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**Forms of help given to the parents of children with high degree of mental disability – a
subjective assessment of received social support**

Families raising children with developmental disorders including high degree mental disability are confronted with a serious challenge to satisfy their children's special needs. They have to carry out duties not only typical of every family but also the new ones related to the rehabilitation process and work out new effective strategies and principles. High activity in the process of early intervention as well as taking long-term actions for the benefit of their disabled children is expected from the parents. Special education has been focused for many years on finding the factors which would influence the family's capability to fulfil these requirements. It has been recommended to make a wider use of rehabilitative capacity of the family. In their works¹ the educators have concentrated on describing both the external and internal situation of the family. Parental attitudes and the child's position within the family have also been examined. Additionally, the family environment and its conditions have been analysed from the point of view of a disabled child. These researches gave rise to recommendations concerning family life organization and tasks set to parents of disabled children.

Attempts at describing parents' psychological situation as well as relations existing between their psychical life and developmental disorders seen at the children have been an important stream of research on the family with a disabled child. Raising such a child is thought to be a difficult process involving stress, loneliness, hopelessness and dissatisfaction with life. The educators through their research², tried to recognise the nature of stress experienced by the parents of children with different degrees of developmental disability, means of coping with

¹Borzyszkowska H., *Social isolation of families raising a child with low degree of mental disability*, Gdańsk 1997, Twardowski A., *The situation of disabled children families (w:) A disabled child in the family*, (ed) I. Obuchowska Warszawa 1991, Ossowski R.(ed), *Life conditions of a disabled child in a family*, Bydgoszcz 1993, Wojciechowski F., *A mentally disabled child in a family*, Warszawa 1990.

² Pisula E., *Psychological problems of parents of children with developmental disorders*, Warszawa 1998; Rola J., *Melancholia rodzinna*, Warszawa 2004.

these commitments and factors affecting the mental state of the parents. They also analysed such issues as: an increased depression tendency in fathers and mothers of disabled children, their emotional inaccessibility, high level of anxiety, less diverse parental identity and the impact they have on the pathological development of a child. A strong parental stress, which was pointed in the research, influences “the capacity to care for a child, can disturb the parent-child relations and their mutual interaction, make learning conditions and gaining new experiences by a child definitely worse and, finally, diminish its sense of security and affect the self-evaluation in a negative way”³.

This research emphasises the necessity of providing the parents with multilateral and comprehensive help to tackle with the difficulties related to the disorders. The assistance may take the form of specialist therapeutic, educational and informative activities but also non-institutional activities coming from the family and friends, from neighbours and self-help groups. Only properly functioning network of social support enables the parents to fulfil their parental tasks and lead a satisfying life.

The social support as a category is not stated unequivocally in social sciences. The demand to define precisely the theoretical concept of this notion remains still up-to-date.

When analysing the social support it becomes essential that the research be based on the consciously selected theoretical model and resulting method of measurement⁴. The nature of this paper does not permit a very detailed analysis of this interesting issue. Let us assume for our consideration the idea of social support suggested by H. Sęk and R. Cieślak⁵. The authors, by mentioning a series of definitions, distinguished the following dimensions (categories) of social support: structural and functional support; the sources of social support; types (kinds) of social support; received and perceived social support; support need and mobilisation.

The results presented in this article are part of a several years' project as a part of a master's seminar and concerning the social functioning of families raising children with developmental disorders. The data come from the research by Ms. Małgorzata Dudek⁶, who developed the study of 6 families raising the children with intellectual disability of high degree paying

³ Pisula E., *Psychological problems of parents of children with developmental disorders*, Warszawa 1998. s.256,

⁴ Cieślak R., *Social support – problems and methods of measurement* (w:), *Social support, stress and health* (ed.) Sęk H., Cieślak R., Warszawa 2004.

⁵ Sęk H., Cieślak R., *Social support – the defining means, kinds and sources of support, selected theoretical concepts* (w:), *Social support, stress and health* (ed.) H. Sęk, R. Cieślak, Warszawa 2004.

