



KAROLINA KALISZEWSKA

Institute of Psychology, Faculty of Humanities,  
Szczecin University

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## The process of adaptation to the role of a parent of a child with Down syndrome as a stress management strategy

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The process of adaptation to the role of a parent of a child with Down Syndrome is very difficult, multi-staged and stress-causing both for mothers and fathers (Będkowska-Heine, 2003; Kościelska, 1998; Liberska and Matuszewska, 2011; Żyta, 2004). Coping with parental stress is a constant challenge for mothers and fathers of a child with Down syndrome and it increases the significance of different types of social support. The choice of the coping strategy can improve the parents' cognitive abilities and competences of emotional and behavioural control and it also facilitates a more positive assessment of their intellectually disabled child (Turnbull et al., 1993). If parents choose a more adaptive, problem-focused coping strategy, adaptation to the parental role proceeds more fluently and more adequately (Abery, 2006; Lackaye and Margalit, 2006; Van Riper, 2003). In addition, it has been proven that receiving social support and using accommodative coping styles may boost the process of adaptation to the role of a parent of a child with Down syndrome (Atkinson et al., 1995; Dunst, Trivette and Deal, 1988; Florian, Krulik, 1991; Friedrich, Wilturner and Cohen, 1985; Lam and Mackenzie, 2002; Sullivan, 2002; Van Riper, 1999).

**KEY WORDS:** Down syndrome, family with a disabled child, adaptation to the parental role, coping with parental stress, social support

## The parental role. Introduction

Each person who belongs to the family system accepts specific tasks and shows specific attitudes and behaviours. The accepted role defines the type of activity and choices that should be and are made. By analogy, it is the assigned or accepted role within the family system that determines our relations and behaviours towards other family members (Będkowska-Heine, 2003). As life goes on, every person accepts or adopts various roles which have define the form and content of activity (Łoś, 1999). Amedeo *Cencini* and Alessandro *Manenti* (2002) argue that the social role is a culturally defined set of expectations towards individuals who have a specific position within the social structure. Norms define the role and the person's behaviour. They are interpreted by that person and constitute the sole explication of the individual system of meanings. It may happen that a person must adapt to the assigned or chosen role in a long process of learning to meet the related expectations and requirements, which is connected with the individual development (Łoś, 1999). For instance, the parental role is not always the outcome of giving birth to a child, but it may be a continuation of a role related to gender or marriage (Ziemska, 1973).

Teresa Rostowska (2009) believes that a family role usually means a model of behaviour (or of its image) that are manifested in social situations related to the functioning of a family (Rostowska, 2009). According to Maria Ziemska, the parental role is the acquired structure of cognition, aspiration and affection that drives the parents' behaviour towards their child (Ziemska, 1973). Parental roles cover behaviours common to both parents and others that are specific to the mother or the father. For instance, the mother conceives and gives birth to the child and then takes care of his/her proper growth and upbringing. The mother's role also includes showing affection, warmth and understanding to the child and bringing him/her into family life and traditions (Rostowska, 2009).

The contemporary expectations with respect to the father's role are different than the ones typical of the traditional, patriarchal family. As a result of social, cultural and economic changes, financial

support and economic stability are not the only expectations related to the role of the father. Today, the parental role of a man includes participation in house works, looking after the children and the active part in the upbringing process (Plopa, 2006; Harwas-Napierała, 2014). The differences between the mother's and the father's role become gradually blurred and their functions are more and more complementary.

By performing the parental role, parents can cater for the needs of their children and their own needs. Their own needs include: recognition, respect, self-development, maternity (paternity), conveying values, knowledge and their achievements to the children.

As regards the children's needs, parents drive their development in all aspects of life and prepare them to function successfully in the society (Rostowska, 2009). The engaged and proper performance of the role may contribute to the positive self-image, system of values, the sense of identity and the satisfaction from meeting the expectations related to the role (Ziemska, 1979).

Researchers distinguish two notions related to the parental role: one is the role requirement, i.e. social expectations related to the role, while the other is the role concept, i.e. the interpretation of this requirement by the individual (*Cencini, Manenti, 2002*).

## **The role of a parent of a child with Down syndrome**

According to Ziemska (1979), parenthood is an important factor that gives a young person the sense of safety and defines his or her social status. Mother and father feel joy and pride, when their children are successful. Children often give their parents the possibility to indirectly experience successes which they did not have the chance to experience in their own life, so children can be a source of personal satisfaction for their parents (Będkowska-Heine, 2003).

