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## THE ROLE OF SOCIAL SUPPORT IN ACHIEVING MENTAL WELL-BEING FOR PARENTS OF DISABLED CHILDREN

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**Abstract:** The article focuses on assessing the psychological situation of parents and adult siblings of people with intellectual disabilities. The aim of the research presented in this article was to check whether social support plays an important role in achieving social well-being of parents raising children with intellectual disabilities and their adult siblings. Analysis of the research results made it possible to conclude which dimensions are particularly important for specific components of mental well-being among parents and adult siblings of people with intellectual disabilities. Research confirmed some theoretical assumptions about the role of support as a determinant of the level of psychological well-being of the respondents.

**Keywords:** psychological well-being, disability, social support, quality of life.

### 1. Introduction

The birth of a disabled child can be a crisis event associated with high stress for the family. Family stressor is an event or circumstance strong enough to cause a change in the family system (Buczyński, 1999, p. 47). The diagnosis of a child's malformation, whether during pregnancy or after his birth, puts the functioning of future or "freshly baked" parents under the sign of sadness and mourning after losing the image of their dream child (Pisula, 2007), which can significantly affect the parent-child relationship. The way in which health care providers communicate a diagnosis concerning the child's illness is also extremely important. Although becoming aware of the illness it is the moment that parents of sick children would often not forget throughout their lives, the right way of passing a diagnosis can significantly affect the reaction of mother and father, as well as the process of coping with difficulties. The appearance of a child with a disability in the family changes the roles in the family system (Kasten, 1997). This also applies to assuming the roles assigned to children at a given time. Healthy children are expected, more or less consciously, to take care of their siblings, but also to be more mature.

Thus, if the disabled child is older, the younger brother or sister is expected to come of age faster in order to be able to look after sibling (Żyta, 2008). Healthy children, in order to draw parents' attention, may show difficult, rebellious behavior, aggression or even physical violence. Studies show that able-bodied siblings experience high emotional tension and increased anxiety in connection with their brother or sister's disability, and therefore such traits as lack of independence, infantilism, lack of aspiration, low self-esteem, excitability and loneliness may develop (Nyga, 1985; Jarzębska-Baziak, 1973). Each of them can assess the world subjectively, what may impact their personal feelings concerning the level of quality of their own lives.

## **2. Mental well-being and social support – research reporting**

In modern psychology, the category of life satisfaction is one of the most commonly used in research on well-being. Mental well-being is defined as a cognitive and emotional assessment of one's own life, which includes both cognitive judgments and emotional responses to various life events. People with a sense of high well-being are characterized by experiencing positive emotions, a low level of negative mood and a high level of life satisfaction (Diener, Lucas, Oishi, 2004). In the context of research on the mental well-being of parents and siblings of people with disabilities, the theory of dynamic balance of well-being created by Headey and Wearing (1989, 1991, by Diener, Lucas, Oishi, 2002) may be useful. It refers to the maintenance of well-being after a crisis event. The authors assume that people have the ability to return to the level of happiness despite various, even unfavorable or difficult events. According to them, there are two groups of factors affecting well-being: i.e. permanent resources and psychological influences. Permanent resources mean everything that never changes in human life or changes rarely and slowly, e.g. social background, gender, age, personality traits, education). Psychological influences are contentment and dissatisfaction with regard to the life events that are subject to change. It seems that in order to indicate the areas of functioning that are particularly important and useful for research on the well-being of parents and siblings of people with disabilities the dimensions provided in the Ryff Scales of Psychological Well-Being may be applied (1989).

According to researchers, in order to achieve a satisfactory level of well-being, a balance should be maintained between two areas: challenges that an individual must face, as well as internal (personal) and external (relational) resources (Dodge, Daly, Huyton, Sanders, 2012). Recent studies (Kózka, Przybyła-Basista, 2018) show that social support is an important predictor of psychological well-being in parents of children with Down syndrome.

Authors of works and studies describe social support in various ways. According to Sarason (1982, by Cieślak, Sęk, 2005, p. 14) it is an aid available to the individual in difficult situations. It is also identified with helping behavior (Gottlieb, 1978, by Cieślak, Sęk, 2005, p. 14), as well as with satisfaction of needs in hard moments, guaranteed by significant persons and reference groups (Caplan, 1997, by Pommersbach, 1990, p. 353-354, by Deręgowska, 2010). Social support is available to the individual at all times and is associated with his presence in the support network, while the demand for it increases in an emergency or crisis. Then it acquires a special meaning for the person. The family - parents, spouses, siblings – play significant role, if not the most significant, in the creation of mental well-being (Campbell, Converse, Rodgersa, 1976, by Krok, 2010). Maintaining social relationships and satisfying the natural need for belonging, contribute to an increase in the level of mental well-being and negatively correlates with feelings of anxiety, jealousy, loneliness and guilt (Myers, 2000, by Jach 2012, p. 63). The authors of the study present many positive effects of receiving social support in various situations. According to Górniewicz and Deręgowska (Górniewicz, 1997, by Deręgowska, 2010), support should be regarded as beneficial and serving the good of others. It promotes effective coping and helps in better adaptation to difficult events, as well as strengthens self-esteem (Silver, Wortman, 1984; Taylor, 1992, by Kubacka, Jasiocka, 1999). Researchers show that perceived support is more important for well-being, stress management and health compared to support received (Łuszczynska, Cieślak, 2005, by Buszman, Przybyła-Basista, 2015).

