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The demand versus support received by parents of disabled children exemplified by local activities in integrated primary school

Abstract

The aim of the study is to determine a space and process of support for parents of children with disabilities, as well as an indication of the neglected areas in the organization of early intervention in Poland. The characteristics of this space relates primarily to the place and role of people taking an active part in the process of support: parents and therapists and their relationship with a disabled child. Considerations revolve around descriptions of various models of assistance provided to families in the process of early intervention.

Keywords: early intervention, family, disability, support.

Poczucie wsparcia otrzymywanego a oczekiwanego przez rodziców dzieci niepełnosprawnych na przykładzie działań lokalnych w szkole podstawowej

Abstrakt

Celem opracowania jest określenie przestrzeni i przebiegu procesu wsparcia rodziców małych dzieci niepełnosprawnych, a także wskazanie obszarów zaniedbanych w organizacji wczesnej interwencji w Polsce. Charakterystyka owej przestrzeni dotyczy przede wszystkim miejsca i roli osób biorących czynny udział w procesie wsparcia: rodziców i terapeutów i ich relacji z niepełnosprawnym dzieckiem. Rozważania oscylują wokół opisów różnorodnych modeli pomocy dostarczanej rodzinom w procesie wczesnej interwencji.

Słowa kluczowe: wczesna interwencja, rodzina, niepełnosprawność, wsparcie.

Establishing cooperation with parents is a difficult and complicated process with which contemporary schools are faced. Specifying aims, ranges and implemented tasks with parental participation allows for better understanding of educational and care processes taking place within the walls of an educational institution. This is also significant for preventive and diagnostic activities concerning possible problems of learners and their families. Parents decide about the shape of their children's education right from the beginning by choosing a kindergarten and school for them. With no doubt, the situation of a disabled child's parents is different due to specific daily life problems resulting from disability. Numerous works on this issue explore the most frequent problems, which can be classified in four groups: mental, emotional, and spiritual problems (M.J. Friehe, A. Bloedow, S. Hesse, 2003, p. 11). How the parent will handle overcoming difficult situations depends on many factors. It seems that the most important determinant is the quality of the provided support and the related ability to accept it. There are frequent situations in which too much stress does not allow for accepting aid activities. What is presented in this study are the results of the research into the processes of support for parents of disabled children in one of integrated primary schools in Cieszyn. This is an attempt at juxtaposing the demand for such support with the actually received support within the school staff's activity. The main goal is to find out whether there is any discord between parental expectations and the school offer for them. The research has the nature of pilot studies and the obtained results cannot become the foundation for any attempts at generalization. The research only indicates hypothetical directions for further studies aimed at improving the quality of joint activities of school and parents of disabled children.

The process of support and the activities of schools

Support is always associated with the situation in which someone in a significantly worse situation needs help. The other indispensable element of support is the presence of at least two people because it is provided for one person by another. Obviously, support can concern groups of people both on the receiving and offering side. It can be stated that processes of support are grounded in certain social groups. Thus, support refers to many aspects of social relations and is defined in reference to e.g. the number of social bonds, their type, structure, aims of activities (B. Lelonek, E. Kamusińska 2011, p. 36). Support can be defined as "a type of social interaction which is undertaken by one or both participants of a problem, difficult, stressful or critical situation" (H. Sęk, 2005, p. 18). What takes place during this encounter is the transmission and exchange of information, emotions or material goods. In order to make this exchange efficient, the sine qua non is an appropriately kept propor-

tion between the type and size of the provided support and the recipient's needs. Only a properly specified and maintained relation between giving and taking will enable the effectiveness of actions and will prevent dependence on support.

According to Ch. H. Tardy (1985, pp.187–202), several aspects should be taken into account in order to understand support better:

direction – the position of either the giver or recipient of support;

disposition – defined as actual use of the available support resources; the availability of support will be understood as the amount and quality of support to which people have access;

evaluation and description – evaluation is specified by people's satisfaction from the received support, whereas description only indicates what kind of support is being dealt with;

contents – the type of support or what a person receives, e.g. money, verbal consolation, information, etc.

network – specifying who and in what number and structure provides support as well as what its sources are.

Analyzing the support provided by school for parents of disabled children in compliance with the above mentioned information, it seems worth consideration how educational and care tasks addressed to parents correspond with the activities directed to cooperation and support for parents, first of all – parents of disabled learners. Another important issue is the effectiveness of support, which is mostly determined by its adequacy – most often in the teacher's proper choice of the provided support for the parent.