It is different for parents of a child with Down syndrome. Studies indicate that the birth of a child with intellectual disability is a difficult situation, often unexpected and hard to accept (e.g. Będkowska-Heine, 2003; Kościelska, 1998; Liberska and Matuszewska, 2011;

Żyta, 2004). Małgorzata Kościelska (1998) argues that a majority of couples who decide to have a child cannot imagine themselves as parents of a disabled child. After birth they expect satisfaction from normal growth and developmental achievements of their child. In such cases, the medical diagnosis is an emotionally wrecking experience and the shock often makes some parents reluctant to take the child home with them. When the child is born and the parents hear the diagnosis of Down syndrome, they feel heavily depressed (Emde and Brown, 1978; Zahn Waxier, Duggal and Gruber, 2002).

Following the initial depression phase caused by the birth and the diagnosis, parents start feeling better until the moment when the child is 4 months old. The second depression sets in, because parents notice the symptoms of Down syndrome. They can see that the child is less responsive to the outside stimuli and smiles less than a healthy child would. Several waves of depression may also occur in the pre-school period, when parents notice their child's development difficulties in walking, speaking, using the toilet and, first of all, learning. Depression might also coincide with the child's period of adolescence and early adulthood. Intense emotional reactions tend to be a permanent element in the process of bringing up a child with Down syndrome at all development stages (Zahn-Waxler et al., 2002).

### **Stress related to the child's disability diagnosis**

Psychological consequences for related to the prenatal screening test and emotional responses of parents who hear the diagnosis of their child's disability for the first time confirm the results of the study by Sue Hall, Martin Bobrow and Theresa M. Marteau (2000). The researchers performed analyses in three subgroups of parents having a child with Down syndrome. They were parents a) who received a false negative result of prenatal tests, b) who did not do the screening test, and c) who refused to do the test. Based on the research, Hall, Bobrow and Marteau determined that the negative emotions reached the peak intensity in the case of parents who re-

ceived the incorrect result of the prenatal screening test, i.e. were informed that the child was perfectly healthy. The false negative result of the test was positively correlated with the higher level of parental stress, a stronger tendency to blame others for the birth of the child and the increasingly negative attitude towards the child in comparison with the parents who refused to do the test. Other behaviours were manifested by the parents who received the correct prenatal diagnosis. As indicated by Hall, Bobrow and Marteau, the parents who knew that the foetus has Down syndrome features, but decided to have the child, showed lesser anxiety, more positive responses and acceptance of the child (Hall, Bobrow, Marteau, 2000). One can find similar results in the research by Brian Skotko (2005). The author argues that the positive emotional state of the parents (especially the mothers) who know that they will have a child with Down syndrome results from the gradual acceptance and becoming accustomed to the non-normative situation (Skotko, 2005). Skotko also observes that who decided to continue the pregnancy after the prenatal diagnosis of Down syndrome were driven mainly by personal beliefs and values. A majority of those mothers knew they would continue the pregnancy, when they took a decision to do the screening test. On the other hand, women who learned that the child will have Down syndrome, but did not yet decide if they would continue the pregnancy, wanted to get more information. Furthermore, a majority of those mothers showed frustration during interactions with physicians and emphasised the need to find the most recent research materials on Down syndrome, and they also asked for a referral to local support groups (Skotko, 2005).

### **The process of adaptation to the role of a parent of a child with Down syndrome**

When analysing the role of parents of intellectually disabled children, one can speak about adopting or accepting the role, but a more precise term would be adaptation to the role. According to

Violetta Będkowska-Heine (2003), the process of adaptation to the role of a disabled child's parent covers the following stages: falling into the trap of the role, becoming accustomed to the role, identification with the role, imprinting of the role, growing into the role, autonomisation of the role, fetishisation of the role, negation of the role and creation of the role.

Stage one, i.e. falling into the trap of the role, comprises shock and confrontation with the diagnosis of disability. There appear many negative psycho-emotional reactions, e.g. fear, confusion, chaos, disorientation as well as anger and aggression. The family system is destabilised and young parents go through a crisis (see: Będkowska-Heine, 2003; Kościelska, 1995, 2000; Ziemska, 1997). At this point, parents see no positive aspects of parenthood.

