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The needs of family with disabled child in the context of week support system

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THE NEEDS OF FAMILY WITH DISABLED CHILD IN THE CONTEXT OF WEEK SUPPORT SYSTEM

The family, as the most important caring and educational environment, is an integral and inseparable element coexisting with the child in his natural mental and physical development. In the life of a disabled child family is the basis of existence, as it gives the chance to function in physical, intellectual and social terms. In my opinion, a properly functioning family matters more to a disabled child than to a healthy one.

For a child the family is the first social environment in life. This fact may have positive or negative consequences for its development, depending on the characteristics of the family in which it is born and with which it remains in various interactions for life.¹

It is a widely shared opinion, that the family of a child with a disability should be treated differently as society is obliged to provide it with a comprehensive care and therapy. Practice shows that such actions lead to a greater acceptance for the child and help increase the confidence of parents towards each other, often it help parents to work together for the benefit of the child, and above all, it motivates and mobilizes a broad range of people in the process of mutual help to overcome difficulties associated with parenting and caregiving to the child with developmental disabilities.

On the basis of the above considerations, it must therefore be assumed that there may be reasons to change the culturally well-established model of the family to be able to describe properly the roles of the family with a disabled child. In my opinion, weak and imperfect system of support for families with disabled children, which does not perform efficiently in the support of the process described above, and does not result in the strengthening of the traditional roles in the family of a disabled child, is one of the factors determining changes in the functioning of such a family.

In face of these inefficiencies, the true support system has become the **social support**. This support, clarifying the general definition of the word, can be defined as a specific form of assistance to the persons or groups to mobilize their forces, capabilities and resources, which they still have, in such a way that they can deal with their problems themselves. The support systems have been described by many authors, but it seems that the collective work of E.M. Minczakiewicz, B. Grzyb and Ł. Gajewski very accurately identifies the key features of the system of support. They state, that: "social support system, as the name suggests, should truly be a system, and so we can't speak of any isolation of facilities designated for this type of activity. All institutions – starting with the first (early intervention),

* Wyższa Szkoła Humanitas w Sosnowcu.

¹ M. Ziemska, *Rodzina a osobowość*, Wyd. Wiedza Powszechna, Warszawa 1975, s. 35.

the institutions and organizations for people with disabilities: social services, health care, government authorities and local governments, education system – are all required to create high-end systems of support for families with children with special needs, depending on the profile of their functioning. Their main aim is to prepare, as completely as possible, the disabled to function independently in society.”²

The support provided to persons with disabilities and their families, lies in the use of such forms of assistance which teach to use the limited set of skills at one’s disposal in order to help lead the most optimal chance of independent, active and creative life. Based on type, we may identify various types of support, including: information support, emotional support, tangible, financial support, support in the provision of services and developmental support.

Due to the low life resourcefulness of families with disabled children, out of enumerated types of support, in my opinion, the most needed is the information support. Because it has a chance to complete gaps in the knowledge possessed by the family, it enables greater efficiency and complexity of activities undertaken for the benefit of a child with disabilities. Properly executed, such support indicates the limitations offsetting the effects of disability and methods of treatment and rehabilitation. It provides opportunities to gain knowledge about the existing rights and functioning of the institutions where the family may obtain all kinds of help.

Another important type of support is the emotional support. This is a very important kind of support needed by a disabled person and their family. Concerns about the future and fears of people with disabilities and their families, indicate the need for emotional support from those who have “the worst” behind them. Families who despite a disease or disability are in some way successful, for example, they cope well in everyday life, have friends, help others, may be a source of optimism and mental strength to the ones in need. These are mainly people with self-help groups, associations of persons with disabilities and associations of families of persons with disabilities.

Material support, based on traditional forms of aid, providing resources and support in the provision of services is also very important in the everyday life of the family with a disabled child. The reality of economically disadvantaged families described here unfortunately points to a shortage of funds in the help system, as well as to the formal, institutional and physical impediments to access to them.

Developmental support, possible only in conditions where the previously mentioned forms of support function efficiently enough, is directly aimed at supporting the development of a disabled person, e.g. by leveling the playing field related to education. This may be the help classmates and teachers provide to children and young learners at schools or availability of individual learning at home. This can be a support for equalization of opportunities in the field of recreation or physical activity (such as holiday travel integration). A very important element of support here is the support of social development, responsibility for others and provision of aid to others.

² E.M. Minczakiewicz, B. Grzyb, Ł. Gajewski, *Elementarz dla rodziców. Dziecko ryzyka a wychowanie*, Oficyna Wydawnicza „Impuls”, Kraków 2003, s. 179.

