's intellectual disability did not change, while according to 36 women (35% of the group) it worsened, and 6 improved 6% of the group). The subjective assessment of the material situation did not depend on the age (χ^2 (2) = 0.13; p = 0.938), place of residence (χ^2 (2) = 3.63; p = 0.162), level of education of the respondents (χ^2 (4) = 3.57; p = 0.467), as well as the degree of intellectual disability of their children (χ^2 (4) = 3.87; p = 0.423).



According to 61 respondents (59% of the group) mutual relations of parents after being diagnosed with a child's disability did not change, only 2 respondents (2% of the group) reported an improvement in this regard. In the opinion of 26 respondents (25% of the group) relations deteriorated, and 14 respondents (14% of the group) reported that the child's disability was the reason for the parents' decision to divorce. Parents' relationships did not depend on the age (χ^2 (3) = 7.26; p = 0.064), place of residence (χ^2 (3) = 6.16; p = 0.104), level of education of the respondents (χ^2 (6) = 7.14; p = 0.309) and the degree of intellectual disability of children (χ^2 (6) = 2.83; p = 0.830).

According to 49 respondents (48% of the group) after diagnosing a child's disability, conflict situations with the partner (the child's father) were more frequent. This frequency did not depend on the age (χ^2 (1) = 1.09; p = 0.295), place of residence (χ^2 (1) = 2.58; p = 0.108), level of education of the parents (χ^2 (2) = 4.52; p = 0.104), or the degree of intellectual disability of their children (χ^2 (2) = 0.67; p = 0.713).

As many as 78 respondents (76% of the group) said that they could count on the support of other family members. The frequency of this support did not depend on the age (χ^2 (1) = 2.74; p = 0.097), place of residence (χ^2 (1) = 0.37; p = 0.542), level of education of the respondents (χ^2 (2) = 2.81; p = 0.244), but depended on the degree of intellectual disability of their children (χ^2 (2) = 6.50; p = 0.038*). Data presented in tab. 2 indicate that the support of relatives was most often available to parents of children with mild mental disability, subsequently parents of children with severe or profound mental retardation and least often parents of children with moderate disability.

Table 2. Family support declared by mothers raising children with various degrees of intellectual disability

Anguar		Degree of intellectual disability of a child								
Answer	M	lild	Mod	lerate	Severe o	rprofound				
	n	%	n	%	n	%	n	%		
Yes	20	95.0	32	67.0	26	77.0	78	76.0		
No	1	5.0	16	33.0	8	23.0	25	24.0		
Total	21	100.0	48	100.0	34	100.0	103	100.0		

Answers of 41 respondents (40% of the group) indicate that the diagnosis of child's intellectual disability did not affect the deterioration of relationships with friends. A large part, because 37 people (36% of the group) declared the lack of time for social contacts. In turn, 16 respondents (15% of the group) lost many friends and 9 people (9% of the group) gained new friends, whom they can always count on. Relations with the social environment did not depend on the age (χ^2 (3) = 1.92; p = 0.589), place of residence (χ^2 (3) = 2.57; p = 0.463), level of education of the respondents (χ^2 (6) = 4.59; p = 0.596), or the degree of intellectual disability of their children (χ^2 (6) = 11.89; p = 0.064).



It was found that 61 respondents (60% of the group) knew other parents of children with disabilities, but did not have close contact with them. On the other hand, 23 women (22% of the group) did not know parents in a similar situation and only 19 women (18% of the group) had close contacts with such parents. Relationships with other parents did not depend on age, (χ^2 (2) = 2.61; p = 0.270), place of residence (χ^2 (2) = 0.31; p = 0.856), level of education of the respondents (χ^2 (4) = 2.89; p = 0.576), or the degree of intellectual disability of their children (χ^2 (4) = 4.44 p = 0.350).

Frequent signals about non-acceptance of a child by peers were received by 32 respondents (32% of the group), occasionally – 50 mothers (48% of the group), and 21 women (20% of the group) declared lack of signals about non-acceptance of peers. The declared frequency of receiving signals about non-acceptance of a child by peers did not depend on age (χ^2 (2) = 0.91; p = 0.634), place of residence (χ^2 (2) = 5.17; p = 0.075), level of education of the respondents (χ^2 (4) = 6.95; p = 0.138), or the degree of intellectual disability of their children (χ^2 (4) = 9.01; p = 0,061).