⁶ Dudek M., *Perception of social support in families raising a child with high degree of mental disability – a study of families*, unpublished master's thesis, Kielce 2006.

particular attention to perceived and received social support and its evaluation. The research aimed to work out the project of network support optimisation and aid for individual families. This research among other things takes advantage of a SSQ6R questionnaire, which is a shorter, six-question version of the Social Support Questionnaire and helps measure the perceived social support. The examined people first answer every question by giving the initials of the individuals they can count on (six at most) and define relations with them (e.g. a friend, brother, mother). Then they evaluate the level of satisfaction with the support they get from these persons using a six-degree scale. The questionnaire estimates **the perceived support availability** (the number of specified people) with **available support satisfaction** (average social power of support network)⁷. The data from the partly classified interview helped describe **the objective family** situation as well as the subjective evaluation of **received social support** encompassing the emotional, informative, instrumental (rehabilitation), material and spiritual support. As required by the article I am now going to evaluate the functioning of the support network of two different families – Marysia’s family and Kasia’s family.

Marysia’s family

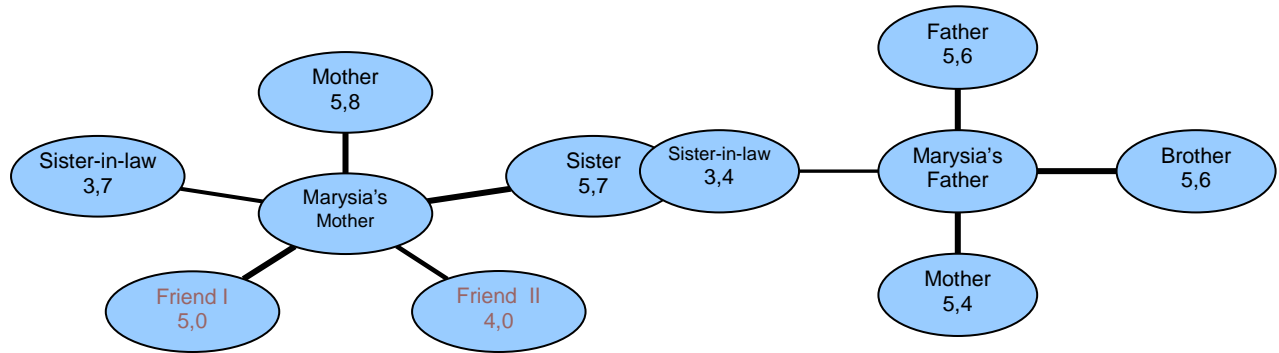
The objective family situation: the structure: *a whole family*, the child’s medical condition: *moderate intellectual disability, health problems in addition*, the child’s age: 11, the family: *a younger and older brothers*, the source of income: *jobs of both parents*, place of living: *city*.

Support perceived by Marysia’s family – the outcome of the SSQ6R questionnaire.

Marysia’s mother mentioned 5 persons she could rely on (three of them were the members of her family and two were the woman’s friends). She pointed to the full support: *help, relaxation, acceptance, custody, mood improvement, calming* (she mentioned at least one person at each question). The average level of support satisfaction was set by her at 4,8. The girl’s father proposed 4 persons he could rely on (all of them were family members). Additionally, he pointed to people in five areas but he did not point anybody he could count on in *calming*. His average level of support satisfaction was at 5,0. The man’s sister-in-law and the woman’s sister deserve a closer attention as they were mentioned by both sides.

⁷ Cieślak R., *Social support – problems and methods of measurement* (w:) *Social support, stress and health*, ed. Sęk H., Cieślak R, Warszawa 2004, s. 116-117.

A simplified figure showing Marysia's parents' network of social support



- ✓ the number of people in social support network MOTHER (3 + 2) FATHER (4)
- ✓ the average result of social support network MOTHER (4,8) FATHER (5,0)

Received social support – by Marysia's parents – based on the interview data

Emotional support. The spouses were the main source of support for each other. They could also rely on their family support (sisters, the husband and wife's parents, Marysia's older brother), friends (old and new ones, after the child birth) and professionals (the rehabilitator). Their statements emphasised the calming nature of conversations with their next of kin, the significance of spending time together with their friends giving them the sense of affiliation and the signs of acceptance coming from the environment. *We have a group of friends, who are with us, we go away together, everyone knows each other, they treat Marysia in a normal way, she knows them, too, it's great. You must learn how to behave in the presence of all people, not only the disabled ones.* And later: *We thought that Marysia would never be able to walk, and it's him (the rehabilitator) who made Marysia walk, he constantly stimulated our hopes.*

Informative support. The local doctors, experts from the Children's Health Centre as well as parents and experts from the Association of People Suffering from Tuberos Sclerosis provided the family with the information about the girl's health. According to the parents the amount and quality of this information was insufficient with the exception of the Children's Health Centre experts who were more helpful. The parents pointed to being left alone in searching for the necessary information and the mother's occupation (a nurse) was of some assistance here.

