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Helping parents in upbringing and rehabilitation of handicapped children

The researchers dealing with the special pedagogy¹ describe a difficult situation of the families that deal with upbringing children with various dysfunctions. These families are neither disturbed nor in any way „sick””. As a result of accumulated problems caused by their special situation they often require help (as the whole family) as do their children.

Helping the families in the context of the special pedagogy takes place not only when the parents recognise such need, clearly articulating it. Usually, people know when they have a problem and when they need a professional support. In other cases we will rather be talking about the care over a family. Such helping cannot constitute a harmful activity, but should always serve the good of the families and their members. In order to avoid limitation of the families' autonomy and trivialisation of the relation processes the helping should take place without authoritarian force, manipulation or control from the helping person. Pedagogues who themselves, without consultations with parents, determine the objectives of the process of helping, disregard the autonomy of family, evoking resistance. A family, in relations with a special pedagogue becomes a co-participant in the creative process of adaptation to the situation it found itself. From the members of such family one does not have to expect significant changes in the way of functioning, but rather small corrections in their current actions. A special pedagogue has to help in organisation of the family's experience and cause its trust in his/her abilities. In the special pedagogy helping does not mean achievement of an ideal state, but it is effective when it improves the state considered as bad, prevents a worsening of the existing situation or cements the state that is desired.

Activities of the helping person should be coordinated with the resources of the family and its individual members, and this can lead to the conclusion that it is the method of work that has to adapt to the family and not otherwise. The family is able to function well only in the conditions that respond to its current structure. An important principle of helping the families with handicapped children is supporting such family as long as it is necessary, and to expect, in return, from the parents their cooperation in achieving the state when the professional help in coping with

¹ Kruk-Lasocka J.(1991), Rodzina i jej dziecko upośledzone umysłowo, Prace Pedagogiczne LXXXVIII, Wydawnictwo Uniwersytetu Wrocławskiego, Wrocław, Pisula E. (1993), Stres rodzicielski związany z wychowaniem dzieci autystycznych i z zespołem Downa, Psychologia Wychowawcza nr 1, s.44-52, Zakrzewska-Manterys E.(1995), Down i zespół wątpliwości. Studium z socjologii cierpienia. ,Wydawnictwo Naukowe Semper, Warszawa, Sekułowicz M.(2000), Matki dzieci niepełnosprawnych wobec problemów życiowych, Wydawnictwo Uniwersytetu Wrocławskiego, Wrocław.

problems is no longer necessary. It is the principle of therapeutic minimalism. It follows from the research that the short-term helping is considered by the clients as more effective than the long-term one, and that it interferes more with the functioning of the families². Summarising the thoughts concerning the general principles of provision of help to the subject of the special pedagogy, it is possible to underline that a special pedagogue should not: assign the guilt to parents; enter into a coalition with a child against parents; ignore the feeling of love and devotion in the family; by any price search for pathologies in the family, but to look for potential and fields of healthy developments. Through their actions the special pedagogues cannot lead to the situation when in the life of a handicapped child there are too many parents (such as when a parent acts as a therapist of his/her own child, as teacher, friend and actually as the only relation alternative).

General objectives of helping the parents of handicapped children constitute reactions to the demand for them. Usually they concern the widening, i.e. increasing the knowledge, competencies and upbringing skills and ways of coping with and the so-called narrowing and decreasing of stress and fear related to the upbringing of handicapped son or daughter or elimination of the parental behaviours that make the upbringing and rehabilitation of children difficult. For solution of the crisis situations the parents need certain range of competencies, i.e. the skills of „making things good” that can be learned. These skills include:

1/ adequate behaviour, 2/ awareness of the need and results of upbringing, 3/ taking responsibility for the results³. The parents of the handicapped children need the cognitive competencies related to the base of the problem situations and giving sense to one's specific situation. Very important is also to learn the strategic competencies based on the newly created structures of activities and to take responsibility for oneself and one's own further life and for the functioning of the child. Important are also the communication competencies of the parents that permit them to understand the other person, but also to develop a satisfying contact with him/her. With development of the parental competencies subject to development are also the skills that are necessary in the process of upbringing. A basis for the creation of skills and competencies is a thorough knowledge (education of the parents). An indispensable condition for overcoming the crisis situations is activation of one's own activities (self-education, self-improvement, etc.) and acceptance of the social aid and

² Ludewig K. (1995), *Terapia systemowa. Podstawy teoretyczne i praktyka*. Gdańskie Wydawnictwo Psychologiczne, Gdańsk, p.189.