According to the respondents' opinions, reactions of the environment to the view of a child with intellectual disability were varied. According to the majority, the child was most often treated indifferently (32 people – 31% of the group). A dislike towards the child was noticed by 22 respondents (21% of the group), 20 mothers (19% of the group) met with unpleasant remarks, 15 women (15% of the group) felt interest of the child's problems in the surroundings, and 14 mothers (14% of the group) met with sympathy and help. Statements about the reaction of the environment to contact with a disabled child did not depend on the age (χ^2 (4) = 4.49; p = 0.342), place of residence (χ^2 (4) = 0.42; p = 0.981), level of education of the respondents (χ^2 (8) = 9.93; p = 0.269), as well as the degree of intellectual disability of their children (χ^2 (8) = 10.24; p = 0.248).

The responses of 38 women (37% of the group) indicated that it was the most difficult for them to accept the child's lack of independence, while 26 mothers (25% of the group) had difficulty accepting the child's behavior resulting from intellectual disability, and for 25 women (24% of the group) discomfort was the prospect of a lack of improvement in the child's functioning. In turn, 9 respondents (9% of the group) indicated a lack of understanding on the part of the environment, and 5 women (5% of the group) had a problem accepting low level of state welfare. The above answers did not depend on the age (χ^2 (4) = 5.45; p = 0.243), place of residence (χ^2 (4) = 2.35; p = 0.672) and level of education of the respondents (χ^2 (8) = 8.77; p = 0.362), but depended on the degree of intellectual disability of children (χ^2 (8) = 17.93; p = 0.021*). The lack of independence of the child and improvement in its functioning was more difficult to accept for mothers of children with a severe or profound degree of intellectual disability. Mothers of children with mild intellectual disability more often indicated the difficulty in accepting behaviors resulting from intellectual disability, as well as insufficient state welfare and misunderstanding by the environment (tab. 3).



Table 3. Factors that are most difficult to accept for mothers raising children with various degrees of intellectual disability

		Degree of i	Total					
Factor		Mild		Moderate		Severe or profound		, tui
	n	%	n	%	n	%	n	%
Characteristic behavior of a child resulting from intellectual disability	9	44.0	9	19.0	8	23.0	26	25.0
Lack of independence of the child	3	14.0	22	46.0	13	38.0	38	37.0
No improvement in the functioning of the child	3	14.0	10	21.0	12	36.0	25	24.0
Insufficient state welfare	3	14.0	2	4.0	0	0.0	5	5.0
Lack of understanding from the surroundings	3	14.0	5	10.0	1	3.0	9	9.0
Total	21	100.0	48	100.0	34	100.0	103	100.0

88 parents (85% of the group) benefited from material assistance provided by various state institutions. The fact that the respondents used material assistance provided by various institutions did not depend on their age (χ^2 (1) = 0.01; p = 0,931), place of residence (χ^2 (1) = 0.22; p = 0.636) and level of education of the respondents (χ^2 (2) = 3.77; p = 0.151), but depended on the degree of intellectual disability of children (χ^2 (2) = 12.22; p = 0.002*). Material assistance provided by state institutions was most often used by mothers of children with medium and severe or profound intellectual disability (tab. 4).

Table 4. The use of institutional material assistance by mothers raising children with various degrees of intellectual disability

Degree of intellectual disability of a child										
Answer	М	ild	Mod	Moderate Severe or pro		profound	10	Total		
	n	%	n	%	n	%	n	%		
Yes	13	62.0	45	94.0	30	88.0	88	85.0		
No	8	38.0	3	6.0	4	12.0	15	15.0		
Total	21	100.0	48	100.0	34	100.0	103	100.0		

Opinions on the amount of benefits offered by the state to cover the costs associated with child care and rehabilitation were divided. 47 women (46% of the group) found them



sufficient. 56 women (54% of the group) answered the opposite. The assessment of benefits offered by the state did not depend on age (χ^2 (3) = 1.86; p = 0.600), place of residence (χ^2 (3) = 6.72; p = 0.081), level of education of the respondents (χ^2 (6) = 5.28; p = 0.508), as well as the degree of intellectual disability of their children (χ^2 (6) = 3.48; p = 0.745).

