SOCIAL SUPPORT NETWORKS FOR MOTHERS WHO RAISE INTELLECTUALLY **DISABLED CHILDREN**

SIECI SPOŁECZNEGO WSPARCIA MATEK WYCHOWUJĄCYCH DZIECI Z NIEPEŁNOSPRAWNOŚCIĄ INTELEKTUALNĄ

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Summary

Background. A social network is a group of people with whom a given person – the central person in the network – maintains contact. Social support networks for families raising an intellectually disabled child offer significant advantages for the functioning of family members: from providing help in performing everyday tasks, to sharing information, and offering emotional support.

Material and methods. The aim of the paper is to analyse the structure of social networks and the types and sources of support received by mothers raising intellectually disabled children. The study was based on quantitative methods. Bizon's Questionnaire of Social Surroundings (Kwestionariusz Otoczenia Społecznego) and a categorised interview were used. Each interview lasted about 2 hours. Fifteen mothers who raise intellectually disabled children have participated in the interviews.

Results. The social support networks of the mothers were usually comprised of more than 10 people. Close relatives and more distant family members act as the most important elements of social support networks for mothers who raise intellectually disabled children.

Conclusions. A multifaceted and complete spectrum of support was found in the mothers who participated in this study. The fact that the support systems are very centralised is alarming – if the main person leaves, the entire network of support might collapse.

Keywords: social support network, intellectual disability, child, mother of intellectually disabled child

Streszczenie

Wprowadzenie. Sieć społeczna to pewna liczba osób, z którymi dany człowiek – centralna osoba sieci – utrzymuje kontakt. Sieci społecznego wsparcia rodziny wychowującej dziecko z niepełnosprawnością intelektualną posiadają istotne korzyści w funkcjonowaniu członków rodziny, od pomocy w wykonywaniu codziennych czynności, po otrzymanie informacji, czy oparcie emocjonalne.

Materiał i metody. Celem pracy jest analiza badań własnych dotyczących struktury sieci społecznych oraz rodzajów i źródeł wsparcia otrzymywanego przez matki wychowujące dzieci z niepełnosprawnością intelektualną. Badania miały charakter jakościowy. Wykorzystano z mepernosprawnością miejektualną. Badania miały charakter jakościowy. Wykorzystano Kwestionariusz Otoczenia Społecznego Bizonia. Posłużono się wywiadem skategoryzowanym. Każdy wywiad trwał około 2 godzin. W wywiadach uczestniczyło 15 matek wychowujących dziecko z niepełnosprawnością intelektualną. Wyniki. W skład sieci wsparcia badanych matek wchodziło zazwyczaj ponad 10 osób. Najważniejszymi węzłami sieci wsparcia matek wychowujących dziecko z niepełnosprawnością intelektualną są grkonkowie bliżgraj i dologoj nadziany.

intelektualną są członkowie bliższej i dalszej rodziny.

Wnioski. W grupie badanych matek można wskazać na wielostronny i pełny zakres wsparcia. Niepokojący jest fakt zogniskowania systemów wsparcia – jeżeli osoby dominującej zabraknie może dojść do załamania systemu podtrzymania.

Słowa kluczowe: sieć społecznego wsparcia, niepełnosprawność intelektualna, dziecko, matka dziecka z niepełnosprawnością intelektualną

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Introduction

In Polish, social support (wsparcie społeczne) is usually treated as a synonym of providing help (udzielana komuś pomoc) [1]. McDowell and Newell indicate that support can be understood as providing a person who is experiencing some kind of difficulties with emotional, informational or material resources by other people that is, by that person's social network [2].

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Thoits perceives social support as a degree to which an individual's basic social needs (such as belonging and safety) are awarded by contact with others [3]. Janocha, indicating the popularity of this term, highlights the fact that it is defined in multifaceted ways by various scholars [4]. Social support can be understood as:

- the expected help that is available for an individual (or a group) in difficult, stressful, life-changing situations which the individual (or group) cannot manage on their own [5];
- the attitude that is based on being ready to bring help to those who need it in order to regain mental balance, or the attitude that is based on being ready to prevent situations that may lead to such a condition [6]:
- passing information that shapes an individual's sense of being respected, cared for and functioning as a member of a specific network of communications and mutual responsibilities [7];
- the resources provided by others that are helpful in coping with various situations, or the exchange of resources in the process of social interaction [8].