Social support plays an important role in the process of adaptation to the new situation faced by parents of children with disabilities (McCubbin, Petterson, 1983). It affects the stress level of mothers of children with autism and reduces parental stress levels for parents of children with holistic developmental disorders (Bristol, Schopler, 1983, by Sekułowicz, 2013). The disability of one family member influences the entire family system, thus it concerns not only parents or guardians, but also siblings, who in many cases are neglected or overlooked. Examining parents and siblings of people with disabilities allows to create an appropriate system of support and assistance for such families (Żyta, 2011, p. 153).

### **3. Methodology of the own research**

The research problem presented in this article concerns the role of relational resources in shaping mental well-being among parents and with regard to intellectual disabilities. The aim of the study was to check which of the selected relational resources are important predictors of mental well-being in the group. The research was also aimed at showing whether the parents and siblings of the sick child differ in relational terms, as well as in the level of mental well-being. In the light of the aforementioned research, it can be stated that social support (relational

resource) constitute an important resource that helps with adaptation to a new situation and return to a satisfactory level of mental well-being. The previous studies on the impact of social support on the psychological well-being of individuals in difficult situations indicate the existence of relationship between these variables. This research is aimed at checking whether there are the individual relationships between the aforementioned variables in the group of respondents.

The following research question was asked: *Are the various dimensions of social support important predictors of the psychological well-being of parents and siblings of people with disabilities?*

In order to answer the research questions posed, the Berlin Social Support Scales – BSSS (Schwarzer, Schulz, in Polish adaptation by Łuszczynska, Kowalska, 2002) was used to measure cognitive and behavioral dimensions of social support. The questionnaire consisted of five scales: perceived available support, received support, demand for support, seeking support, protective support. There was also a scale used for examining the person providing support (support currently provided). Individual scales showed high reliability: perceived available support ( $r = 0.90$ ), received support ( $r = 0.90$ ), demand for support ( $r = 0.71$ ), seeking support ( $r = 0.80$ ), protective support ( $r =$  ). The second test was the Psychological Well-Being Scale (PWB). This scale was based on the eudaimonistic concept of psychological well-being (Ryff, 1989) including six dimensions: self-acceptance, environmental control, personal development, positive relationships with others, life purpose and autonomy. It consists of 42 statements, to which the examined person refers on a 7-point scale. Polish adaptation was made by D. Krok (Krok, 2009) for the purpose of research on quality of life.

The research group consisted of 107 people, 77 (72%) women and 30 (28%) men. The respondents were in the age range between 28 and 55 years old.

In order to answer the research questions, the obtained data were subjected to statistical analyses. According to regression assumptions, the distribution of each variable was checked in the first place. All variables, except for autonomy and personal development (dimensions of psychological well-being), had different distribution compared to normal state. Then, after checking the correlation between variables, a regression analysis was performed, which made it possible to identify important factors of mental well-being.

The regression analysis showed that among many factors, perceived social support should be regarded as an important predictor of autonomy, in particular with regard to its emotional dimension. It explains 11% of the variance of the dependent variable. The proposed regression model proved to be well fitted to data. Based on the regression coefficients, it can be concluded that the perceived social support, and especially the emotional dimension, are moderately weak and positively associated with mental well-being. The results are presented in Table 1.

**Table 1.**  
*Important predictors of autonomy*

	<b>b*</b>	<b>p</b>	<b>F (df)</b>	<b>R2</b>
Perceived support	<b>0,333</b>	<b>0,04</b>	4,218	0,104
Perceived emotional support	<b>0,343</b>	<b>0,04</b>	4,532	0,111

Subsequent analyzes of the results revealed predictors of positive relationships with others as a dimension of psychological well-being. Among these predictors there are perceived and received social support along with its dimensions (emotional, instrumental and informational support). Received support turned out to be the strongest predictor explaining 50% of the variable's. The dimensions of received support also constitute strong predictors as follow: emotional, informational and instrumental support. Selected models were well matched. Satisfaction with the support received is also a strong predictor of positive relationships with others. It explains 34% of the variance of the dependent variable. The weaker, but equally important predictors are the dimensions of perceived support, explaining the variable from 15% to 23%. The results are presented in Table 2.