Nowadays, both media and particular ministries emphasize the significance of family and its cooperation with various institutions and of supporting parents in the process of their children's education¹. The detailed rules and fields of support for parents are comprised in the Directive of the Ministry of National Education of 30th April 2013 on the principles of providing and organizing psychological-pedagogical support in public kindergartens, schools and institutions (Journal of Laws 2013, item 532). In particular, this support should consist in aiding parents and teachers in their activities aimed at solving didactic and educational problems as well as in developing their educational skills. The aid addressed to learners in a particular institution needs to co-occur with participation of parents. They should be informed about the forms, periods and ranges of the provided support. Legal guardians can also initiate aid activities. Support can be provided through advice, consulting, workshops

¹ Introduced by the Ministry of National Education on 17th November 2010, the set of directives concerning the organization of education and psychological-pedagogical support in kindergartens, schools and institutions (Journal of Laws 2010, No 228, item 1487-1994) can be found among legal acts of the Ministry with later changes (Journal of Laws 2013, item 532, Journal of Laws 2013, item 199, Journal of Laws 2013, item 532).

or training. What becomes a new quality of (understood in this way) organizational model of psychological-pedagogical support is the principle that it ought to be organized, among other things, nearer the parents – treating them as the best specialists in dealing with their children (J.R. Łuniewska, p. 8).

Regardless the legal regulations, good support should bring measurable benefits to the supported person. Support should be treated as a specific relation of a person with the environment, indirectly determining the optimal regulation of behavior in difficult situations, such as upbringing, care and education of a disabled child (Bartosz, 1992, p. 46). Support for parents of disabled children, understood in this way, may result e.g. in raising their parental competences and resourcefulness in situations associated with difficult behavior or in better organization of additional educational aid. It is essential that the activities of the supporting (teachers) should directly result from the needs of the recipients of support – parents of disabled children. In the process of efficiently developed and applied support in overcoming problems, B. Bartosz (*ibid.*) distinguishes several stages based on the analysis of three groups of factors (personal, situational, relational – person – problem):

the first stage – reinterpretation of the meaning of an event, which takes place as a consequence of a supporting relation; a particular problem situation is presented from the perspective of the supporting person. This should result in a new interpretation of one's own difficult situation and in realizing that it may happen to other people. Such re-formulation along with a different perspective on the approach to the problem will enable searching for possible solutions. This process depends on the quality of the supporting relation, personal traits of the supporting and the supported and the type of the problem. The major task is maintaining the support for a person handling a difficult situation;

the second stage – mobilization, which is based on the reconstructed (in the previous stage) potential of the supported person. The superior task here is to undertake activities aimed at the cognitive-rational analysis of the problem. This analysis is manifested in the search for information, ways of managing in life, re-valuing the superior aims. What takes place at this stage is another reintegration of the ways of active managing in a difficult situation. As in the first stage, this process depends on the same personal, situational and relational factors. Support at this stage has mobilizing qualities for the person in a difficult situation;

the third stage – autonomic activities, which appear here and are aimed at restoring or improving the level of previous functioning. These activities are undertaken by a supported person, who should be prepared for solving problems through the conduct in previous stages. It is of due significance that the responsibility is on the part of the supported person and that temporary responsibility of the supporting person should be gradually terminated.

In the school context, the process of support may take place without clear distinction of the discussed stages due to the specificity in the functioning

of educational institutions, which mostly focus on the educational process. However, the situations requiring psychological-pedagogical support for parents should be based on an appropriate diagnostic process (specifying support areas), followed by the choice of proper forms of support and then by the process of actual acting. Disregarding these three major stages might result in undertaking inappropriate steps – and therefore in their weak effectiveness. Such activities frequently become fiction which is only present in a written form in school documents.

Methodology of own studies

The conducted pilot study has been aimed at the analysis of both the demand and providing support for parents of disabled children in the course of education in primary school. The main research problem has been comprised in the following question: Is there a dissonance (What dissonance is there) between the support received by parents of disabled children and the one provided by teachers?

The pilot study has been conducted with the application of categorized interview among a group of parents with disabled children by means of purposive sampling, where the basic criterion was possessing a disabled child or a child with developmental disorder. As the research has comprised parents of children with different types and intensity of disability, the studies could only allow for some selected generalizations on a particular level – common problems of families with a disabled child and the support received due to this. The obtained data indicate merely a certain tendency concerning the experienced social support and may be used for potential amendments in particular institutions.