The majority, that is 73 respondents (71% of the group) declared their child attend special schools, while children of 13 women (13% of the group) attended early intervention centers, children of 9 respondents (9% of the group) attended integrative schools, and 8 mothers (7% of the group) provided individual education to their child. The form of education used by the child did not depend on the place of residence (χ^2 (4) = 7.17; p = 0.127), the level of education of the respondents (χ^2 (8) = 11.03; p = 0,199) and the degree of intellectual disability of their children (χ^2 (8) = 8.92; p = 0.348), but it depended on the age $(\chi^2 (4) = 11.51; p = 0.021*)$. Children of the respondents between 41 and 60 years old more often attended special schools or received individual education, while mothers between 20 and 40 years old more often decided to take early support for child development at the Center for Early Intervention (tab. 5).

Table 5. Forms of child education selected by mothers in specific age ranges

	Mother's age range										
Form of education	ation 20–40 years			41–60 years	Total						
	n	%	n	%	n	%					
Special school	39	69.0	34	71.0	73	71.0					
Integrative school	5	9.0	4	9.0	9	9.0					
Early Intervention Center	9	17.0	4	9.0	13	13.0					
Individual education	3	5.0	5	11.0	8	7.0					
Total	56	100.0	47	100.0	103	100.0					

Only 13 women (12% of the group) definitely showed satisfaction with the results of their child's education, while 80 mothers (78% of the group) answered 'rather yes'. 10 mothers (10% of the group) expressed dissatisfaction. Satisfaction with the child's education outcomes did not depend on age (χ^2 (2) = 0.36; p = 0.835), place of residence (χ^2 (2) = 1.92; p = 0.381), level of education of the respondents (χ^2 (4) = 0.37; p = 0.984), as well as the degree of intellectual disability of their children (χ^2 (4) = 6.04; p = 0.195).

In response to the question about additional forms of therapy, 28 respondents (27% of the group) declared children attending classes in a psychological and pedagogical counseling center, 21 women (20% of the group) going to rehabilitation stay, while children of 15 respondents (15% of the group) went to early intervention centres and 7 mothers (7% of the group) declared that children additionally attended workshops of occupational therapy. A fairly large group of 32 respondents (31% respondents) replied that their children did not attend extra classes. The type of preferred additional activities did not depend on the place of residence (χ^2 (6) = 4.40; p = 0.622), the level of education of the respondents (χ^2 (12) = 11.59; p = 0.488),



as well as the degree of intellectual disability of children $(\chi^2 (12) = 12.12; p = 0.435)$, while it depended on the age of the mothers $(\chi^2 (6) = 15.63; p = 0.015*)$. Respondents in the 41-60 age range more often chose rehabilitation stays for their own children or did not use any additional activities. In turn, mothers aged 20-40 more often chose classes as part of early support of child development (tab. 6).

Table 6. Forms of additional classes provided to the child by the respondents qualified for individual age ranges

	Mother's age range									
Form of additional classes	20-	40 years	4	11–60 years	To	otal				
	n	%	n	%	n	%				
Occupational therapy workshops	13	23.0	11	23.0	24	23.0				
Classes in the center of daily stay	1	2.0	3	6.0	4	4.0				
Going for rehabilitation stays	9	16.0	12	26.0	21	20.0				
Classes in psychological and pedagogical counseling center	16	29.0	12	26.0	28	27.0				
Early support of child development	14	25.0	1	2.0	15	15.0				
The child does not attend extra activities	3	5.0	8	17.0	11	11.0				
Total	56	100.0	47	100.0	103	100.0				

It was found that 34 respondents (33% of the group) independently sought information on the possibility of obtaining support for a child, 22 mothers (21% of the group) obtained information from a physiotherapist, 20 mothers (19% of the group) consulted a psychologist,, while 14 respondents (14% of the group) – from parents of other children with intellectual disabilities, and 13 mothers (13% of the group) – from a pedagogue. Information sources did not depend on age (χ^2 (4) = 5.31; p = 0.256), place of residence (χ^2 (4) = 2.69; p = 0.609), level of education of the respondents (χ^2 (8) = 6.69; p = 0.569), as well as the degree of intellectual disability of their children (χ^2 (8) = 10.94; p = 0.204).