In many cases, the entire responsibility of caring for people with disabilities falls upon the closest ones in the family, e.g. the parents. Unfortunately, over-protectiveness and care by family can make-up the whole world of a disabled person, who becomes limited to their own house, which significantly reduces the level of their socialization. This is why it is very important that a disabled person has the chance to maximize independent activity and self-reliance.

One should also consider the fact that disability interferes with exercising certain rights by the disabled.³ It is therefore necessary to guarantee the disabled the opportunity to exercise their rights and to create mechanisms that would help them to equalize and allow full enjoyment of civil rights enjoyed by all others. What relates to the aforementioned issues, is that people with limited efficiency should benefit from the special powers specific to their social group, because only this guarantees the enjoyment of those rights.⁴

The family, as the most important institution in society, can assist both the disabled child and the disabled adult, provided it has all necessary institutional help guaranteed by the state.

The best example of institutional support are the assumptions of the Charter of Rights of Persons with Disabilities.⁵ The Charter gives the interpretation to the rights of persons with disabilities, and clearly defines the issues of social functioning for persons with disabilities. These are summarized in table 1.

Table 1. Social functioning issues included in the Charter of the Rights of Persons with Disabilities

Form of functioning	What particular emphasis is put on
Participation in society	Allowing access to all services and goods
Full access to treatment, health care, early diagnosis and therapeutic education	Taking into account the type and degree of disability in medical services and supply of orthopedic and rehabilitation equipment and aids
Access to the multiple forms of comprehensive rehabilitation	Tending to overall social adaptation
Education in various schools	Optimization of the educational offer of special schools, access to individual learning, the availability of inclusive schools
Specialized forms of educational, psychological and other related aid	Enabling development and achieving or improving the qualifications of both general and vocational nature
Access to the open labor market	The opportunity to gain work according to education and skills, the use of placement or career counseling and creating specially adapted working conditions
Social protection of the higher cost of living	Adaptation of the system of financial support and tax reliefs

³ D. Szeligiewicz-Urban, *Sposoby wspierania rozwoju zawodowego osób z niepełnosprawnościami na współczesnym rynku pracy*, [w:] B. Pietrulewicz, M.A. Paszkowicz (red.), *Osoby z niepełnosprawnościami na współczesnym rynku pracy*, Wydawnictwo Naukowe Polskiego Towarzystwa Profesjologicznego, Zielona Góra 2010, s. 220.

⁴ P. Przybysz, *Prawa Człowieka a Prawa Niepełnosprawnych*, www.pfron.org.pl [dostęp: 15.01.2015].

⁵ Resolution of the Polish Sejm on 1 August 1997, *Charter of Rights of Persons with Disabilities*, No. 50, par. 475.

Life and movement	Eliminating barriers through improved access to public buildings, the public means of transport and to information
Having an independent and autonomous representation of the environment	Opportunity to influence the content of the public sector projects and legislation to allow full access to the social, public, artistic, cultural life and to sports and participation in recreation and tourism

Source: study of author.

Good examples of aid measures in place in 2015 may be integration programs in countries of the European Union (e.g. The exhibition “Dialogue in the Dark” by Andreas Heinecke) or the Sectoral Operational Program – Human Resources Development (Measure 1.4 for vocational activation of the disabled).

One can assume that when the institutional system supports the family in accordance with its objectives, it leads to its strengthening, and this refers in the most part particularly to families with disabled children. The above examples of institutional activities are only a small extract of outreach activities for the disabled, but unfortunately, most of these activities are imperfect due to too small an involvement of the disabled people in the integration process. Also they are not part of the direct support to families, not fulfilling its role efficiently.

It goes without saying that the birth of a child with a disability brings about broad changes in the functioning of the family. Parents, after undergoing an emotional crisis, try to get back to a normal family life and restore the disturbed balance. Most of them is formed by the situation to give up their own plans and dreams, to be able to devote the time to the disabled child's care and upbringing. Noteworthy changes take place in the relationship between the spouses. In most of cases, primarily mother becomes devoted to everyday care of the child and is often forced to give up work. Frequent lack of assistance and cooperation from the male spouse leads to loosening of family ties and worsening of emotional ties between spouses. Transformation of social life of both parents also takes place. Past meetings with friends and acquaintances suddenly become impossible, changing circle of people surrounding the family. The family rarely visits others, and guests come by less frequently. Married life becomes distorted. This condition often causes frustration of spouses, or at least one of them. Without adequate compensation through a system of social and institutional support, factors listed above directly affect the change in the pattern of family functioning. An important element, generally absent in such a situation, is the development of proper intrafamily relationships, possible only in suitable atmosphere in the family home. In families where is a warm and friendly atmosphere and relationships between spouses are generally positive, the disabled child is also perceived positively.

