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**Community support for families with sick and disabled children as exemplified by the studies in the powiat of Sokółka**

The interest of social work focuses on the area common to an individual and their community, which causes both sides to experience different, both positive and negative consequences of initiated support activities. The most important phenomenon in this respect is the transaction between a person and their community. It is understood as an exchange based on the activity of an individual and the intervening effect of their surroundings. This transaction concerns the exchange of resources both inside a specific system (e.g. between a child and its family) and among different systems (e.g. the recipients and the providers of social services)<sup>1</sup>.

With regard to my own studies, fragmentary results of which I present in this paper, an ecological perspective allows to identify the problems and difficulties of families with disabled children within the boundaries of their specific systems, as well as in the context of the local community.

Referring the process of supporting a disabled child and its family to the ecological perspective makes it easier to abandon the approach based on examining the resources and potential embedded solely in an individual or a family circle in favour of engaging the forces of the local community in support activities. The development of a disabled child, the functioning of its whole family, the possibilities to satisfy their existential, emotional and social needs or the overcoming of obstacles are affected not only by the conditions present in the micro- or individual scale. In social work the ecological perspective that focuses on the holistic perception of the person and the community as a whole<sup>2</sup> facilitates the understanding of the fact that the specific situation of a child and its family depends on multiple factors that occur in the social micro-, meso-, exo- and macrostructure. The problems of individuals, or

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<sup>1</sup> Dubois B., Miley K. K., *Praca socjalna zawód, który dodaje sił (Generalist social work practice: An empowering approach)*, Tom I, Katowice 1999, s. 79.

<sup>2</sup> Stelmaszuk Z. W., *Podejście ekologiczne (An ecological approach)*, (w:) Pilch T. (red.), *Encyklopedia pedagogiczna XXI wieku. Tom IV (Pedagogical encyclopedia of the 21<sup>st</sup> century. Volume IV)*, Warszawa 2005, s. 449.

community barriers, are therefore understood as the consequences of transactions taking place between an individual and its surroundings.

As the subjects of my research explorations I chose the pathways and forms of activities aimed at supporting families with disabled children suffering from mental impairment, mobility and sensory dysfunctions and chronic diseases, provided by self-government institutions and non-governmental organizations operating within the poviát of Sokółka. My study covered 80 families and 66 workers employed in the public and non-profit sectors. In order to find answers to the formulated, detailed research problems I have applied the method of diagnostic poll, as well as the method of institutional monograph.

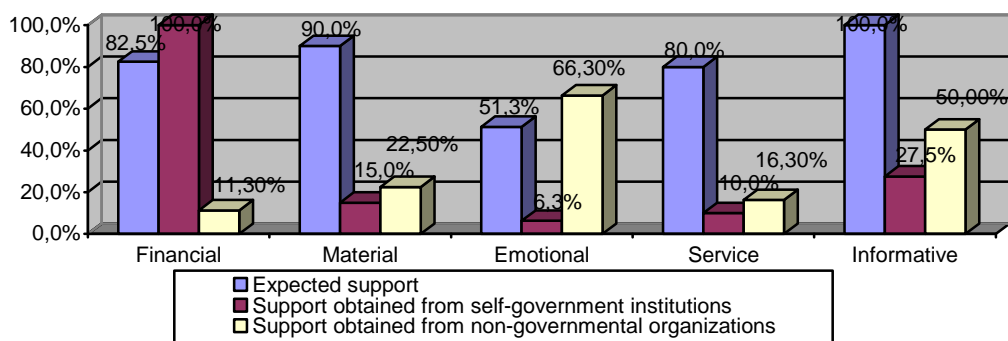
On the basis of gathered reports from the years 1999–2004 and interviews with representatives of **self-government support institutions** (Social Support Centres, Poviát Centre of Family Support and Community Support House) I have determined that the prioritized activities in the sphere of support for the disabled take many different pathways that include mainly therapeutics and prophylaxis (66.7%), revalidation (50.0%), compensation (33.3%) and rescue (16.7%). What can be observed, however, is the clear domination of therapeutic activities focused on health improvement (83.3%). The most frequent form of help offered and available to the applicants of all the examined self-government institutions is informative support implemented mainly by providing news on the possibilities and criteria of receiving aid from entities operating in both the public sector and the local non-profit sector. The support related to services and social work is provided almost as frequently (66.7%) and involves the provision of care services in the houses of people under care, the intermediation in resolving issues related to maintaining a household and contacts with other agencies and social groups. An occasional form of support that is available in the studied sector is specific emergency response assistance, family mediation and psychological and pedagogical counselling (16.7%).

