Ondrej Botek & Nadezda Kovalcikova: The usefulness of the sources of formal and informal support in the context of the needs of families with children with disabilities

Absztrakt

A tanulmány háttere: Egy fogyatékossággal élő gyermek nagy változást hoz a család életébe és a család minden tagjának életminőségére hatást gyakorol. Megváltoznak a család szükségletei, különösen, ha támogatásra van szükségük.

A tanulmány célja: A tanulmány célja annak feltérképezése, hogy a fogyatékkal élő gyermeket nevelő családok a családi szükségletek összefüggésében mennyire érzik hasznosnak a rendelkezésükre álló formális és informális támogatási forrásokat. Ez az információ nagyon fontos visszajelzés a szociális munka, a szociálpolitika, valamint a formális és informális környezet szereplői számára.

Módszerek: A vizsgálat kvantitatív kutatási módszeren alapult. A vonatkozó adatokat két standardizált kérdőív, Dunst, Jenkins és Trivette Családtámogatási skálája (FSS) továbbá a Bailey és Simeonsson (1988) által készített The Family Needs Survey segítségével szereztük be. A válaszadók mintáját 493 fogyatékossággal élő gyermek szülei alkották, akik között jóval több nő – anya (N= 427), mint férfi – apa (N= 66) volt.

Eredmények: A vizsgálat eredményei azt sugallják, hogy a fogyatékossággal élő gyermeket nevelő családok számára a legmarkánsabb igény a hozzátartozóik által nyújtott segítség, ugyanakkor egyre nagyobb anyagi támogatásra is szükségük van. A források hasznosságának megítélése szempontjából az informális támogatás volt dominánsabb, leghasznosabbnak a férj/feleség/élettárs és a közeli hozzátartozók támogatását ítélték meg. A tanulmány igazolta különböző statisztikailag szignifikáns összefüggések létezését. Ilyen például a szülői csoportok, az anyagi szükségletek és a közösség támogatásának szükségessége közötti informális segítő kapcsolat.

Következtetés: A vizsgálat fontos tényt igazolt: bármilyen formális, de főleg informális támogatás közvetlen hatást gyakorol a szükségletek kielégítésének mértékére. A támogatási források megléte és hasznossága pozitívan befolyásolja a családi szükségletek kielégítését.

Abstract

Background: A child's disability changes the family and has an impact on the quality of life of all its members. Consequently, the family's needs change as well, especially when it comes to their need for support.

Goal: The goal of this study was to map how families with children with disabilities perceive the usefulness of the sources of formal and informal support in the context of family needs, as very important feedback for social work and social policy as major actors in formal support.

Methods: The study was conducted using a quantitative research strategy. The relevant data was acquired using two standardized questionnaires – The Family Support Scale (FSS) by authors Dunst, Jenkins and Trivette (1984) and The Family Needs Survey by authors Bailey and Simeonsson (1988). The sample of respondents was comprised of 493 parents of children with disabilities, out of which there was a much larger number of women – mothers (N= 427) than men – fathers (N= 66).

Results: The results of the study suggest that for families with children with disabilities, the most dominant need is the support from their relatives, while they also feel an increased need for finances. In terms of the perception of the usefulness of sources, informal support was more dominant, and the support of a husband / wife / partner and close relatives was determined the most useful. The study proved the existence of various statistically significant links, such as the link between informal support in the form of parent groups, financial needs, and the need for support from the community.

Conclusion: The study proved an important fact – that whichever kind of formal, but mainly informal support has a direct influence on the extent of the satisfaction of needs. The presence and usefulness of sources of support positively impacts the satisfaction of family needs.

Keywords: Family; Disability; Family needs; Social support

Introduction

Parents see their child's health as one of the most important values, and only a few life events can be graver than discovering that their child will not develop how they imagined. The birth of a child with a disability, or alternatively the development of disability later in life, brings a series of changes into the lives of the family. They find themselves in a new situation that requires a change in lifestyle, assuming new roles and fulfilling new tasks. Disability also affects the needs of the individual members of the family and new, specific needs emerge, one of which is the need for support from the family of the child with disabilities. Family support can act as a defense mechanism with dampening effects, which may impact the family's wellbeing as well as the quality of parenting and the child's resilience in critical situations. Support is also perceived as an important determinant of the impact of stressful events on personal well-being (Mak and Ho, 2007). In the context of the need for support of families with children with disabilities, we could talk about formal and informal sources of support. Informal sources represent support from other family members, other parents with children with disabilities and the community at large. Formal sources of support include professional help, pediatricians and general practitioners and professional services. The presence and availability of both formal and informal sources of support is essential for an optimal functioning of families with children with disabilities. It is for this reason that we conducted a study aimed at the perceived effectiveness of formal and informal sources of support by the families with children with disabilities.