Taking into consideration the functioning of a family with a disabled child, and the fact that the appearance of a child who does not develop in a standard way is a difficult situation, I assume that support is a type of social interaction that has been initiated by one of a few individuals who participate in a difficult, problematic, stressful, or critical situation [8]. This approach can also be found in J. S. House's works (1981) – he treats social support as an interpersonal transaction, a type of interpersonal exchange [9].

There are various ways of supporting a family who raises a disabled child. According to Janocha, help can take the form of emotional, informational, or material support, as well as showing understanding, acceptance, and reassurance [4]. Social support may come from various sources. Singer and Lord indicated three categories of sources of support: personal, formal and professional. Friends, relatives, and acquaintances constitute the first one. The second one is made up of various organisations such as charities, institutions whose role is to provide help, social security, sports clubs, or church groups and communities. The third category is reserved for clinics that offer professional help and psychotherapy, as well as access to special, dedicated support groups [10].

According to Axer's definition, a social network is a certain number of people with whom a given person – the central person in the network – maintains contact [in: 11]. A social network is different from a small social group because not every member needs to know every other member [12].

The close relationship between an individual's social network and the support that is available to that individual is emphasised [2]. The existence of social networks is seen as a sufficient indicator of social support. A social network might be seen as "a structure or an arrangement, through which support is provided" [2].

In the case of a family group, the social network is made of the closest and more distant relatives, as well as non-related people whom the individual meets in various places and circumstances. For a given individual, all these people are important to various degrees. They are sources of both positive and negative stimuli; they provide support but they also add burden. This is why the terms "social network" and "social support network" should not be treated as synonyms – as we know, social interactions do not always influence an individual in a positive way [13].

Social support networks of families that raise a disabled child offer noticeable benefits in the context of the family members' functioning, from offering help in everyday chores to providing information that is valuable in terms of rehabilitation, treatment, or taking care of a disabled child [14]. Axer describes three views on social support offered by the environment to a disabled person: people who constitute the closest environment (their feelings, attitudes, and behaviours may have a positive influence), organisations offering support, and institutions that provide medical, social, and psychological help [12]. A. Maciarz discusses the support of a family raising a disabled child in its psycho-emotional aspect, in terms of social structures and services, in terms of care and upbringing and, finally, in terms of rehabilitation [15].

A family that raises a disabled child needs constant support – it is necessary not only when a diagnosis is presented. Social support facilitates the formation of an adequate image of a child's disability, adaptation, and the process of learning skills associated with care and rehabilitation. Social support networks also play an important role in the quality and effectiveness of education, rehabilitation and socialisation of a disabled child.

The aim of the study

The aim of the study was to analyse the structures of social networks, as well as the types and sources of the support that mothers who raise an intellectually disabled child receive. The main research problem was defined in the following question: what is the individual perception of their own support networks for mothers who raise a disabled child?

Material and methods

The description of the research method

The research was based on qualitative methods. A categorised interview has been employed. Bizoń's Questionnaire of Social Surroundings (Kwestionariusz Otoczenia Społecznego) was used – it was created in the 1980s. The tool is made of the following elements: the Map of Social Network (Mapa Otoczenia Społecznego), the List of Social Network (Lista Otoczenia Społecznego), and the Support System Record Sheet (Arkusz Zapisu Sytemu Oparcia). The second, revised version has been used – it is the one that is referred to as the research version (wersja badawcza) by the authors [16].

In order to determine who belongs to the category of a social support system for mothers of disabled children, eight fields were specified within the social environment: household members (1), closest relatives (2), other relatives and family members (3), colleagues (4), neighbours (5), other friends and acquaintances (6), therapists (7), other significant people (8). In the case of the first two groups, participants were encouraged to list all the people who meet the given criterion. In the case of the remaining groups – only those people who, for some reason, are more significant for the participant than others. These people are recorded by the participant on the Map of Social Network (Mapa Otoczenia Społecznego), which illustrates a social network in a graphic form.

The next stage is based on filling in the List of Social Network (Lista Otoczenia Społecznego) – using a questionnaire and the Map of Social Network. A participant responds to questions related to the length of their relationships with the aforementioned people and their intensity, as well as questions about the availability of those people.