The next stage is when the parents try to overcome the crisis by becoming accustomed to the role. When parents have the certainty that the child's disability and irreversible and incurable, they strive to cope with the crisis by various defence mechanisms such as denial, rationalisation or repression. At this stage, parents do not enjoy their role and see no positive aspects of difficult parenthood, but if they do not reject the child, they take all actions related to the care, upbringing and rehabilitation of the child.

The next natural stage is identification with the role which means they become more engaged in the tasks of the role. They gain experience and parental competences. They perform the parental activities more efficiently and as a result both mothers and fathers have more confidence and trust in their parental skills. Gradually, a common space of the parents and the child emerges.

The imprinting-of-the-role stage covers the conscious search and implementation of methods to bring up an intellectually disabled child. The parental identity is being formed. The mother and the father seek, learn and apply the ways and methods of upbringing. In this period, parents care more for happiness and peace of the child than for supporting the child's development.

When the predictable daily routine sets in, and the parental tasks and role are clearly defined, the period of growing into the role can

begin. The parent identity becomes generalized and the sense of alienation disappears. Parents of an intellectually disabled child stop perceiving themselves as stigmatized or worse. The child become a member of the family system and a part of the parent's mental structure.

The autonomization of the role occurs when the parental role brings satisfaction to the mother and the father who see it as an essential value in their life. The parents realize the development opportunities of their children and can provide information and support to other young parents of intellectually disabled children. They ask for specialist help without feeling guilty or embarrassed. This stage results from the acceptance of the parental role and the extended awareness of the child. The proper adaptation to the role of a parent of an intellectually disabled child means that both mothers and fathers take care of the child and raise him/her, but they also adopt a therapeutic attitude.

Będkowska-Heine (2003) specifies four additional types of parental roles which indicate the lack of adaptation of the mother/father of an intellectually disabled child to the parental role: fetishisation of the role, manipulation of the role, negation of the role and creation of the role. Fetishisation of the role means that parents focus entirely on the parental role. The author believes that such behaviours are often shown by mothers who let no one else look after the child (Będkowska-Heine, 2003). Personal needs are adjusted to the child's needs and the parent has no private life or leisure time. The development of the child's autonomy and self-reliance causes fear and objection in the carer. Manipulation of the role happens when the role of a disabled child's parent serves as a means to gain social and material benefits. Negation of the role refers to the situation when the child is rejected, the parent refuses to look after the child and denies the parenthood. Creation of the role means a compulsive performance of all other roles which are not needed or required by the environment. A special case of the creation of the role may be a decision about the sole parenthood.

A different process of adaptation to the role is presented by Kościelska based on the research conducted in 1993 by Anna Kraw-

czyk (see: Kościelska, 1998). The research by Krawczyk covered young mothers with disabled children in the period of up to three months after birth (see: Kościelska, 1998). The women were of similar age (average: 26 years) and shared a similar financial and family situation, i.e. each lived with the child's father, enjoyed proper housing conditions and finished at least secondary education. Krawczyk contacted the mothers three times and the purpose of the meetings was to conduct an interview and obtain such information as: a) the level of satisfaction from motherhood, b) the sense of competence in performing new tasks, c) emotions in interactions with the child, d) the mother's image of the child, e) the child's functioning, f) the time devoted by the mother to the child and the way of spending that time, g) the mother's image of changes in family life. Based on the obtained narratives, three groups of mothers were distinguished with respect to the level of adaptation to the maternal role: a) mothers well-adapted to the parental role, b) mothers having difficulties adapting to the parental role, c) mothers ill-adapted to the parental role.

Kościelska (1998) informs that mothers that are very well adapted to motherhood show high satisfaction from the parental role. These women felt joy and pride due to the very fact of being a mother, the contact with the child was positive, they devoted a great deal of time to the baby, showing warmth and positive emotions. The children became more peaceful when the mother was around. Both mothers and children quickly learnt about each other, which was the starting point for a mutually positive, strong bond based on the sense of safety, warmth, mutual understanding and enjoying the time together. The women manifested a high level of maternal competences and did not complain about the excessive number of duties or the lack of support by other family members. As a result of effective adaptation of the women to the maternal role, the fathers had the opportunity to develop their parental competences. Partners of well-adapted mothers of intellectually disabled children indicated that they developed as a carer, a father and a spouse.



On the other hand, mothers who had difficulties adapting to motherhood showed (Kościelska, 1998) high level of satisfaction from becoming a mother, but problems emerged when they learnt how to take care of the child.