³ Czerepaniak-Walczak M.(1995), *Między dostosowaniem a zmianą. Elementy emancypacyjne teorii edukacji*, Wydawnictwo Naukowe Uniwersytetu Szczecińskiego, Szczecin, s.134 and following

support⁴. Thus, the educational participation of the parents is strongly related to their own development.

If a special pedagogue is to be the person that in a professional way, through education, helps the parents to develop their upbringing and rehabilitation skills and competencies, then very important becomes the way of implementation of the role of the special pedagogue in the contact with parents. He/she has to combine the skills of a guide, adviser, and companion in suffering and sometimes a therapist. He gives his knowledge and expertise to disposal of the parents, supports the existing structures, helps introduce and stabilise the new ones and gives an impulse for solution of problems. The shape and contents of these relations result from the realisation of the need of partnership of the parents in the process of their parental development and revalidation of their children.

During the meetings with parents, present is the dialog of their two equal participants that not only get to know each other, but also learn from each other. A central, theoretical and cognitive principle of the relation specialist-parent is „autonomy of the living processes or respect for the autonomy of clients”⁵. Because the task of the participants in the process of helping is to create the reality that reflects, to the highest extent, the living processes, the metaphor of power that parents often meet when asking for help for themselves and their children is improper here. The relations between the special pedagogue and parents should mean consultations during which the equal partners jointly construct the new reality.

In what fields can the special pedagogues work with the parents? I think that among the helping and revalidating strategies there are two important ones: increasing the parental competencies that are used to direct their families, and parallel revalidation activities directed towards the handicapped child supported by the educational institutions such as schools. These strategies may be implemented by:

- education of parents (widening of the parental abilities by making one's knowledge available for the parents; learning new skills; directing the process of self-education);
- advisory (searching in the family for the development potentials that are present in it, strengthening them, taking advantage of the abilities of both the child as well as the family);
- accompanying in difficulties (such as introduction of the new elements in the family system; social support; understanding the difficulties in the introduction of changes when the problem situation gives no hope for change).

⁴ Malewski M. (1998), *Teorie andragogiczne. Metodologia teoretyczności dyscypliny naukowej*. Wydawnictwo Uniwersytetu Wrocławskiego.

⁵ Deissler K.G.(1998), *Terapia systemowa jako dialog. Odkrywanie samego siebie?*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków, p. 34.

An intervention of the special pedagogue in the family may be conducted using the **socio-therapeutic and consultation model**. In the socio-therapeutic model important is helping the families through the educational and supportive groups. In the consultative model it is possible to indicate the form of a domestic educational and supportive intervention and rehabilitation consultation.

Education and support groups⁶. are different from the self-help and therapeutic groups mainly because they are based on the theory of education of adults. The purpose of their work is a cognitive and practical preparation of the mothers and fathers to functioning as parents (caretaker, educator, controller and partner that permits autonomy) and sometimes as a therapist of their own handicapped child and aid in development of a good functioning in the outside-parental roles. It is a proposal directed mainly to the families that live away from the large medical and therapeutic centres. The parents who want to play a proper role in regard to their handicapped children have to develop constantly and change the way they function. They also have to feel the direction of the changes involved. Upbringing of a handicapped child (just as upbringing of a healthy child) requires from the parents energy and motivation, skills and knowledge of strategy. Through education and support we help the parents to achieve this goal. In the work of a group we use the so-called „wonder of compatriots in misery”⁷. we teach the parents what they can require from various specialists and how to work with them properly and to copy when reaching them is beyond the abilities of the family. It is the professionals who initiate the creation of a group. Participation in it is voluntary and free of charge for the parents. The relation of parent-specialist is based on partnership, and contents of the meetings are selected depending on the parents’ needs. In the work used are the methods of active learning (brain storm, drama, discussion, etc.). The meetings start from the analysis of experience in the role of parents. We meet once or twice a month, working 14-18 hours in the Friday-Saturday cycle or we execute the daily tasks during a rehabilitation and rest period. The „classes” have three subjects:

- personal difficulties of parents in their parental and other roles;
- entertainment and recreation as the way of coping with stress;
- methods of compensation and equalising work with a child and using help from specialists and other parents.

There is also time for the individual contact of parents with specialists.