Then, we use the Support System Record Sheet (Arkusz Zapisu Sytemu Oparcia). An interviewer records answers to questions related to the specific types of support. The aim is to distinguish people who fulfil specific supportive functions, and to eliminate those network members who do not offer any kind of support. These questions allow us to characterise the surroundings, the support system, and the supportive functions in detail.

Indexes used to characterise social support networks

The criteria for the evaluation of the supporting features of a support system are divided into the scope of support and the level of support.

- 1. The scope of support this is the number of a network's functions in a person's system; it does not depend on the number of people who fulfil a given function. We have:
 - A/Very narrow systems 1 to 2 functions
 - B/Narrow systems 3 to 4 functions
 - C/Average systems 5 to 8 functions
 - D/Broad systems 9 to 10 functions
- 2. The level of support expressed through the support system index.

The support level index (wskaźnik poziomu podtrzymania, wpp) – includes the number of a network's functions in a given system (the scope of support) and the degree to which a given function can be replaced by other sources; it is also sensitive to the differences in the significance of particular functions. The value of the support level index also depends on the deficits in the support system – i.e., it takes into consideration the importance of the functions that are missing in the support system.

The support level index is calculated as follows: functions with one source – 1 point, functions with two sources – 2 points, functions performed by 3 three or more sources – 3 points. In the case of a lack of functions, we deduct points according to the following rules: the lack of the function indicated in questions 7 and 10 – we deduct 3 points, the lack of the function indicated in questions 1 and 8 – we deduct 2 points, the lack of the function indicated in the remaining questions – we deduct 1 point. Thus, the value of the support level index ranges from -18 to +30 points.

The criteria for the evaluation of the features of a support system are also based on the size, components and structure of the system.

- 1. The size of a support system (the number of the support sources) this is the number of people who belong to the social environment of a participant and who perform supportive functions for the participant (at least one supportive function). We can have small (1 to 3 people), medium (4 to 10 people) and large systems (more than 11 people).
- 2. The components of a support system this is the description of the area of social environment, which is made up of people who act as sources of support. We differentiate between the following types of systems:

- family systems (areas I, II, III),
- non-family systems (all the other areas), including institutional ones (area VII).

In terms of the length of a relationship, we have old systems (those in which relationships with the majority of members are over 10 years old), intermediate systems (those in which the relationships with the majority of members are from 1 to 10 years old) and new systems (those in which the relationships with the majority of members began less than 1 year ago).

3. The structure of a support system is based on its homogeneity of heterogeneity, its concentration or dispersion, and the density of relationships within the system.

A homogenous system is the one in which sources come from a single area. A heterogenous system is the one in which sources come from at least three different areas of the surroundings.

A concentrated system is a system in which one person dominates all the other members in terms of the performed functions (i.e., that person performs at least 3 more functions than the others). In a dissipated system, all the members perform the same or a similar number of functions.

The description of the studied group

The research was conducted with the use of a categorised interview in a group of mothers who raise intellectually disabled children via nonprobability sampling, were the fundamental criterion was being a parent of a disabled school-age child. Some of the children were mildly disabled, others had medium-degree disabilities, and others were seriously disabled. The research was conducted among mothers whose children attended Zespół Szkół Specjalnych (Special School Complex) in Biała Podlaska in 2017 and 2018. Fifteen women participated in the study. Every interview lasted about 120 minutes.

The mothers' age ranged from 33 to 60 years. The majority was 40-50 years old (11 women), three were younger – 33, 33 and 29 years old – and the oldest participant was 60 years old. The majority finished a vocational school or less (6 graduated from a vocational school, 4 had primary education). Three finished high school, and two were university graduates. Seven of them were single mothers, they had been divorced and were often conflicted with their children's fathers. Two of the fathers had rejected their disabled children, the others did not really maintain contact with their children. Eight women lived in complete families and they indicated that they do have the support of their husbands or partners. Three mothers reported that when they had given birth to a disabled child, their closest relatives (in-laws, more distant relatives) avoided contact. Other women have not experienced such reactions from their family members, neighbours or friends.

The families lived in both blocks of flats (8 families) and houses (7 families). None of the mothers worked professionally.