These women spoke about their troubles with childcare, regulating the rhythm of sleep, lack of free time and the excessive duties they could not manage. In addition, the mothers mentioned physical ailments and needed time to develop parental competences and the sense of effectiveness. Their emotional sphere also started evolving. After the birth of the child, they felt ambivalent: joy, enthusiasm and happiness were mixed with fear that they lack skills and could inadvertently hurt the child. The image of the child was varied in this group of women. On the one hand, the mothers saw the child as the source of joy and love, but at the same time the cause of fatigue, irritation and frustration. Children of the mothers who were partially adapted to the role did not have a regular rhythm of sleeping and feeding, they cried a lot and had digestive problems. It must be noted that these women's partners worked, so the mothers had to do all housekeeping and chores. The women felt isolated and alienated, they wanted to find a job.

The third group specified by Kościelska (1998) included women who were ill-adapted to the parental role. The research indicated a low level of satisfaction from the role. They complained about numerous body ailments and suffered from excessive fatigue, lack of sleep and general malaise. All these women wanted to get back to work as soon as possible. They had low parental competences and needed a great deal of help and support from the family. Their emotional state was poor: the mothers showed more negative than positive emotions and they had a negative image of the child, i.e. they saw their children as troublesome, fussy, weepy and absorbing excessive time and energy. The children's functioning was disturbed: they slept little and in too short intervals, the parents devoted insufficient time to their babies and focused exclusively on care-related activities.

## **Change of the evaluation perspective regarding the influence of disability on the family system**

In the last 4 decades, the research approach to the adaptation process of the parent of a child with Down syndrome switched from the perspective of pathology and crisis (Blacher, Neece, and Paczkowski, 2005) to the perspective of stress and coping with difficulties related to the atypical parenthood (Abery, 2006; Van Riper, 2003). This change may result from the need to get away from the reductionist, problem-oriented approach (Richardson, 2002).

The overview of studies related to families with intellectually disabled children from the period before the 1980s indicates that such a child may have a negative influence on the functioning and well-being of the parents as well as on various aspects of the family life and atmosphere (Hodapp, 2003).

The first studies in this field demonstrated that mothers of intellectually disabled children tended to be depressive and had problems with managing anger towards the children in comparison with mothers of healthy babies (e.g. Cummings, Bayley and Rie, 1966; Friedrich and Friedrich, 1981). Similarly, the fathers of intellectually disabled children were depressive and neurotic and they showed a lower level of domination, self-esteem and the joy of having children with intellectual disability in comparison with fathers of healthy babies (e.g. Friedrich and Friedrich 1981). In these studies, families with intellectually disabled children demonstrated a lower level of marital satisfaction and a higher level of marital conflicts and divorces (Cummings, Bayley and Rie, 1966; Friedrich and Friedrich, 1981). In those families, mothers were strongly engaged in looking after the child with intellectual disability, while fathers tended to be more reserved, both emotionally and physically (Beckman-Bell, 1981).

Since 1980, researchers change the approach to a disabled child as a cause of psychopathology by introducing the concept of stress factors in a family with a disabled child (Hodapp, 2003). In line with this change of perspective, stress factors in the family system may lead to negative parental effects such as malaise, a higher depres-

sion level (Friedrich and Friedrich, 1981) or a negative image of the child (Kościelska, 1998). On the other hand, the new research perspective allowed to see that the child's disability can also reinforce the parents. It was observed that as a result of experiencing the child's disability, parents may strengthen their personal qualities and thus the entire family system can be reinforced and consolidated (Greenberg et al., 2004; Hodapp et al. 2007).

### **Problem-coping skills of parents of children with Down syndrome**

The overview of sources related to the family stress coping strategies in families with intellectually disabled children in comparison to families with healthy children indicates that the former show a higher level of stress and anxiety (see: Leinonen et al., 2003). Disproportions between the two groups are convincingly exemplified in the study of the parental stress level in groups that are similar in social and economic terms (Roach et al., 1999). In this comparison, it was observed that parents of children with Down syndrome spoke about considerable difficulties in taking care of the child, a higher level of stress related to upbringing (cumbersome tasks, no acceptance of the tasks involved in looking after a disabled child) and of parental stress (lack of competence, depression, health problems, deterioration of the parental role and the marital role) in comparison to families with healthy children. For both groups the maternal stress resulted from care-related difficulties, while the paternal stress was connected with the very presence of a child with Down syndrome. Mothers who manifested more engagement in looking after the child suffered from health problems and received less support from the spouse, while experiencing difficulties in performing the marital role. Fathers who were more involved in the care of the child had fewer difficulties with respect to parental competences. The parents also felt anxiety about the limited time for rest and leisure, which resulted in lower recreational activity and more need to plan the

rest. One must note that with respect to the level of satisfaction with free time management, parents of children with Down syndrome often observed the potential benefits of spending the free time together with children or the entire family (Wayne, Krishnagiri, 2005).