The study has involved 24 parents of disabled children and 19 teachers from an integrated primary school in Cieszyn.

The applied research tool has been Schwarzer and Schultz's Berlin Social Support Scales (BSSS) in its Polish adaptation (Łuszczynska, Kowalska, Mazurkiewicz and Schwarzer, 2006, pp. 17–27). BSSS measures cognitive and behavioural dimensions of social support and consists of five independent scales (Schulz, U., Schwarzer, R. 2003, pp.73–82). They are the following:

- I – perceived available support (8 questions),
- II – need for support (4 questions),
- III – support seeking (5 questions),
- IV – received support (15 questions),
- V – protective buffering support.

The subscales I and V enable evaluation of emotional and informational support. The questions concerning instrumental support and satisfaction from

the received support are comprised in subscale IV. Answers are provided on the four-point evaluation scale. The result of each subscale is specified in the range of 1–4 points, where 1 stands for a totally false statement and 4 for a totally true one. The higher the number of obtained points is the bigger social support is identified.

Research results

While evaluating the structure and functioning of support for parents with disabled children in primary school, the particular subcategories of the scale (Table 1) were subjected to analysis as the first ones. What is important here is confirming the fact itself that the process of supporting parents of disabled children exists and that teachers are aware of aid activities addressed to these parents. Only confirming such coexistence allows for more detailed analyses, also concerning satisfaction, its evaluation or availability as well as openness to the conducted activities.

In talks with respondents – both parents and teachers – the existence of the phenomenon of support was confirmed clearly. Teachers along with school authorities are aware of the provided aid and its significance for parents. Yet, parents have the awareness of support provided by school. This is confirmed by the results presented in Table 1 – especially scale I, which concerns perceived available support and in which they are the highest (mean: 3.3).

Table 1. Results obtained by parents in particular subscales

Support scales	N* – numer of parents	Minimum	Maximum	Mean	Standard deviation
I. perceived available support	24	1.63	4.00	3.3	0.66
II. need for support	24	1.75	4.00	2.9	0.67
III. support seeking	24	1.00	4.00	3.0	0.79
IV. actually received support	22	2.00	4.00	3.0	0.60
V. protective buffering support	22	1.00	3.17	1.9	0.70

* 24 parents were examined, however 2 of them filled only the first three scales.

What draws attention is the fact that parents of disabled children manifest an active attitude and they search for support on their own as well. It is confirmed by the mean equalling 3 in the subscale of support seeking. This involves seeking advice, consolation, talking and other examples of direct asking for help. In order to specify which way prevails in parents' search for support,

percentage ranges have been calculated for particular questions. The obtained results are presented in Table 2.

Table 2. Support seeking scale

Questions in the support seeking scale	Totally false		True to a small extent		True to a moderate extent		Totally true	
	%	number of responses	%	number of responses	%	number of responses	%	number of responses
In critical situations, I prefer to ask others for their advice	8.3%	2	20.8%	5	29.2%	7	41.7%	10
Whenever I am down, I look for someone to cheer me up again	12.0%	3	20.0%	5	44.0%	11	24.0%	6
When I am worried, I reach out to someone to talk to	4.0%	1	16%	4	40.0%	11	40.0%	10
If I do not know how to handle a situation, I ask others what they would do	8.3%	2	8.3%	2	33.3%	8	50.0%	12
Whenever I need help, I ask for it	4.2%	1	16.7%	4	50.0%	12	29.2%	7

The presented results unambiguously show that parents of disabled children seek support in difficult situations mostly through talking and exploring good practices used by other people. This might result from different evaluations of their effectiveness while searching for support in difficult situations and from their individual personality traits.

The analyzed results do not change the fact that the obtained general means in particular subscales are very similar. Only the data obtained in the analysis of the subscale concerning protective buffering support differ slightly when compared to other results. As it has been highlighted earlier, what becomes an important element in an attempt at describing support activities is the convergence of activities of the two groups: the recipients and the givers of aid activities. As the last two subscale parameters will contribute to the description of hypothetical dissonance between the support received by parents of disabled children and the support provided by teachers, it is necessary to analyze particular constituents of the subscales (Table 3).