In one case, the disabled child was the only child, in five families there were two children, in six families there were three children, one family had four children and one had five. In one of the families there were 14 children. In three of them, there were two intellectually disabled children, and in one there were twins. In total, there were 18 disabled children in these families. Ten of the children were severely disabled, five had medium-degree disabilities, and three were mildly disabled. Three children had to use a wheelchair apart from their intellectual disability, one boy had been diagnosed with autism, most of the children could perform everyday tasks on their own (15 children could perform everyday tasks unassisted, 3 needed help).

The youngest of the disabled children of the mothers who participated in the study was 6 years old, the oldest one was 22 years old. The children of the mothers do not have non-disabled friends at the moment, even though a few mothers indicated that the situation was different when the children were younger – when they were in kindergarten.

The mothers were asked about the most common difficulties that they experience in their everyday lives and in raising a disabled child. They could choose between: difficulties in providing health care and rehabilitation, difficulties related to education, architectural barriers, difficulties associated with that fact that other people treat a disabled person differently, and difficulties in obtaining information related to disabilities and disabled people's rights. Three women selected architectural barriers as problems, since their children use wheelchairs – one of them was a single mother raising a son. The most popular choice was the one related to difficulties in obtaining information related to disabilities and disabled people's rights – this point was selected 7 times. Three mothers mentioned negative social attitudes towards their intellectually disabled children, describing these situations as particularly difficult.

Summarising the description of the studied group, it should be noted that the mothers are usually not well-schooled, they live in both blocks of flats and detached houses, and they are either single mothers or they live in complete families. They do not work professionally – they take care of their children full-time. Their economic

situation and living conditions are average. Their children are of various ages and have various degrees of intellectual disabilities. The description proves that the mothers constitute a varied group, which is beneficial for the study.

Results

The type and the scope of support

Ten types of support were determined: appreciation/recognition, replacement (performing certain tasks for the mother), taking care of the mother's rest, support/protection, providing information, providing care, providing help with unexpected problems, comforting, offering a chance to confide in, and unconditional support – "they won't leave me when the situation is extremely bad" (results from 0 to 10).

In the selected group, one can see a multifaceted and complete scope of support. The social environment provided support in a broad scope for 11 mothers (9-10 functions; in detail: 7 mothers – 10 functions, 4 mothers – 9 functions). The remaining four participants indicated an average scope of support (5-8 functions; in detail: 1 mother – 6 functions, 2 women – 7 functions, 1 woman – 8 functions). None of the mothers indicated fewer than 5 functions of support. All of them indicated in their environment some people who express their **appreciation for and recognition of** what the mothers do, people who can **comfort** them when they are worried and cheer them up, people that they can **confide in** and tell them about their most personal worries and problems, and people who **will not leave them when the situation is extremely bad.** People who take care of the mothers' opportunity to rest were most often missing (there were no such people in the case of 5 of the mothers), just like people who would take care of the women themselves (in the case of 3 women), and people who would act as important sources of information about the world and people (in the case of 3 women). Two mothers indicated the lack of people they could depend on when support is needed, or when an important matter has to be taken care of (Table 1).

The mother who functions in the narrowest system (participant number 10) did not have anyone in her environment who would take care of her (function number 6), who would take care that she had a chance to rest (function 3), who would help her settle important matters (function 2), and on whom she could count in case of a serious problem (function 7).

Table 1. The scope of support for mothers of intellectually disabled children in relation to the type of social support; support level index (wskaźnik poziomu podtrzymania, wpp)

No.	Types of social support	Participant number														
	Types of social support		2	3	4	5	6	7	8	9	10	11	12	13	14	15
1	Appreciation/recognition	4	11	8	4	5	12	5	9	17	6	3	19	10	11	6
2	Replacement	0	2	3	3	4	3	2	2	3	1	2	1	3	3	2
3	Taking care of rest	0	2	0	2	1	1	1	2	3	0	0	0	1	3	3
4	Support/protection	1	11	3	3	5	5	2	1	3	0	0	1	3	3	1
5	Providing information	0	6	4	3	1	13	2	0	0	3	1	1	2	3	1
6	Providing care	1	2	3	2	3	2	1	2	7	0	0	0	0	2	1
7	Helping with unexpected problems	2	10	3	2	5	6	2	3	7	0	3	1	3	3	3
8	Comforting	2	9	2	4	5	6	1	3	1	2	1	8	1	2	2
9	Confiding in someone	2	10	1	3	1	2	1	5	7	2	1	2	1	2	2
10	Unconditional support "they won't leave me when the situation is extremely bad"	2	5	3	3	5	2	1	7	7	1	4	1	2	2	4
	Support level index (wpp)	10	28	23	27	24	25	16	21	24	6	11	11	18	26	21

The level of support

The size of a support system depends on the number of people that the mothers can count on within the various types of support.