The study of the activities of **non-governmental organizations** in the field of support for the disabled confirms, similarly as in the case of the public sector, their great diversity, though the majority of them are initiatives focused on prophylaxis (80.0%), compensation (50.0%) and therapy (40.0%). A more profiled offer of support may be found in the field of therapy and education (20.0%). On the basis of the obtained research results it is also ascertained that the most frequent form of aid available in the sweeping majority of the studied organizations is informative counselling (90.0%) and service and material support (60.0%).

What seems disturbing is that the forms of emotional support are poorly developed, especially in light of a serious deficit thereof in the self-government sector. At the same time this situation proves that there are numerous lacks in the work of support organizations and institutions when it comes to activities that would reduce the feeling of helplessness and seclusion in parents, as well as their concerns and fear of the future. This family-unfriendly situation is deepened by the lack of an appropriate institution in the poviát that would be able to provide professional interventions 24 hours per day.

The adequacy of the support offered in the community to the expectations and needs of families with disabled children may be explained through analyzing empirical evidence related to the support actually received by the studied families from institutions and organizations. The distribution of answers concerning this matter is illustrated by the graph below.

**Graph 1. Forms of support provided for the studied families with disabled children by self-government institutions and non-governmental organizations**



Source: own studies

The findings of the study show great discrepancies between the support expected by the studied families and the support actually obtained from **self-government institutions**. There is an unquestionable lack of coherence in the case of support in the form of services applied for by parents wanting to satisfy their need to participate in improvement courses that would facilitate their vocational re-adaptation (22.6%), as well as in the case of pedagogical consultations (28.8%) and the provision of temporary care for a family member (7.5%).

Another noticeable discrepancy emerges in the field of emotional support, where out of 41 people motivated to seek help in solving their family or personal problems and to establish or improve their relations with the community only five found this kind of support in the studied public institutions. This is probably the consequence of the lack of professional qualifications among social workers in the field of working with problematic families, as well as their reluctance to take on initiatives associated strictly with social work.

The emotional support received by the studied subjects, provided mainly by other parents during rehabilitation sessions financed by PFRON (State Fund for Rehabilitation of the Disabled), covered families that were capable of fulfilling their emotional needs on their own and did not require any intervention from the outside. These are mostly circles where situations that cause arguments, distress, inhibition in expressing feelings do occur, but the basic norms and principles of communication are nevertheless observed. What is disturbing is the lack of emotional and spiritual support for families that demonstrate obvious dysfunction in this respect.

The data presented in the graph above unambiguously indicate that in the case of the examined **non-governmental organizations**, similarly to the support offered by self-government institutions, there is visible dissonance between the support expected by the respondents and the support they actually receive. In light of the obtained results it is possible to ascertain that the preferred form of support provided by non-profit organizations is emotional, valuating and spiritual support offered irrespectively of the needs signalled by the applicants. This results mainly from human resources available in the studied sector, i.e. voluntary and regular workers who possess documented professional qualifications entitling them to provide therapeutic and psycho-therapeutic support which is conducive to the improvement of both social and psychical functioning of the beneficiaries who often grapple with the problem of the disability of their children.

The greatest contrast between the support applied for and the support actually received by the studied families can be seen in the financial sphere. This may be explained by the insufficient income of the organizations and their inability to change the purpose of subsidies received for the implementation of specific projects from PFRON (State Fund for Rehabilitation of the Disabled) or the budget of gmina or powiat. A large percentage of beneficiaries applying for this kind of support are mainly families with children suffering from mobility and hearing deficiencies that seek financing in order to purchase expensive rehabilitation equipment or materials necessary to eliminate architectonic barriers.

The studies that I conducted allowed me to demonstrate which activities bring expected results in which areas and what is their **effectiveness**. Using a measurement scale prepared for this purpose I evaluated real financial and non-material benefits granted to families in the assumed research period<sup>3</sup>.

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<sup>3</sup> The evaluation of the efficiency of activities initiated in local support institutions at the level of the gmina and powiat allowed to distinguish three levels of this support, i.e. *small* that refers to support allowing to receive up to two „benefits” per family, *medium* (2-4 “benefits”) and *large* (at least 5 “benefits”).