Rehabilitative support. Forms indicated by the parents included: aid with kinetic rehabilitation (currently stopped), expert medical help – neurological (systematical), aid with

readaptation at where the daughter goes to school, parents' mutual help with treatment. The parents were extremely critical of the assistance they received in these terms from local health care. They complained about restricted access to specialist help but spoke highly of the Children's Health Centre: *It's a different world at the Centre, the head of the ward embraced us, invited to his office, provided full information and arranged an appointment (-) He is such an amiable man, great doctor, who is devoted to these children and knows everything about this illness.*

Material support. Sources and forms of help referred to by the parents included: the Municipal Family Aid Centre (nursing benefit, rehabilitative periods, special equipment means); family members – the husband's parents (financial and material help, access to their house, periodical care of the girl). When evaluating the help they mentioned an unsuccessful attempt to obtain the means to purchase special shoes for the child. *You don't want to abuse, it's our child and we have to deal with it.*

Spiritual support. In the beginning, just after having been informed about their daughter's disability they temporarily turned away from the Church. The mother commented on it: *I asked myself: why it had to be her, so pretty, good, smiling... I felt sorry. I bore a grudge against God, the whole world, and even me.* But even at this difficult time the prayers filled her with real hopes.

Kasia's Family

Objective family situation: the structure: *a one-parent family (the mother had been a widow for 10 years)*, the child's medical condition: *the Down's syndrome, health problems in addition*, the child's age: 17, the family: *an older independent sister (very limited contact with the mother)*, the source of income: *pension, benefits*, place of living: *city*

Support perceived by Kasia's parents – the outcome of the SSQ6R questionnaire.

A simplified figure showing the network of social support of Kasia's family



- ✓ the number of people in social support network MOTHER (2) FATHER is deceased
- ✓ the average result of social support network MOTHER (4,5)

Kasia's mother entered the names of two persons she could rely on (family members). She gets support only in these areas: *help and relaxation* (she mentioned at least one person at each question). The average level of support satisfaction was set by her at 4,5. The girl's father had been dead for 10 years.

Received social support – by Kasia's parents – based on the interview data

Emotional support. It is hard to find any fragments in her statement attesting to the existence of people she could rely on. She feels lonely, helpless and heavily burdened with the responsibilities. *Sometimes it makes you angry (-) I can't leave her alone for a second right now, she gets so impossible, she constantly does things just to spite me and hides everything from me. I have no idea what to do with her. Go to a psychiatrist of some sort ... I don't know what to do with her, where to go. And more: ... I can't read a newspaper or a book. She disturbs me all the time. And I am constantly busy with her. I don't really have time for myself just to get relaxed and get away from it all.* Asked about help she claims she knows the girl and her needs best and it is only her who can properly deal with the child.

Informative support. Paediatrician (child's nutrition) and a nurse (means of kinetic improvement) were the main source of information for the mother. The staff notified only her about her child's disability and, therefore she was confronted with conveying this difficult message to her husband. In her opinion the notification was unclear and inadequate. She had to look for the information about aetiology and possible forms of therapy completely on her own. *I bought a newspaper (-) it read about this Down's syndrome. It was not until I read it that I realised what it meant..*

Rehabilitative support. Forms of help pointed out by the mother included: kinetic rehabilitation help, expert medical care – neurological, orthopaedic, allergic (systematical), help with readaptation at SOSW where Kasia goes to school, help from the older sister (currently stopped). She shows a negative attitude to the forms of help received from the local health care and complains about restricted access to the expert aid (her daughter was admitted to the specialist centre at the age of four). She seems very satisfied with where her daughter is readapted.