The size of a support system is measured by the support level index (wskaźnik poziomu podtrzymania, wpp), which ranges from -18 to +30. In the selected group of mothers who raise intellectually disabled children, the value of the wpp index ranged from 6 to 28. There were no values below zero, which is a positive trait. For the

majority of the studied women, the value of the index exceeded 20 (9 mothers), for one the value was below 10, and the others had a support level index (wpp) of 10, 11 (two mothers), 16, and 18 (Table 1).

If a given function is performed by only one person, then the person is practically irreplaceable. If that person leaves the system (e.g., due to an illness or travelling), the mother loses support in the given category. In the case of 12 mothers, there was an irreplaceable person (Table 1). Most of these cases were noted in the area of the following types of social support: taking care of the mother's rest, offering a chance to confide in, and comforting. The functions in which someone could be replaced (doubled functions) belonged to one category of social support: recognition/appreciation (Table 1).

The size of the support system

The size of the support system is understood as the number of people in the participant's environment that perform supportive functions for the participant. These are the people on whom the mothers can count in various situations.

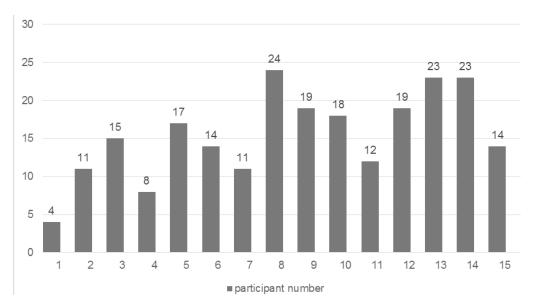


Figure 1. Number of people in mothers' social support networks

The number of people in a system ranges from 4 to 24. Most of the systems included more than 10 people (in the case of 13 mothers) (Figure 1).

In the studied group of mothers who raise disabled children, one could notice medium-sized systems (4 to 10 people), and large ones (more than 10 people). Large systems were the dominant type: 13 mothers functioned in this kind of a network, while two had medium-sized networks. Small systems (ones that include fewer than 3 people) were not recorded (Figure 1).

Participant no. 1 had the smallest social support network (4 people). This can be explained by her personal experiences. She has been raised in an orphanage and did not have a family of origin, and the disabled child's father does not maintain contact with the family. The mother has also struggled with alcohol addiction. The largest support system (for participant no. 8) included 24 people. The mother has five children who have their own families (all of them, apart from the intellectually disabled son). The other children accept their disabled brother. The mother is an active, open person. An article that she wrote has been published in the "Bardziej Kochani" quarterly, and she is the chair of the Parents' Council in Zespół Szkół Specjalnych in Biała Podlaska.

The components of a support network

The components of a support system are the detailed features of the social environment to which the people who provide support belong.

	11 5	-																
No.	Support systems	Total		Participant number														
		n	%	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
	FAMILY:	130	56															
1	Household members	47	20,3	1	5	2	2	2	1	2	2	4	5	4	4	6	4	3
2	Closest relatives	56	24,1			3	3	4	3	4	9	4	3	3	4	3	7	6
3	Other relatives and family members	27	11,6			5		3	2		3	4		3	2	2	3	
	OUTSIDE OF THE FAMILY:	102	44															
4	Colleagues	0	0															
5	Neighbours	22	9,5			1	1	4	2		3	3	1		2	3	1	1
6	Other friends and acquaintances	30	12,9	1	2	1	1	1	4	1	2		5	1	2	4	3	2
7	INSTITUTIONAL: Therapists, teachers	48	20,7	2	3	3	1	3	2	3	5	4	4	1	5	5	5	2
8	Other significant people	2	0,9		1					1								
	Total	232	100	4	11	15	8	17	14	11	24	19	18	12	19	23	23	14

Table 2. Areas in the support system of mothers who raise intellectually disabled children