⁶ Będkowska – HeineV., Sekułowicz M. (1999), Wpływ zajęć edukacyjno wspierających na poziom funkcjonowania rodziców dzieci niepełnosprawnych, w: J. Patkiewicz (red), *Udział rodziny w kompleksowej rehabilitacji i życiu dzieci i młodzieży niepełnosprawnej*, Polskie Towarzystwo Walki z Kalectwem, Wrocław.

⁷ Ohme R.K. (1996), *Dzielenie niepowodzenia z innymi a samopoczucie: fenomen towarzyszy niedoli*. *Studia Psychologiczne*, t.XXXIV, zeszyt 1-8,8-9.

The problems appearing in the work of the education and support groups, and effectiveness of this form of help is described in a separate article⁸.

The education and support groups constitute an offer for the parents who want to break the passivity and do something good for themselves and other people. They are also a proposal for the motivated people and those who want to improve their style of functioning as parents. It is rather an offer for the younger parents upbringing their children to the end of their growing up.

The other model of work with parents (so-called **consultation model**) can be implemented in the domestic conditions or visits in various guidance services or consultation outlets.

The first form constitutes a **supportive domestic intervention** concentrated both on the family as well as on the child. Within this form of helping parents and children there are several meetings with parents supplemented with the telephone consultations with a special pedagogue. The cycle of meetings has the following course:

Meeting I. Determination of the essence of problems.

Objectives: 1. Making contacts with parents and handicapped child;

2. Determination and description of the problems with upbringing and rehabilitation of the child and problems with the functioning of the family.

3. Assessment of the seriousness of problems.

4. Selection of the strategic problems.

5. Description of the expectations from the parties involved and determination of the rules of the next meetings. These expectations can be recorded in order to more easily verify their implementation in the future.

Meeting II . Diagnostic meeting with parents.

Objectives: 1. Determination of the causes of the problem behaviours of the child with a special focus of the family-originated causes (typological diagnosis, phases, meanings and prognostic diagnosis) such as:

- where the parents locate the causes of dysfunctions in their child?
- do they think a change is possible?
- what, in their opinion, can be done to make such change possible (what can they change in themselves or in the surrounding environment if they are able to invest the energy in such change);

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Będkowska – HeineV. ,Sekułowicz M. (1999), Wpływ zajęć edukacyjno wspierających na poziom funkcjonowania rodziców dzieci niepełnosprawnych, w: J.Patkiewicz (red), Udział rodziny w kompleksowej rehabilitacji i życiu dzieci i młodzieży niepełnosprawnej, Polskie Towarzystwo Walki z Kalectwem, Wrocław.

- do they have competencies and skills (and what kind) permitting them to support development of the child and what skills and competencies they lack and should develop?
2. Determination of the objectives of helping:
- how the parents recognise if there is an improvement in their functioning and functioning of their child?

Meeting III . Diagnostic meeting with the child.

Objectives: 1. Assessment of escalation of dysfunctions (broadness, frequency, length of appearance, how drastic it is, etc.) .

2. Second analysis of conditions and confrontation with the parental diagnosis.

- what changes (from the perspective of the special pedagogue) in the functioning of the child and family are necessary for the members of the family to function better?
- are these changes possible?
- what everybody needs to do to achieve such change?
- how the special pedagogue, parents, child, other people and institutions can help in this?

Meeting IV. Planning of changes with parents and child (if this is possible) .

Objectives: 1. Determination of the plan of changes.

2. Negotiations concerning conditions.

3. Determination of the principles of functioning related to failures and successes, and provision (for the parents) of the basic information on the rules and principles of the process of upbringing.

The plan (project) is earlier developed by a pedagogue and only verified during meetings with the family.

Meeting V. Verification and control.

Objectives: 1. Control of changes.

2. Correction of the plan of helping.

- are the tasks successfully executed?
- what makes their execution difficult?
- is it possible to eliminate the obstacles and in what way?

Between the meetings IV and V, there are telephone consultations or additional meetings should the problems arise. This way of helping the parents strongly interferes in the family life and that's why it is chosen by the parents who are desperate and feeling completely hopeless after many attempts at independent coping with the problems with upbringing and rehabilitation. It works in the families that are motivated and not very disturbed. From my experience it follows that the best

effects are gained with small steps, motivating parents to work with their children while exposing the areas of health in the family and strong sides of parents and children. The helping person has to have an experience in the work with families, proper knowledge of the theory of their functioning and be guided by the motto that the families are not capable of large changes in their lives and activities.