Methodology

The goal of the conducted study was to discover how families caring for a child with a disability perceive the usefulness of formal and informal sources of support in the context of family needs. The study was conducted using quantitative research strategy. In order to acquire the relevant data necessary to fulfil the pre-determined goal, we used two standardized questionnaires. The first questionnaire was "The Family Needs Survey" by authors Bailey and Simeonsson aimed at identifying the individual needs of families with children with disabilities. The Cronbach's alpha for the study of family needs was $\alpha = 0{,}891$. The second standardized questionnaire was "The Family Support Scale" (FSS) by authors Dunst, Jenkins and Trivette and it was used to measure the usefulness of the individual sources of support for the family. There are 18 sources defined in the questionnaire, including family and other relatives, informal and formal sources of support, as Co-workers, Parent groups, Social groups/clubs, Professional agencies, etc. The Cronbach's alpha held the value of α = 0,940.

The standardized questionnaires were extended to include questions on the demographic data of respondents, i .e. their gender, age, family status, education, residence, number of children and number of children with disabilities, the child's diagnosis, the age of the child with a disability and medical devices used by the child.

The study included parents with children with disabilities. The selected respondents were the result of a deliberate choice (personal home care for the child with disabilities) and snowball sampling. The final number of respondents in this study was 493 (n = 493). The overall number of women – mothers participating in the study was 427. The rest of the respondents were men numbered at 66. The average age was 38, 15 ± 7, 62, the range = 18 – 65 respondents. The acquired data was processed using the statistical program Statistical Package for the Social Sciences 23.0 from the company IBM.

Results and discussion

Table 2 – Mean scores of the key variables

	Mean	SD	Range of the scale
Information	2.12	0.58	1 - 3
Family a Social Support	2.02	0.59	1 - 3
Financial	2.09	0.72	1 - 3
Explaining to Others	1.64	0.61	1 - 3
Child Care	1.75	0.68	1 - 3
Professional Support	1.76	0.62	1 - 3
Community Services	2.00	0.66	1 - 3
Family Needs Total	1.95	0.45	1 - 3
* Higher score in this scale indicates a higher level of perceived needs of the family			
Kinship	2.87	1.24	0-5
Spouse/Partner	2.66	1.30	0-5
Informal Support	2.07	1.20	0-5
Programs/Organizations	1.80	1.31	0-5

Professional Services	2.30	1.27	0-5
Informal Support Score	33.32	16.20	0-75
Formal Support Score	9.19	5.09	0-20
Family Support Score Total	42.51	20.17	0-95

*****Higher score in this scale indicates a higher helpfulness of support sources for families

When identifying the individual needs of families with children with disabilities, the highest average score was recorded in the subscale of financial needs (2.0933) as well as the subscale of need for support (2.0266). The functioning of the family is dependent on their economic conditions. Caring for a child with a disability immediately means an increase of financial expenses, which is often connected to the loss of financial income of one of the parents who cares for the child. Higher financial expenses are also connected to more frequent visits to specialists, necessary medication, medical rehabilitation, specific nutrition, as well as special medical devices. The above-mentioned aspects create a need for compensation of the increased financial expenses. Families deal with compensation in different ways, for example regular or one-off contributions. As stated in (Bazalová, 2014), allowance is not sufficient for families with children with disabilities given their necessary expenses. Despite the fact that caring for a child with disabilities is financially demanding, recent research suggests that the situation in Slovakia is slowly improving. The period between 2012 and 2015 marked a gradual decrease of the risk of social exclusion and poverty in households with a person with disabilities (Repková et al., 2016).

The need for support from relatives, which the parents identified as “secondary”, is closely related to the presence of various sources of support. It is one of the most important factors impacting overall quality of family life. The quality of life of families caring for children with disabilities is influenced by several factors, including the presence and availability of various sources of support. As is stated by the authors (Vágnerová and Hadj-Moussová, 2003), familial support is a key factor with respect to the future, especially when the family is caring for a child with disabilities. The presence and availability of sources of support is considered to be a strong determinant that impacts the quality of life, the reduction of stress and the improvement of adaptation. In terms of family support, they state both formal and informal sources of support. The formal sources include mostly professional help, intended to provide material, financial, socio-psychological, social, socio-educational and educational support and help. Informal social support includes family members, friend groups, interest groups, colleagues, neighbours and other groups that help empower the family and do not operate through any particular institution.