In a support system, the closest relatives and more distant family members function as the sources of support most often. In terms of composition, family members constitute 56% of the entire support system for mothers in comparison to all the other areas. Interviews prove that contacts with the closest relatives were initiated directly or via phone calls every day or at least a few times each week. When it comes to more distant relatives ("other relatives and family members") these contacts were not as frequent, and they usually took the form of phone calls or online messaging – they were not direct as often as those initiated with the closest family members. Institutions dominated the fields outside of family: they constitute 20.7% of entire systems. Mothers mentioned lead teachers and teachers who specialise in oligophrenopedagogy. Moreover, they indicated speech therapists, physiotherapists, psychologists, the headmaster, and the school's club room teacher. The mothers usually contacted these people directly, and in many cases the contact took place everyday. In the case of specialists – it was two times a week, and in the case of the headmaster – only when there was a specific need. The next group of people that mothers can rely on are friends and acquaintances. Other mothers of disabled children were mentioned most often in this context (Table 2).

The majority of relations in the mothers' support systems have lasted for more than 10 years (old systems), and this refers to family members, teachers, and therapists, as well as neighbours and acquaintances. Hence, we see an indicator of prominent preservation and continuity of a support system, as well as its low elasticity or openness, understood as the ability to include new people who could act as sources of support.

The people indicated by the mothers are usually easily available. But is should be noted that some of the women experience difficulties in maintaining contact with their disabled children's fathers (5 cases of divorce, one of the fathers passed away) and sometimes with their in-laws, too.

The structure of a support system

The structure of a support system is based on its homogeneity of heterogeneity. A homogeneous system is one in which all the sources of support come from one area. In a heterogeneous system, sources come from at least three different areas of the environment. The closest relatives and more distant family members should be treated as one area, while non-relatives who live together with the respondents should be treated as a separate category – no such situation occurred among the participants. The people who support the mothers come from at least three different types of groups, so these support systems might be described as heterogeneous. In one case (respondent no. 1) the supportive people came from only three areas (Table 2).

Defining the degree of concentration or dispersion of a system was the next task. A concentrated system is a system in which there is one major source of support – i.e., one person fulfils a large number of supportive functions (they perform at least 3 functions more than the other members). In a dispersed system, various types of supportive functions are distributed among various members.

By analysing the degree of concentration or dispersion of a support system for mothers who raise disabled children, one can propose two theses: the first one says that the character of the degree of concentration varies; the second one says that it depends on the mother's marital situation. Six of the systems were dispersed – these were the mothers' families which were not complete. Nine of the mothers functioned in concentrated systems: in six cases, only one person dominated over others in terms of performed functions – the systems were extremely

concentrated. That person was usually a husband/partner, or a mother (the child's grandmother), and one woman indicated her older son. In the remaining concentrated systems, two people were dominant (a daughter and a sister, a husband a mother – the child's grandmother – a husband and an older sibling).

The danger of concentrating the majority of supportive functions in one person is based on the fact that a respondent is much more prone to a loss or a disruption of the entire system of social support.

Discussion

While comparing families who raise a non-disabled and a disabled child, we notice a higher degree of dysfunctional elements and the need for support in the case of the families who raise a disabled child. Significant differences can be observed in the areas of adjustment, partnership, development, tenderness, determination, the coherence of a family, support, organisation, and communication [17].

The findings reported here are in line with Wrona's conclusions – she used the same research tool (Bizoń's Kwestionariusz Otoczenia Społecznego – Questionnaire of Social Surroundings). 25 parents who raise disabled children and live in śląskie voivodeship participated in the research. The findings showed that the respondents' own families constituted the foundations of all the networks, and functioned as the most important factors of support. In S. Wrona's analysis teachers and specialists constitute the second most numerous group in terms of connections, which is similar in the case of the present study [14].

Seybold, Fritz, and Macphee arrived at similar conclusions based on interviewing 163 mothers of intellectually disabled children. The mothers declared that they receive more instrumental and emotional help from informal networks than from formal ones. The degree of satisfaction related to the support was related to a mother's sense of her own parenting competence and her ability to overcome the numerous demands that a mother of a disabled child experiences. As a result, the authors propose to use informal support networks while working with a family. Mothers who received higher education and those living in complete families were coping better – they were more often able to use instrumental support [18].