Children with disabilities, stronger than their healthy peers, instinctively sense the negative changes in the emotional sphere of the family. This leads to all kinds of disorders of internal feelings, which may be the reason of various types of abnormal behavior, which in turn may increase the existing disfunctionality. Particular importance is attached to the

conflicts between spouses. Their impact on the child depends largely on the very course of conflict and the way parents solve it. It is also important that the child is not a direct observer of such situations.⁶

Needs of families with disabled children have their own face. Meeting the basic needs is accompanied here by the need to meet the specific and individual needs. Experience shows how strong are the needs of social acceptance, specialized care, access to competent sources of information and special help to the disabled child.

But also parents need psychotherapeutic help and support. Social community can give parents psychological and spiritual support, a sense of connectedness and social support, and may help model patterns of constructive thinking in dealing with the situation. It may share its experiences and aid. An active role in this area can be played by a family group, a friendly-neighborhood and various associations for children and people with disabilities. The technical improvements, not only for the disabled but also for families who carry the burden of disability, are also important.⁷

Based on years of experience and working with families of children with disabilities, as well as with the children themselves, I can say with full responsibility that the system of psycho-pedagogical support is imperfect. At each stage of the development of a child with a disability or with a fragmentary deficit, child support system is complex, but there is a lack of support for the functioning of the family as a whole, there is no support for reinforcing family ties. Families must organize their own assistance to each other to form support groups, societies or associations, and through these structures to mobilize each other, pointing the way out of all sorts of problems in the upbringing, rehabilitation and education of children.

All the deficiencies of the support system described in this article lead to modifications of family functioning, its disintegration and stratification and the difficulty in achieving of its maximal potential as a social unit.

In view of the above considerations, it must be taken into account that in spite of the great need of assistance, any request for such assistance is sometimes still seen as an affront to dignity, and to entrust the child's care to specialists brings about a sense of their own imperfection in parents, it often feels like lack of parental knowledge and competence.

Therefore, the immediate family should be an important element of support for itself. It's still a rare event, but observable social changes go in the right direction. Newly noticeable hope and belief in a better life of a disabled child, gives strength to survive the difficult moments, and the circle of people supporting the ones that have had the same problems keeps expanding. Among people of good will, volunteers, and with effective social and institutional support, one may do a lot more for a child with a deficit, which is why it is so very important to help parents to take support and show them warmth, understanding and kindness.

⁶ A. Kozubska, *Opieka i wychowanie w rodzinie dziecka upośledzonego umysłowo w stopniu lekkim*, Wydawnictwo Uczelniane Akademii Bydgoskiej im. Kazimierza Wielkiego, Bydgoszcz 2000, s. 106-114.

⁷ M. Kościelska, *Oblicza upośledzenia*, Wyd. PWN, Warszawa 2000, s. 94-96.

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Abstract: The family is a basis source of every child, but this institution is especially important in the case of disabled child. The birth of disabled child is a cause of crisis in family. This situation is a cause of changes in the functioning of family. This type of family has a specific needs and requires another type of support compared to typical family. This is an informational, emotional, material support. The author claims that the institutional support is imperfect and doesn't fulfil its role. In the author's opinion the family is uppermost element of support.

Keywords: the family with disabled child, the needs of family, relation in family, institutional support

POTRZEBY RODZINY Z DZIECKIEM NIEPEŁNOSPRAWNYM W KONTEKŚCIE SŁABEGO WSPARCIA INSTYTUCJONALNEGO

Streszczenie: dobrze funkcjonująca rodzina stanowi podstawę egzystencji każdego dziecka, lecz ta instytucja jest szczególnie istotna w przypadku dziecka niepełnosprawnego. Narodziny dziecka niepełnosprawnego częstokroć wywołują kryzys w rodzinie, powodując konieczność zmian w jej funkcjonowaniu. Ten typ rodziny ma inne potrzeby, zarówno te dotyczące pomocy dziecku, jak i jego najbliższymi. Tym samym taka rodzina wymaga innego wsparcia, do którego zalicza się wsparcie: informacyjne, emocjonalne, materialne, wsparcie przy świadczeniu usług oraz wsparcie w rozwoju. Zdaniem autorki system wsparcia na rzecz osób niepełnosprawnych jest dalece niedoskonały, przez co nie spełnia swojej roli. Autorka konstatuje, iż w takich warunkach sama rodzina stanowi dla siebie najważniejszy element wsparcia.

Słowa kluczowe: rodzina z dzieckiem niepełnosprawnym, potrzeby rodziny, relacje w rodzinie, wsparcie instytucjonalne