Feelings about the future of the child that accompanied the respondents included fear (42 mothers -41% of the group) and lack of faith in improving its functioning (18 mothers -17% of the group). It was found that 13 respondents (13% of the group) showed concern about the lack of independence and self-reliance of the child in adult life, 8 respondents (8% of the group) expressed concern about the lack of opportunities to



help the child in adult life due to the process of their own aging, as well as anxiety related to the child's dependence on third parties, in turn, 3 respondents (3% of the group) in the 'other' answer group showed fear that they would not live until the child reaches adulthood. Only 11 mothers (10% of the group) were optimistic about the future. Feelings about the future that accompanied the respondents did not depend on the age (χ^2 (6) = 2.92; p = 0.818), place of residence (χ^2 (6) = 5.95; p = 0.427), level of education of the respondents (χ^2 (12) = 10.53; p = 0.569), but were dependent on the degree of intellectual disability of their children (χ^2 (12) = 30.58; p = 0.002*). Mothers of children with severe or profound intellectual disabilities more often expressed concern about their future, while mothers of children with mild disabilities more often believed in improving the child's condition (tab. 7).

Table 7. Feelings in relation to the future, accompanying mothers raising children with various degrees of intellectual disability

	Degree of intellectual disability of a child							Total	
Kind of feeling	Mild		Moderate		Severe or profound		rotar		
	n	%	n	%	n	%	n	%	
Fear for the future of the child	8	35.0	17	35.0	17	49.0	42	41.0	
Lack of faith in improving the functioning of the child	6	32.0	10	22.0	2	6.0	18	17.0	
Fear of being unable to help a child in adult life due to their own aging process	0	0.0	4	8.0	4	12.0	8	8.0	
Fear of a lack of self-reliance and independence of the child in adult life	0	0.0	6	13.0	7	21.0	13	13.0	
Anxiety about a child's necessity to depend on other people	0	0.0	5	10.0	3	9.0	8	8.0	
Optymism	7	33.0	4	8.0	0	0.0	11	10.0	
Other	0	0.0	2	4.0	1	3.0	3	3.0	
Total	21	100.0	48	100.0	34	100.0	103	100.0	

Discussion

There are available studies in the literature on the quality of life of people with disabilities and their families. The authors express the opinion that a child's disability affects relationships with family and friends. Wędzińska [15] carried out the survey with the Profile of Mood States questionnaire



(PoMS) that involved 73 parents of children suffering from cerebral palsy. On the basis of that survey she concluded that significant, often exceeding their own capabilities, parents' involvement in caring for a child with a disability, as well as a sense of hopelessness and pessimistic assessment of the child's future may be the cause of conflicts and emotional problems in the family. Mothers, thanks to the nursing activities, establish a close relationship with the child easier, while fathers, who less often perform these functions, can detach from the family. According to Olcoń-Kubicka and Kubicki [16] parents and their disabled children often experience feelings of social exclusion, mainly as a result of a lack of professional activity or a lack of understanding by the environment of the specific situation related to caring for a disabled child. Wedzińska [15] emphasized that mothers of disabled children experience stress related to the awareness of child's development disorders, while fathers have problems with attachment to the offspring. Parents' age may affect the functioning of the family. People who become parents later find it easier to adapt to the situation arising from the child's illness, but as it grows up, they worry about the future if they pass away. People with higher education coped with stress better and were more open to the needs of the child. Our study demonstrated that after learning about child's disability, relationships with a partner did not change in most families, but the main reaction was fear of the future. Most of them still maintained good relationships with acquaintance after the birth of the child. The overwhelming number of mothers felt that in the wider social environment their children were treated indifferently and a half received signals that their children were not accepted by their peers.

Wiśniewska [17] emphasized the importance of material resources in the process of treatment and rehabilitation of a child with a disability. Rosińczuk et al. [13] on a basis of a diagnostic survey of 50 parents whose children suffered from cerebral palsy and attended the Special School Complex in Ostrów Wielkopolski noted economic problems associated with bearing high costs of treatment and rehabilitation. Parents with lower education declared a particularly unfavourable financial situation. Olcoń-Kubicka and Kubicki [16] prepared an analysis of the costs incurred by parents of children with disabilities. The authors used the results of research conducted as a part of the 'Everything Clear 2011' project, which consisted of 38 in-depth interviews with carers of the disabled and local government representatives. According to the authors, definitely the largest costs are related to child therapy and rehabilitation. In addition, parents must finance the cost of childcare when it is outside the care institution. In some cases, childcare does not allow one parent (more often a mother) to remain professionally active. Emotional costs are also extremely important, although the most difficult to measure. Daily care, organizing rehabilitation, fighting for proper education and respecting the rights of children with disabilities can contribute to the emotional burnout of parents. The authors also spotted alternative costs. They called them the cost of lost opportunities, because they result from the necessity to give up some areas of life to care for a child with a disability. According to Bakiera [18] raising and caring for a child with