Material support. She named the Municipal Family Aid Centre as the major form of help in this respect (family pension, child's benefit, nursing allowance and rehabilitative periods). She was very critical of her daughter's stay at the periods on account of the troubles she made there. Especially at the beginning of her custody over the children the poor living conditions posed the biggest difficulty to the family. As she recalls: *There (her first flat) was no water,*

no central heating, I had to heat with a stove (-) I had no luxuries. I could use some better conditions when the children were little because I needed it most then. The living conditions have improved over the years.

Spiritual support. She often refers to a great significance of religion in her life. The prayers and the practices have offered her strong support but she also alludes to some doubts and regret. *Sometimes I have these worse days that I get so rebellious; when I happen to have these difficult situations I bear a grudge against God why it happened to me, why everything collapsed just on me.*

Received social support – a summary

Natural support network prevails in **Marysia's** family, which is constituted by an extended family integrated around the disabled child. Although it is composed of economically independent and somewhat scattered nuclear families, numerous family members provide mutual services especially in terms of emotional and material help. Additionally, both informative and rehabilitative areas are supplemented with professional help. This family is capable of inspiring actions which would stimulate support.

Mainly **institutional sources of help** prevail in **Kasia's** family, which is deprived of natural support network. Their deficiency is particularly evident in emotional but also material support (reduced generally to financial benefits). External help with medical rehabilitation and financial support seem sufficient. On the one hand this family shows helplessness and help anticipation but on the other hand lacks any actions stimulating support.

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A summary

Child's disability confronts the parents with additional tasks in terms of education but is also the source of a series of difficult and stressful situations. They need a comprehensive help with overcoming difficulties related to disabilities. Only properly functioning social support network can enable the parents to fulfil their parental tasks completely and enjoy a happy successful life. This article presented the descriptions of social support networks of two families with a child suffering from mental disability of high degree. SSQ6R questionnaire helped to recognise perceived support availability as well as satisfaction with available support. This research also utilised the data from the partly classified interview which provided means of describing the objective family situation as well as the subjective evaluation of received social support encompassing the emotional, informative, instrumental (rehabilitation), material and spiritual support. Natural support network prevails in one of the families, which is supplemented with professional help in informative and rehabilitative areas. In the other family, deprived of the natural support network, there are mainly institutional sources of help. Their deficiency manifests itself particularly in emotional and material support.

Formy pomocy udzielanej rodzicom wychowującym dzieci z niepełnosprawnością intelektualną w stopniu głębszym – subiektywna ocena uzyskiwanego wsparcia

Niepełnosprawność dziecka stawia przed rodzicami dodatkowe zadania w zakresie wychowania, ale jest także ciągiem sytuacji trudnych, będących źródłem silnego stresu. Rodzice potrzebują kompleksowej pomocy w przezwyciężaniu problemów związanych z niepełnosprawnością dzieci. Tylko właściwie funkcjonująca sieć społecznego wsparcia umożliwi rodzicom wywiązanie się w pełni ze stawianych im zadań rodzicielskich i szczęśliwe, udane życie. W artykule przedstawiono opis sieci wsparcia dwóch rodzin wychowujących dziecko z niepełnosprawnością intelektualną głębszego stopnia. Za pomocą kwestionariusza SSQ6R poznano spostrzeganą dostępność wsparcia oraz zadowolenie z dostępnego wsparcia. W badaniach wykorzystano także dane z wywiadu częściowo skategoryzowanego, które pozwoliły na opisanie obiektywnej sytuacji rodzin oraz subiektywnej oceny otrzymywanego wsparcia społecznego, w zakresie wsparcia: emocjonalnego, informacyjnego, instrumentalnego (rehabilitacyjnego), rzeczowego, duchowego. W jednej z rodzi dominuje naturalna sieć wsparcia, którą tworzy zintegrowana wokół niepełnosprawnego dziecka rodzina poszerzona. Siła

tego wsparcia widoczna jest zwłaszcza w zakresie pomocy emocjonalnej i rzeczowej, która jest uzupełniana, w sferze informacyjnej i rehabilitacyjnej pomocą profesjonalną. W drugiej rodzinie pozbawionej naturalnej sieci oparcia występują głównie instytucjonalne źródła pomocy. Ich niedoskonałość widoczna jest zwłaszcza w zakresie wsparcia emocjonalnego ale też rzeczowego.