Richard R. Abidin (1995) distinguished the various sources of parental stress. He specifies two types of stress. The first is the parental stress felt by every parent and related to children's behaviours which generate troubles for the parents. The second is the stress resulting from the child's intellectual disability. In the latter case, the sources of stress may include the diagnosis of disability, non-adaptive behaviours of the child, developmental difficulties or additional health complications (Abidin, 1995). Brian Abery argues that the variables mentioned with respect to the first and the second type of stress refer to the sense of parental efficiency, the trust in professional help, the sense of competence as well as the parent's beliefs, values and expectations (Abery, 2006). According to Gary Peterson and Charlesa B. Hennon, both types of stress cause an increase of tension in the family system as well as emotional instability and excessive reserve in the family members' behaviour (Peterson, Hennon, 2005, p. 34). Regarding the emotional instability, one must underline that it is particularly excessive in families with small children suffering from Down syndrome. Hanna Liberska and Mirosława Matuszewska observe that such families show a chronic experience of stress (Liberska, Matuszewska, 2011). Such a situation can lead to social isolation or heavy depression (Beckman-Bell, 1981; Keller and Honig, 2004). Parental stress in families with small children seems to result from the discrepancy between the higher level of care-related needs in the case of children with retarded or irregular development and the parental competences and the level of acceptance of the child's disability (Saloviita, 2003). The low sense of competence, the insufficient adaptation to the parental role and the parents' sense of being in a negative situation constitute the key factors of the parental stress among parents who raise children with Down syndrome (Saloviita et al., 2003). In addition, it must be emphasised that mothers and fathers differ in the way they define their

role of a parent of a disabled child. For mothers the negative aspect of motherhood is related to the behavioural problems caused by the child, while fathers give more attention to the social lack of acceptance of the child (Saloviita, Itäläinen, Leinonen, 2003)

Studies of the parental stress also show that the stress related to the process of adaptation of the mother and the father of a child with intellectual disability to their parental role touches both the parents and the child and it can have a considerable impact on the disabled child's well-being as well as emotional and social development. Kościelska describes this interdependency as a mechanism of mutual influence between the mother and the child. While observing how mothers of intellectually disabled children fulfil their care-related and upbringing duties, the author noted that the mother's level of adaptation to the parental role had an impact on how the child functioned (Kościelska, 1998, p. 68).

Hanna Liberska and Mirosława Matuszewska (2011) arrived at similar conclusions. The researchers argue that a disabled child tends to disorganize the family life and destabilise the existing system to a larger or lesser degree. It can be seen in the basic spheres of life, i.e. emotional, social, axiological and economic (Liberska, Matuszewska, 2011). Moreover, when a disabled child enters the family and disrupts the balance in the system, other family members may lose the sense of safety (Kulik, Otrębski, 2011).

The achievement of the emotional balance and the related stability in the family can happen when the parent become fully adapted to the role of a parent of a disabled child in emotional terms (Liberska, Matuszewska, 2011).

### **Problem-coping strategies of parents of children with Down syndrome**

There is a general consensus that the way parents cope with problems caused by the child's intellectual disability contributes to improvement of their cognitive abilities as well as the control over

emotions and behaviours (Turnbull et al., 1993). However, few studies contain an in-depth analysis of the problem-coping strategies among families of persons with Down syndrome. Problem-coping is defined as thoughts and behaviours used to manage external and internal requirements in order to deal with stressful situations (Folkman and Moskowitz, 2004). Two types of stress management strategies have been identified. The first strategy is problem-oriented and refers to the efforts that aim to cope with the stress sources through a change in behaviours of particular people, a change of environmental conditions or by combining these two. The second type is the emotion regulation which covers all efforts to reduce the emotional exhaustion and to maintain a satisfactory internal balance (Folkman, Lazarus, 1988). These types of stress-coping responses are interrelated: they complement each other and are strictly tied to emotional reactions. In general, parents felt better (a lower level of depression and psychosomatic symptoms, a higher level of self-reliance and self-acceptance) if they used the adaptive strategy in coping with stress (Folkman, Lazarus, 1988).