a disability can sometimes exceed the adaptive abilities of parents, disrupting marital relationships and parental roles. Disability of a child can make it difficult or even impossible for a woman to achieve a maternal identity. Also, fathers feel loss, anger, guilt or frustration and it is more difficult for them to relieve the tension they experience. Our research found that after diagnosing a child's disability, the material situation of the family and relationships with the partner did not change for the majority.

Both the help of the immediate family and institutional assistance provided by the state are extremely important in raising a disabled child. On the basis of a diagnostic survey, Barłóg [19] noted that 95% of parents of children with intellectual disabilities expect various forms of support in the child's education and rehabilitation process and 67% of them admitted they received it. The vast majority declared help from their spouse, while the help of other family members was occasional and to a limited extent. The respondents highly rated institutional support, especially from psychological and pedagogical counseling centers and social assistance. Bishop et al. [20] based on a study of 110 mothers of children with autism spectrum disorder with the Child and Adolescenct Impact Assessment questionnaire (CAIA) and author's survey showed that low support from loved ones translated into a low assessment of the quality of the respondents' life. Lu et al. [21] came to similar conclusions as a result of research on the impact of selfesteem and support of loved ones on the quality of life of parents of children with autism spectrum disorder compared to parents of children without disabilities. The authors used the Parenting Stress Index - Short Form (PSI-SF), Multi-Dimensional Scale of Perceived Social Support (MSPSS), Satisfaction with Life Scale (SWLS). According to Olcoń-Kubickia and Kubicki [16], nursing benefits or rehabilitation relief are not always sufficient to cover the needs of the family. Therefore, some parents characterized by determination and consistency in action, use the support of non-governmental organizations or set up subaccounts for children, for which a 1% tax can be paid. In our research a high rate, especially the parents of children with mild disability, claimed they could count on family support. Most used material assistance provided by various institutions. The frequency of using the services increased in proportion to the child's disability. Almost half of the respondents considered these benefits to be sufficient or rather sufficient.

Mikołajczyk-Lerman [11] based on a survey of 601 parents of children with disabilities, found their poor contact with the environment. Meetings with other parents of disabled children were the most common forms of contact. Despite the fact that such acquaintances are an important form of family support, 15% of the respondents could count on information on caring for a disabled child from parents experiencing similar problems, and 10% of the respondents could count on obtaining knowledge in the field of specialist treatment from parents who were in a similar situation. Similarly, in our material, a small rate of parents of children with disabilities maintained contacts with families in a similar situation.

Mikołajczyk-Lerman [11] emphasized that parents of children with disabilities mainly struggle with problems such as poor



financial situation and the lack of child involvement in school activities. Włodarczyk and Sowa [22] recognized that one of the main problems of parents of children with disabilities is fear of the future associated with fear of the child's lot when its parents pass away. Also Iacolino et al. [23], on the basis of research with the Family Assessment Device (FAD) and Family Adaptability and Cohesion (FAC) questionnaires, found that parents of children with an autism spectrum disorder were more susceptible to stress compared to parents of children with physical disabilities and expressed greater concern about the child's lot after their death. In our study, the respondents on the one hand most often fear of the future and disbelieve in improving the child's functioning on the other while thinking about the child's future. The higher degree of intellectual disability of the child made mothers more worried about its future and was the reason for the weaker faith in improving its func-

Research by Rosińczuk et al. [13] showed that the needs of a family with a disabled child are specific and change as the child grows up. The authors noted that, according to parents of younger children, the most important need for a disabled child is diagnostics and implementation of an individual therapeutic programme, as well as financial support and assistance in childcare. In turn, parents of older children emphasized the importance of their education, proper preparation of teachers, as well as the existence of centers that can provide care in case of random events. Comparisons of the opinions of mothers of children with various degrees of intellectual disability in our studies showed that for mothers of children with a greater degree of disability, the lack of independence of the child and the lack of improvement in functional status were more difficult to accept. In turn, mothers raising children with a mild degree of mental retardation more often indicated the difficulty in accepting behaviour typical for this type of disorder, as well as little help from the state and misunderstanding on the part of the environment.