**Table 2.**  
*Significant predictors of positive relationships with others*

	<b>b*</b>	<b>p</b>	<b>F (df)</b>	<b>R2</b>
Perceived support	<b>0,493</b>	<b>0,002</b>	11,056	0,234
Emotional perceived	<b>0,391</b>	<b>0,01</b>	6,495	0,152
Perceived instrumental	<b>0,420</b>	<b>0,008</b>	7,695	0,176
Support received	<b>0,692</b>	<b>0,000</b>	36,975	0,506
Received emotional	<b>0,688</b>	<b>0,000</b>	34,273	0,487
Received instrumental	<b>0,648</b>	<b>0,000</b>	26,068	0,419
Received informative	<b>0,653</b>	<b>0,000</b>	26,851	0,427
Satisfaction	<b>0,586</b>	<b>0,000</b>	18,897	0,344

The regression analysis performed showed that the important predictors of having a life goal are the dimensions of perceived support and the support received (overall score). The proposed regression model is well suited. Based on the results of regression, it can be concluded that the dimensions of support are moderately weak and positively related to life goal. The strongest predictor is perceived support, which explains 22% of the variance of the dependent variable. The results are presented in Table 3.

**Table 3.**  
*Significant life goal predictors*

	<b>b*</b>	<b>p</b>	<b>F (df)</b>	<b>R2</b>
Perceived support	<b>0,460</b>	<b>0,002</b>	10,224	0,221
Emotional perceived	<b>0,380</b>	<b>0,02</b>	5,756	0,137
Perceived instrumental	<b>0,439</b>	<b>0,004</b>	9,114	0,202
Received emotional	<b>0,351</b>	<b>0,03</b>	4,791	0,117

A recent regression analysis showed four important predictors of self-acceptance. They are: optimal regulation and received social support along with its dimensions – emotional and instrumental support. The results are presented in Table 4.

**Table 4.**  
*Important predictors of self-acceptance*

	<b>b*</b>	<b>p</b>	<b>F (df)</b>	<b>R2</b>
Support received	<b>0,359</b>	<b>0,02</b>	5,327	0,128
Received emotional	<b>0,343</b>	<b>0,03</b>	4,826	0,118
Received instrumental	<b>0,377</b>	<b>0,01</b>	5,977	0,142

#### 4. Conclusions

The analyzes made it possible to answer the research questions. According to the results, parents of people with disabilities may show a higher level of anxiety, as well as they may more often be excluded from social contacts (Gold, 1993; Fisman, Wolf, Freeman, 2000). There is a risk of emotional and adaptive problems or difficulties in dealing with others. These are factors that can reduce well-being.

Regression analyzes revealed significant predictors of mental well-being. It was noticed that a different predictor can be assigned to each dimension of well-being. Perceived social support, and especially its emotional dimension, turned out to be an important predictor of autonomy. The result of the research is important in the light of other studies (Siegel, Silverstein, 1994) which show that support in the family, especially the perceived one, can enable healthy parents of a child with a disability to feel autonomous and independent.

Important predictors of positive relationships with others as a dimension of psychological well-being are: perceived and received social support, together with its dimensions (emotional, instrumental and informational support).

The strongest predictor turned out to be received support and its dimensions. The research Dunkel-Schetter and Bennet (1990, by Łuszczynska, Kowalska, Mazurkiewicz, Schwarzer, 2006) also proved that perceived support in comparison with received one, has a greater and more direct impact on well-being and health. However, according to the research, the support received constitutes stronger predictor among parents of children with disabilities. Perceived support turned out to be a strong predictor of the sense of having a life goal.

The last important predictor of self-acceptance turned out to be relational dimension: social support received, together with its dimensions – emotional and instrumental support. The research results obtained confirmed the impact of relational resources, i.e. social support, on the individual's psychological well-being (Campbell, Converse, Rodgers, 1976, in Krok, 2010). It can be also concluded that for people bringing up a child with a disability, it is very important to receive support from others, but also to have the feeling that they are around people

who will support them in a difficult situation. Emotional support will build a sense of security, and this in turn will affect the level of self-acceptance and development independence.

In further research, it will be worth paying attention to assessing the quality of life of parents of children with disabilities. It is recommended to carry out qualitative research which would show specific areas where parents of these children would need help.

The research conducted showed a great role of relations with other people and support received from them (cf. Kucharewicz, Kornatka, 2019), in shaping mental well-being, especially on self-acceptance. The creation of support groups or places, also dedicated to the siblings of disabled people, in which they would learn about the functioning of their sick loved ones, could be a specific action. Additionally, it would be important to create classes for parents on how to support the development of a healthy child, but also how to support a child in difficult situations after the birth of a child with a disability. The next step would be rehabilitation for people who cannot cope with disability of a child or siblings, but also actions to support these people.

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