The other variation of actions in the consultation model is rehabilitation **consultation** that is most often used by the special pedagogues and favoured by parents. A special pedagogue does not interfere in the problems with upbringing since, at least in the beginning, the parents do not voice such need. Their main problem is the diagnosing of the child and reception of instructions how the child can be helped in development. Only during the next meetings with parents disclosed are (often overlapping with the problems of handicapping condition) the problems with upbringing and the ones existing within the family. Then a typical rehabilitation consultation has to be broadened by the elements of the previous methods of work, but implemented in the office of the pedagogue. The rehabilitation consultation comprises five steps:

- 1/ diagnosing the psycho-social situation of the child and the level of his/her development;
- 2/ determination of the areas that require intensive actions supporting the child's development
- 3/ provision, for the parents, of a detailed plan of work with the child, the best in the written form with division of tasks into the time periods;
- 4/ precise explanation, for the parents, of the rules of „lessons” with the child, ways of reacting to difficulties, application of supporting measures, evaluation of progress;
- 5/ control of the effects of work and possible correction of the programme taking into account the difficulties and obstacles in the achievement of the objectives.

This type of work with the child requires self-discipline from the parents, and in the families that are not disturbed it works well being fast and inexpensive. Often, in the development of the programme participate the students who, during their studies, face such tasks. Very often they themselves make supporting devices for the work with the child that we later give to the parents. In any case, the voluntary works of the students of the special pedagogy who support parents in rehabilitation of their handicapped children constitute the next very important way of helping them in difficult situations.

The presented, focused on education, ways of helping the parents of handicapped children by the special pedagogues constitute only a small part of the various helping actions. Questionable is

often the availability of these actions because of the financial or mental barriers or the peculiar, institutional void. It happens that the parents, outside contacts with physicians, do not use advice of other specialists. A quite large group of parents go with their children to rehabilitation centres, but there, most often, the helping is limited to the medical rehabilitation. The families of the handicapped children often have the feeling of social isolation since they feel unsure when trying to take care for the help for their children. That's why it is important to underline the good characteristics of these families, praise them for the successes they achieve and treat with understanding their failures. It is necessary to understand what mechanisms they use and what enormous effort they input to survive and develop. It is also necessary to remember that the professional help for the people is an adequate reaction to their needs and explicit declaration of the need of help. Thus, not all parents of the handicapped children will be taking advantage of these forms of help.

References:

1. Będkowska – HeineV. ,Sekułowicz M. (1999), Wpływ zajęć edukacyjno wspierających na poziom funkcjonowania rodziców dzieci niepełnosprawnych, w: J.Patkiewicz (red), Udział rodziny w kompleksowej rehabilitacji i życiu dzieci i młodzieży niepełnosprawnej, Polskie Towarzystwo Walki z Kalectwem, Wrocław.
2. Czerepaniak-Walczak M.(1995), Między dostosowaniem a zmianą. Elementy emancypacyjne teorii edukacji, Wydawnictwo Naukowe Uniwersytetu Szczecińskiego, Szczecin.
- 3 Deissler K.G.(1998), Terapia systemowa jako dialog. Odkrywanie samego siebie?, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków.
- 4 Kruk-Lasocka J.(1991), Rodzina i jej dziecko upośledzone umysłowo, Prace Pedagogiczne LXXXVIII, Wydawnictwo Uniwersytetu Wrocławskiego, Wrocław.
- 5 Ludewig K. (1995), Terapia systemowa. Podstawy teoretyczne i praktyka. Gdańskie Wydawnictwo Psychologiczne ,Gdańsk.
- 6 Malewski M. (1998), Teorie andragogiczne. Metodologia teoretyczności dyscypliny naukowej. Wydawnictwo Uniwersytetu Wrocławskiego.
7. Ohme R.K. (1996), Dzielenie niepowodzenia z innymi a samopoczucie: fenomen towarzyszy niedoli. Studia Psychologiczne, t.XXXIV, zeszyt 1-8,8-9.
- 8 Pisula E. (1993), Stres rodzicielski związany z wychowaniem dzieci autystycznych i z zespołem Downa, Psychologia Wychowawcza nr 1,44-52.
- 9 Sekułowicz M.(2000), Matki dzieci niepełnosprawnych wobec problemów życiowych, Wydawnictwo Uniwersytetu Wrocławskiego, Wrocław.
- 10 Zakrzewska-Manterys E.(1995), Down i zespół wątpliwości. Studium z socjologii cierpienia. ,Wydawnictwo Naukowe Semper, Warszawa.