Ćwirynkało and Żywanowska analysed the types of support that families who raise intellectually disabled children receive. They analysed 20 families in which there were children with mild, medium-degree and severe intellectual disabilities. The authors indicted that 81% of families use social support. 19% of the parents reported that they have no access to support – especially in small towns and in rural areas. Kindergartens, schools, healthcare institutions, and early intervention centres, as well as psychological and pedagogical clinics were listed as those institutions that provide support most often. Support offered to the children in the form of classes included speech therapy classes, psychological sessions, and pedagogical meetings. The parents emphasised the value or Parent's Associations (Koła Rodziców) – self-help groups that share information and offer mutual support. It seems that institutional organisations such as clinics focus on diagnoses and opinions, while they do not pay enough attention to other forms of support such as therapy for the whole families, the children, or the parents [19].

The help provided for families raising a child with a mild intellectual disability was analysed by Kazanowski and Byra. A community interview that they conducted using their own original questionnaire was focused on families whose children attend vocational schools. The authors found the results disturbing. More than 40% of the families believed that their children did not need special psychological and pedagogical help, and the parents' expectations in terms of help were focused on material aid -40% – and financial aid -20% [20].

Many academics emphasise the correlation between a high level of social support and a lowered level of stress associated with the necessity of taking care of a disabled child. They also focus on the degree of the received support, and the intensity of satisfaction; they take the size of a support network into consideration, as well as the type of the support provided, making these variables dependent on the type and the degree of a child's disability [21].

Crnic and colleagues used an approach based on development and working with the entire family was emphasised. A methodically planned training for parents will lower the degree of their stress and it will generate indirect benefits for the behavioural competence of the children [22].

In a later study based on analysing the situation of 50 families with disabled children, it was determined that a complete family – and especially healthy relations between the parents, and the parents' personal resources (such as the willingness to take risks and openness) – influences the quality of the family's life and helps all the family members in coping with stress [23].

In 2011, Silibello et al. used a questionnaire to study 154 families. The study defined the needs and changes that occur in the everyday lives of families that include children suffering from rare diseases of various degrees of severity – including intellectual disabilities. Deficiencies in social support systems – particularly in relations

within families – were found. The need to focus on the family and improving the quality of its members' lives was highlighted [24].

Conclusions

- 1. In the group of the studied mothers, one can indicate a multifaceted and complete scope of support. The social surrounding provided 11 mothers with a support characterised by a broad scope: 9-10 functions (out of 10 in total).
- 2. All the mothers indicated in their environments people who express appreciation for what they do, who can comfort them and cheer them up, who can be confided in, and who will not abandon the mothers in an extremely bad situation.
- 3. The support systems usually lacked people who would take care of a mother's opportunity to rest, who would take care of the mothers themselves, and who would provide information about the world and people.
- 4. The environments of 12 of the mothers included irreplaceable functions (ones that were fulfilled by just one person). The disappearance of this person from a mother's social surroundings will result in the lack of this kind of support. This situation was found in the following areas: taking care of rest, confining in, comforting.
- 5. The mothers' support systems usually included more than 10 people. One of the participants listed 24 people belonging to her network, while two respondents indicated only 4 and 8 people who have ever provided them with help.
- 6. The members of the closest and more distant family act as the most important elements of the support systems of mothers who raise intellectually disabled children.
- 7. The fact that teachers who specialise in oligophrenopedagogy are the second most important group should be treated as a positive factor they support the children's upbringing and education. These people have very good relations with the mothers, and the contact between them is frequent and direct. The cooperation between parents and teachers is very important in the context of effectively raising and teaching intellectually disabled children.
- 8. Friendships between mothers whose children attend the special school are a strong suit of the systems. Not only do these interactions provide information, but they also offer mutual support, specific forms of help (writing and submitting applications and requests) and, as the mothers said, they also help because they allow the mothers to spend time together outside of school which is where they usually meet.
- 9. The studied systems of social support were usually concentrated. The concentration of a support system for mothers seem to be significant in the context of prognoses. If the dominant person disappears, the entire system may collapse.

The family as well as specialists still continue to function as irreplaceable sources of support for mothers who raise intellectually disabled children, and this support helps them in overcoming difficult situations. The fact that the systems of support are so concentrated is worrying, just like the lack of such people in the systems who would take care of the mothers' opportunity to rest for shorter or longer periods of time.

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