Table 3. Results obtained by teachers in particular subscales

Support scales	Minimum	Maximum	Mean	Standard deviation
Actually received support	1.86	3.93	3.4	0.44
Protective buffering support	1.33	3.67	2.6	0.78

Having compared the results presented in Table 3, what comes into focus is the point difference between the analyzed subscales. A significantly higher mean of the obtained points is typical of the support provided by teachers. However, it should be made clear that particular single sentences subjected to teachers' evaluation are associated with sincerity in mutual contacts, possible parents' criticism and the assessment of their emotional state resulting from the support situation which they face. Therefore, a lower mean of the obtained points does not mean low intensity of support activities.

The major goal of the study has been comparing the support received by parents of disabled children with the support provided at school in teachers' opinion. In order to do this, two results have been compared – the ones obtained from parents and from teachers (Table 4).

Table 4. Comparison of results obtained from parents and teachers

Support scales	Mean – parents	Mean – teachers
Actually received support	3.0	3.4
Protective buffering support	1.9	2.6

The analysis of the presented data unambiguously indicates that the evaluation of the provided and received support is convergent. Thus, it can be stated that in the case of the examined primary school there is no dissonance between the received and the perceived support. This is confirmed by the earlier presented results which concern perceiving the available support (Table 1). Yet, it should be emphasized that the school in which the research has been done belongs to integrated schools employing special education teachers, who are familiarized with possible educational difficulties and the daily life of disabled learners and their families. Thus, appropriately trained staff, with both the knowledge and awareness of disability, might have been the main determinant of such convergent research results. Referring to theoretical foundations of the appropriate support process, it can be unequivocally stated that the fundamental condition has been fulfilled: there is convergence of support activities on both sides – of the recipients (parents) and the givers (teachers). Some attention should be drawn to a slightly different view on protective

buffering support. What is observed here is a slight difference between the obtained results. Therefore, it seems interesting to analyze what the point means are in particular categories of questions comprised in the discussed scale (Table 5).

Table 5. Scale of protective buffering support

Questions for the scale of protective buffering support	Totally false		True to a small extent		True to a moderate extent		Totally true	
	parents	teachers	parents	teachers	parents	teachers	parents	teachers
I kept all bad news from him/her (patient)	46.2%	26.9%	15.4%	50%	19.25%	7.7%	3.8%	0
I avoided everything that could upset him/her	50.0%	30.8%	15.4%	26.9%	19.2%	7.7%	19.2%	0
I showed strength in his/her presence	23.1%	0	23.1%	19.2%	11.5%	19.2%	26.9%	42.3%
I did not let him/her notice how bad and depressed I felt	46.2%	15.4%	11.5%	19.2%	19.2%	0	7.7%	38.5%
I avoided any criticism	42.3%	7.7%	11.5%	19.2%	15.4%	34.6%	15.4%	23.1%
I pretended to be very strong, although I did not feel that way	53.8%	30.8%	7.7%	3.8%	19.2%	3.8%	3.8%	34.6%

* the sum of the results is not 100% because some parents and teachers provided no response or did not mark all answers

The largest point difference between the groups of parents and teachers occurred in the question concerning criticism. The analysis of the most extreme responses (totally false, totally true) indicated that over 40% of the examined parents stated that they do not avoid criticism towards teachers and their support activities, whereas only 7.7 % of the teachers gave the same answer. This may prove high awareness of parents' expectations and desires, they are not afraid to talk about them openly.

Some interesting data also appeared in the case of pretending "inner" strength. While most of the parents try to express themselves and their current emotional state, teachers constitute a very heterogeneous group, consisting of two well-distinguished subgroups. The members of the first subgroup pretend they are very strong, although they do not feel so, the second subgroup – just the opposite. This might result from the fact that some teachers are afraid of losing the authority of a specialist.

Conclusions

The obtained results, especially those concerning the lack of dissonance between the support perceived by parents of disabled children and the support provided by teachers, can be viewed as an effect of contemporary changes taking place in the functioning of school. First of all, what is changing is the role of a parent at school. Parents are now partners in all activities conducted within the territory of school. Disability brings about a particular kind of conduct resulting from specific everyday problems of families in which it is present. It is important that teachers in the examined primary school are aware of this. However, the presented research results, although they point at a well-functioning process of supporting parents with disabled children at school, need further analyses. It should be taken into account that these are the results of pilot studies. They do not apply to other institutions and they only exemplify good practice. Further research will require broadening the examined group and taking into account new variables, such as e.g. the type and extent of disability, educational level, form of special education, level of parents' stress.

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