When researching the individual sources of support in families with children with disabilities in the conducted study, the highest score was achieved in the subscale of kinship (2.8742), while the lowest score was recorded in the subscale of programs/organizations (1.7956). This means that close relatives remain the most essential element of support, and their support isconsidered to be the most useful.

An analysis of the results of the conducted study demonstrated the existence of a link between informal sources of support for the family and all observed dimensions of needs of families with children with disabilities. The research focused on finding a link between the individual groups of sources that could be categorized as informal. Each group consisted of an individual subscale.

Table 3 - Spearman´s correlation coefficients (r) for the formal and informal support variables

	Information	Family and Social Support	Financial	Explaining to Others	Child Care	Professional Support	Community services
Kinship	-	-.112[a]	-	-	-	-	-
Spouse/partner Support	-	-.157[b]	-	-	-	-	-
Informal Support	-	-	.162[b]	-	.150[a]	-	-
Programs/ Organizations	-	-	.167[b]	-	.176[b]	-	.163[b]
Professional Services	.116[a]	-	.112[a]	-	.153[b]	-	.173[b]
Informal Support Score	-	-	.098[a]	-	-	-	-
Formal Support Score	.116[a]	-	.112[a]	-	.153[b]	-	.173[b]
FSS Total	.089[a]	-	.120[b]	-	.116[a]	-	.122[b]

[a] Correlation is significant at the 0.01 level (2-tailed)
[b] Correlation is significant at the 0.05 level (2-tailed)

The first subscale of informal sources of support titled “Kinship” consisted of a group of people: partner’s friends, own friends, other parents and church. The second subscale titled “Spouse/Partner Support” included spouse or partner and spouse’s or partner’s parents and other relatives. The third subscale of informal sources of support labeled “Informal support” included own parents, own relative/kin, own children, neighbours and etc. Social groups and clubs, parent’s groups, school or daycare centers, coworkers and others were included in the last group of informal sources titled “Programs / Organizations”. Parents of children with disabilities may often feel lonely, abandoned and forced to do everything by themselves. It is understandable given how after receiving the diagnosis, they are surrounded by a great deal of new information, stimuli and demands that they have to process. The presence of a child with disabilities forces the family into a new situation and often impacts the functioning of said family. The care for the child presents new challenges and obstacles that the family has to overcome together. When caring for children with disabilities, it is essential that the family be united. Support and help from people who belong in the family’s closest circle is irreplaceable. Mutual support and help may strengthen the relationship of the parents as well as the whole family. The research by Jaser et al. (2009) proved that mothers experience a greater deal of emotional stress than fathers. This is caused by the fact that mothers are more involved in care, they are more frequently subjected to stigmatization from other people and in most cases, they remain at home with the child. Other results of the aforementioned research confirmed a correlation between the levels of stress in fathers and the levels of stress and depression in their spouse. As stated by authors Friedrich et al. (1985) social support in the form of marital happiness and positive family climate is connected to more effective coping strategies. The conducted study also confirmed the significance and usefulness of the partner as a source of support and discovered a statistically significant link between the need for support and the subscale of husband/partner (r= .157; p= .000).

Family support is related to a network of other social relationships, be it extended family or friends. The attitudes of these essential people significantly contribute to the formation of the parents' own perspective. If the mutual communication is open, direct and positive, these people can act as an important source of help and support, but also provide incentives towards viewing the difficult situation from another perspective. The presence of good and sensitive friends helps the families cope. Parents perceive the support they receive from their loved ones as an important protective and alleviating factor. Another important source of support are other parents of children with a similar diagnosis. Families seek out other parents with similar experiences and a similar perspective. These parents, however, do not want the child's diagnosis to be the only focus of the relationship. In a friendship, it is necessary to share other aspects of life as well. The conducted study only supports this, as it recorded a statistically significant link between the need for support and the subscale "Kinship" (r= -.112; p= .012). It would be possible to conclude that if the usefulness of a source of support from relatives increases, the need for support in parents with children with disabilities decreases.