The findings of the study show that the efficiency of the activities initiated in **self-government institutions** for the benefit of families with disabled children is clearly too low. The greatest influence on the process of social and therapeutic rehabilitation of children and the improvement of the functioning of their families is exerted by financial support (13.8%). Significant profits, according to the studied families, were regularly obtained family, designated, periodical and nursing benefits (52.5%), as well as subsidies for the participation in rehabilitation camps (71.3%); the purchase of hearing devices (15.0%) and computers with specialist software and internet access with the purpose of eliminating communication barriers (42.5%); the adaptation and equipping of sanitary spaces (26.3%), the elimination of doorsills, floor levelling and the construction of a ramp and an access road to a residential building (3.8%), the purchase of diapers (16.3%), orthopaedic shoes (20%), glasses (10%), wheelchairs, including wheelchairs with electrical drives (13.5%), cassette recorders for musicotherapy classes (7.5%), a Braille device, anti-bedsore cushions and mattresses and stationary bicycles (1.3%).

The results obtained from the study confirm that the most valuable activity performed in the local **non-governmental sector** is the support focused on the emotional condition, including its valuation and spiritual sense. Its source is the support received from other parents both from within the community that the studied subjects belong to (84.9%) and during integration events (64.2%) and group leaves to rehabilitation camps (49.0%). An important role here is played by the support received from the employees of organizations (45.3%) and professional psychologists and pedagogists employed there (18.9%). Minor effectiveness may be observed in the field of the provision of material support, which involves mainly the delivery of new and used clothing (61.1%), food (27.8%) and gift packages (22.2%), the rent of adaptive equipment (27.8%), the purchase of meals (5.6%) and school utensils (5.6%) for children.

A complete lack of efficiency is observed in the case of the provision of financial benefits where only 10 families in total used this kind of support. Poor efficiency of activities is also visible in the field of support provided in the form of services. Important advantages here turned out to include educational services provided for children with speech and hearing dysfunction, care services provided at homes and the help of voluntary workers during occasional meetings or sport events.

Summarizing the analysis of the results of the study that related to the pathways and forms of support for families with disabled children provided in their residential communities allows to make several observations.

A rather diversified range of the types of support addressed to the disabled and discovered during the study turned out to be unavailable to most of the studied families. The offered services and benefits were evaluated by the respondents as poorly or moderately effective, mainly due to the excessively limited possibility of using them that results from their inadequacy to the needs of the families and the financial deficits indicated by employees. On the basis of the gathered research material it can be observed that the self-government institutions turned out to be effective mostly in terms of **measurable forms of support** that include granting and providing financial resources to specific tasks and projects, whereas the non-governmental organizations were the most effective in providing **emotional support** by advising parents in difficult situations and lifting their spirits in the moments of breakdown. According to the studied parents this support is only fragmentary and as such it cannot fill the lacks experienced by children and their families and it can in no way motivate them to overcome problems on their own (52.2%).

The constant decentralization of the tasks of social assistance undoubtedly creates new opportunities of supporting the disabled, especially in terms of identifying their needs more accurately and personalizing the way of providing them support. Its main objective is to improve the functioning of local systems of social assistance and, consequently, improve their effectiveness<sup>4</sup>. The systemic and ecological approach used in studying the process of supporting the disabled in their community allowed therefore to identify problems existing in families with disabled children and to recognize threats in the work of local support institutions and organizations that may prevent the overcoming of these problems.

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## **Community support for families with sick and disabled children as exemplified by the studies in the poviát of Sokółka**

### **Abstract**

The primary goal of the study presented in the paper was to determine the pathways and forms of support offered to families with disabled children in self-government institutions and non-governmental organizations. The obtained findings revealed distinct differences in the support activities addressed to families in the two sectors. The former one concentrated mainly on providing financial and legal support, whereas the latter one provided mostly emotional, valuation and spiritual support.

Fragmentary results of own studies focused on how the parents of disabled children evaluate the adequacy of the support they actually receive from support institutions and organizations to their actual expectations.

## **Wsparcie środowiskowe dla rodzin z dzieckiem chorym i niepełnosprawnym na przykładzie badań w powiecie Sokólskim**

### **Streszczenie**

Podstawowym celem badań prezentowanych w artykule było określenie kierunków i formy pomocy oferowanej rodzinom z dziećmi niepełnosprawnymi w instytucjach samorządowych i organizacjach pozarządowych. Uzyskane wyniki wskazały na wyraźne różnice w działaniach wspomagających rodziny podejmowanych w obydwu sektorach. Pierwszy z nich koncentrował się głównie na udzielaniu pomocy finansowej i prawnej, drugi natomiast wyraźnie zapewniał wsparcie emocjonalne, wartościujące i duchowe.

Przedstawiono również fragmentaryczne wyniki badań własnych dotyczące ocen rodziców dzieci niepełnosprawnych w zakresie trafności wsparcia przez nich oczekiwanego a rzeczywiście otrzymywanego w instytucjach i organizacjach pomocowych.