Therapy and education of children with disabilities requires comprehensive impacts on all spheres of their lives. It requires combining various methods to improve motor, psycho-pedagogical and various forms of social adaptation [24]. Ćwirynkało et al. [25] based on a study of 282 parents of disabled children using the Parental Attitude Scale, found that the pedagogical attitudes of parents of disabled children and their approach to rehabilitation are important for children's development. Respondents in Mikołajczyk-Lerman's study [11] noticed many inconveniences in the process of educating their own children, from a small number of facilities for the disabled, to a long wait for a visit to specialists, mainly speech therapists and psychologists. A significant problem was the lack of acceptance and the associated with loneliness of a disabled child at school. Fishman and Nickerson [26] study involving 137 parents of children with disabilities from primary schools in New York showed that parents with higher education were more often involved in the education of their own children and independently looked for various methods of supporting this education. In turn, parents with lower level of education mainly relied on the opinion of teachers. Cheng et al. [27], based on data from the National Household Education Survey, found that parents whose children



were taught at home showed greater satisfaction with the learning outcomes and support they received than parents whose children attended public or private schools, including those for students with special educational needs. The authors, taking into account the level of parents' satisfaction as one of the most important indicators of the quality of education, decided that parents teaching at home are not necessarily able to objectively assess the results of education. Grzelak et al. [28] stated that the proportion of students with disabilities attending integrative departments in Poland decreases as the level of school education increases. Parents' opinions about the schools where their children study were very good in the case of special and integrative schools and slightly worse in the case of public schools. Booth and Ainscow [29] came to the conclusion that effective educational activities require not only a teacher using various methods, but the involvement of the entire inclusive school. In turn, the results of Mitchell's [30] research carried out in Great Britain showed that the success of a teacher in inclusive education requires the use of many strategies, personalization of teaching style and involvement of the school community, including parents and supporting institutions. Parents of children with disabilities must overcome more obstacles than average parents in engaging in child's education. Our research showed that the form of education used by the child depended on the age of the parent. Mothers aged 20-40 more often decided to take early support for their child's development. Children of mothers between 41 and 60 years old more often attended special schools or were individually taught and optionally more often underwent rehabilitation stays or did not use any additional classes. Most mothers were satisfied or rather satisfied with the results of their children's education.

Our research and reports of other authors suggest that most parents were accompanied by fear of the future of a disabled child. A special difficulty was the need to combine caring and economic functions. Help from relatives was rated well, but institutional support, according to respondents should be higher. Therefore, families raising a child with a disability require comprehensive support in dealing with problems. Organizing support groups and creating opportunities for frequent contact of parents of children with disabilities among themselves would bring positive effects. Meetings of parents in a similar situation could serve to exchange views and mutual assistance in the child's education process, as well as motivating and encouraging them to take joint action to improve their development, and thus create opportunities for participation in social life at the possible optimal level.

Conclusions

- 1. The age of mothers determines the forms of education and the type of extra activities. Mothers aged 20-40 more often decided to take early support for their child's development. Children of mothers between the ages of 41 and 60 more often attended special schools or had individual education and optionally more often underwent rehabilitation stays or did not use any additional classes.
- 2. The place of residence does not determine the situation of families raising a child with intellectual disability.



- 3. The level of education of mothers determines the frequency of using sources of information about the specificity of a child's disorder. Mothers with primary or vocational education more often obtained information from a physiotherapist and women with higher education from a doctor.
- 4. The degree of intellectual disability of a child determines the frequency with which mothers can count on the support of loved ones, the frequency of using material assistance provided by institutions, as well as the most difficult to accept factors and feelings about the future. Mothers of children with mild disabilities most often received the support of loved ones. The material help provided by state institutions was most often used by mothers of children with moderate and severe or profound impairment. The lack of independence of the child and improvement in its functioning was more difficult to accept for mothers of children with severe or profound disabilities, while mothers of children with mild disabilities had a problem with the acceptance of their unusual behaviors, as well as insufficient state welfare and misunderstanding by the environment. Mothers of children with severe or profound disability more often expressed concern about their future and mothers of children with mild disability more often believed in improving the child's functioning.

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