It is important for the family to create and build new social connections, which can often help them contact other parents and specialists. Creating connections also includes networks created with the help of parent organizations, i.e. organizations with a common goal to cover the individual forms of disability or even disability in general. A positive aspect of these organizations is the opportunity for the parents to exchange essential information, related to for example caring for a child with disabilities, raising a child with disabilities, personal experiences, subjective feelings, etc. The fact that parents of children with disabilities consider programs/organizations (r= .176; p= .000) and informal support (r= .105; p= .020) to be useful and helpful is also proven by the results of the conducted study. A statistically significant link was found between the need for care for the child and the subscale of programs/organizations and the subscale of informal sources. In the eyes of the parents, organizations represent the community; a place where they belong and feel safe. The conducted study also proves that families with children with disabilities consider these programs/organizations to be useful sources of support when fulfilling the need for support in the community (r= .163; p= .000).

As was mentioned in the introduction, caring for a child with disabilities is financially demanding. Families find themselves in financial distress and that is where organizations and other informal sources of support can be immensely helpful. This fact is confirmed by the results of the data analysis in the conducted study, which discovered a statistically significant link between financial needs and the subscale of programs/organizations (r= .167; p= .000) and the subscale of informal sources (r= .162; p= .000). These results suggest that the bigger the financial need of a family with children with disabilities, the higher the perceived usefulness of informal sources of support and the usefulness of programs and organizations dealing with the given issue.

The analysis of the results of the conducted study has proven a link between formal sources of support for the family and all observed dimensions of family needs. Formal sources of support include specialists ready to help, medical doctors and professional services. The conducted study stated sources in the subscale labeled "Professional services". It discovered a statistically significant link between formal sources of support in the subscale of professional services and financial needs, the need for care for the child and the need for support in the community. It is possible to conclude that the higher the stated needs, the higher the perceived usefulness of the formal sources of support labeled as "professional services".

Each family with a child with a disability should be entitled to professional as well as counseling help. These families require a multidisciplinary approach, which should include support and help from physicians, psychologists, special education teachers and social workers. Their presence in the process of caring for the child helps the family deal with the stressful situation and cope with it. Their help and support are also needed when creating ideal conditions for the child's development. For families with children with disabilities, formal sources of support mean the presence and availability of competent specialists and professionals ready to provide help in various areas of care for the child and also provide general support to the family. The usefulness of professional services as a source of support hinges on the relationship between the specialists and the families. As long as the cooperation is based on trust, good knowledge of the whole family system and the issue itself, there is a high chance that the relationship will be positive and beneficial for all parties. Professional support is important when providing information, educating parents, solving issues and developing the connection between families and services. When talking about the need for care for the child and the source of support from professional services, it is necessary to mention the service of early intervention. The service of early intervention is intended for families with children under the age of 7. It is provided if the child's development is at risk due to health issues. Early intervention includes specialized social counseling, social rehabilitation and help with the complex development of a child with disabilities. This form of help is carried out either in the field or on an outpatient basis. The services of early intervention play an important role in the life of the child and the family as early as the prenatal period. Turnbull and Turnbull (2010) state that relationships built between families and specialists are beneficial for both parents and children.

As was stated above, we discovered a statistically significant link between financial needs and sources of support labeled "professional services." The financial resources available to families with children with disabilities can hardly satisfy even the most basic needs of the child, which should be a matter of course, not to mention the needs that are above standard. Weak financial security has an adverse effect on the satisfaction of the needs of all family members and the management of the household. Similar to being orphaned, loosing a job, etc., the society perceives disability as a social event, i.e. a state when the citizen is entitled to one of the forms of help given by legislation. A specialist, especially a social worker, should be able to inform such parents on conditions that the society creates for the future education of their child and the preparation for his or her employment; inform them on assistive devices currently on the market, and explain, which of them are fully or partially covered by the insurance and which are eligible for an allowance from the government (Levická, 2007). The state provides financial support by compensating for increased expenses in the domain of mobility and orientation, communication, dietary regime, expenses related to hygiene or the wear of clothing, linens, footwear and furnishings, as well as the provision of a motor vehicle. Financial allowance is also provided for the purpose of personal assistance, purchasing assistive devices and related training, adjustment and maintenance of said devices, transport and adjustment of the apartment, house or garage (Halušková, 2010).

Social policy and social work implications

It’s already mentioned that the highest average score was recorded in a subscale of financial needs and the subscale of need for support. This fact indicates that families perceive the financial help from state as one of the most important. Despite the fact that decrease of the risk of social exclusion and poverty in household with persons with disabilities is observed in last years, financial support is perceived as not sufficient. This view could be caused by unclear understanding of the benefits and the goals they should reach. We find as very important to present these goals more clearly to beneficiaries. Research results also show that close relatives remain the most essential element of support and their support is considered to be the most useful. This finding indicates the need to focus social work intervention also to the closest relatives, who plays important role in satisfying the needs of families with children with disabilities. Where these interventions are already available, we need to make them more visible and accessible. Our study has also proven a link between formal sources of support for the family and all observed dimensions of family needs. Especially efficient networking of these formal sources of support has been stressed. Particularities of Slovak system, where health and social affairs belongs to two different ministries, often cause lower perceived availability of these interventions. More efficient network and collaboration between health and social services is thus needed to ensure higher accessibility of multidisciplinary intervention.

Conclusion

The results of the research clearly prove that despite the growth of supportive services, families with children with disabilities are still facing similar and recurrent problems rooted in three key pillars: support, knowledgeableness, and financial needs. Support provided by relatives and specialists is an important source of assurance that there are people, who are ready to help not just on an emotional, but also a material level. Informal sources of support are a part of the natural and close environment of the families. If we are to speak of formal support provided by specialists, it is often unclear and unavailable, especially from a geographical and sometimes from a financial standpoint.

We would also like to emphasize that a very important support tool for families with children with disabilities is an opportunity to meet other parents with similar issues. Specialists should thus do their best to create and coordinate self-reliant groups.

Specialists also play an important role in fulfilling the need for information, which is on one hand connected to the process of diagnosis, treatment and prognosis, and on the other hand connected to constant care for the child, information on support services, financial aid, etc. Sufficiency of information on the state of health and information on the options of support are an essential source of assurance for the parents and have a significant impact on the elimination of stress, which likely impacts the level of care and attitude towards the child with disabilities and determines the relationships and interactions within the family.

It follows from all the foregoing that coordinated multidisciplinary attitude is important from the moment of discovering the diagnosis until the time when the parents reach out for help and support. This multidisciplinary attitude should be guaranteed by services of early intervention. In Slovakia, such services are still in their infancy. Examples of good practice from abroad and from existing centers of early intervention in Slovakia show that these services have an apparent impact on the whole family.

Securing the needs of children with disabilities as well as other family members in an optimal and economical way is necessary for the functioning of the family and the quality of their lives. Disability should not be an economic burden, but reality suggests otherwise. Covering family expenses often from a single source of income is insufficient and governmental financial support, for example in the form of parental allowance and later care allowance, is low as well. Other research suggests that care for children, medication and rehabilitation increase the financial burden when compared to families with children without disabilities. Sustaining financial needs should not just be up to the family, who have usually exhausted all options of increasing their income, but up to the state or third-party organizations, which seem to be very beneficial. Families with children with disabilities need a certain level of help and support in order to achieve an optimal level of functioning, health and stability. All helping specialists engaged in helping and supporting families with children with disabilities should aim to positively impact how the family functions. Families with a strong support system tend to have a better quality of life, as they have access to a wide range of sources (Duns et al., in McWilliam and Scott, 2001). We agree with the opinion of author Hovorková (2006) that before providing any help or support, it is essential to first identify the social, emotional and material sources available to the family. Identifying the sources will provide the assisting specialist important information on the primary needs of families with children with disabilities.

We agree with the opinion of authors Matoušek et al. (2014) that when working with families with children with disabilities, it is important to acknowledge the fact that until the initial shock fades, the parents' reactions might be intense and might not immediately fade. It is essential that during this period, specialists encourage the parents to openly express their emotions and encourage the support from their relatives. Specialists are expected to critically and tactfully approach the defensive reactions of the parents trying to assign blame for their "misfortune". As we mentioned, such families are going through a period of certain changes which often erode their stability. It is thus essential to support the unity of the family as much as possible and support the working relationships within the family and with other loved ones. When dealing with families with children with disabilities, it is necessary to support their relationship with the wider social environment, which protects the families from social isolation that so often threatens them. Maintaining or creating social connections helps the parents adapt to the new situation they are finding themselves in. It is necessary that families with children with disabilities know that they are not alone and that they, too, can live full lives. Each area of the needs of families with children with disabilities should be sufficiently satisfied. It is thus important that the assisting specialists form a single multidisciplinary unit marked by close cooperation and mutual reinforcement. The presence of a multidisciplinary team will provide the families with the help and care that are complex and timely.

Research and surveys aimed at families with children with disabilities (quality of life, functioning and needs) are an important reference point for the future planning of necessary services, and yet, they also reflect the current level of their quality. It is thus necessary to conduct research such as this one, so that the services used by the family truly satisfy the family's needs and have a positive impact on their lives.

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