Very few cross-cultural studies on stress-coping strategies of parents raising children with Down syndrome demonstrated results similar to those revealed in the early research (Lam and Mackenzie, 2002; Sullivan, 2002; Van Riper, 1999). For instance, Lai-Wah Lam and Ann E. Mackenzie (2002) described the cases of Chinese mothers raising children with Down syndrome. The results showed that these mothers frequently used stress-coping strategies consisting in the avoidance of stress factors and the search of social support. Anthony Sullivan's comparisons of mothers and fathers raising children with Down syndrome revealed several gender-based differences in the parental strategies of stress management. Women scored much better than men in terms of seeking emotional and social support, control of emotions and their expression as well as limitation of competing activities (Sullivan, 2002).

Another study of the relation between the cognitive style of stress coping by mothers (acceptance, avoiding stress factors), the emotional state and sensitivity consisted in observing 56 mothers

and their children with Down syndrome for the period of 2 years (Atkinson et al., 1995). Stress coping was analysed in the context of cognitive processes and the regulation of affective disorders, while sensitivity was evaluated on the basis of the quality of the mother-child relations. Results indicated that approachability and the avoidance of stress factors kept stable for 2 years. These variables of stress coping translate in a complex way into the sufferings of parents raising children with Down syndrome. The mothers with a strong tendency to react to stress factors indicated more extensive affective disorders than the mothers who adopted a less sensitive approach to stress management. On the other hand, the cognitive avoidance of stress factors and affective disorders reduced the behavioural sensitivity of the mothers towards their children (Atkinson et al., 1995).

### **Social support and its importance in parental stress management in families with an intellectually disabled child**

As mentioned before, the process of adaptation to the role of a parent raising an intellectually disabled child is difficult and extremely stressful for both the mother and the father. Coping with parental stress is a constant challenge for mothers and fathers and it increases the significance of the available types of social support. Social support gives the parent of an intellectually disabled child the sense of being cared for, the sense of belonging to a community of people with similar problems and the conviction that his or her experiences may be valuable and helpful to others (Dunst, Trivette and Deal, 1988).

Helena Şek, argues that the proper understanding of social support requires the context of the knowledge about how people function in a social group, in interactions with others, and in the existing problematic and difficult situations (Şek, 1986, p. 791ff.). Social sup-

port can be conceived in multiple ways: 1) as an individual perception of the supporting network that is available to the individual; 2) as a result of a supporting social exchange; 3) as a specific type of support given to the individual (Johnson, 1992). Usually, this term is used interchangeably with relations, ties, bonds and social relationships (Kacperczyk, 2006, p. 18). Following Żółkowska, it can be assumed that social support is dynamic and depends on the individual's current situation and the entire course of life. One should note that support is perceived subjectively and cannot be a measure of how the social environment responds to the individual needs of parents and persons with intellectual disability (Żółkowska, 2004, pp. 327-328). Social support brings many benefits, the most important being the affirmation of one's effectiveness, which may be crucial in rebuilding the faith in oneself in the face of weakened parental effectiveness (Lent, 2004).

Social support may take the form of simply being with and for the other person, providing financial assistance or vital information. Keeping someone company creates the feeling of closeness, recognition and appreciation. Financial assistance is about providing resources and actual help, while the informational support pertains to counselling and advice. Support and assistance may be given in various ways, e.g. a formal assistance (from psychologists and teachers) and informal help (from a friend or another parent)

The support satisfaction assessment is an important indicator of how parents evaluate the benefits of the support they receive and how capable they are of actually using that support (Shin, 2002). According to Hyun Song *Shin*, the factors that influence satisfaction are personal qualities of the parent of the disabled child, especially those which make the parent accept the offered support (Shin, 2002). Sullivan believes that gender may also impact the satisfaction with the support. The author considers the parental expectations regarding the support. According to Sullivan, women expected emotional support more often and needed to verbalise their experiences, while men tended to focus on the financial assistance and advice on problem solving (Sullivan, 2002).



Malka Margalit (Margalit et al., 2006) also performed some interesting research on the satisfaction with the provided support in the case of mothers having babies with Down syndrome. The studies revealed that the mothers' expectations regarding the support and direct assistance for the babies depended on their perception of their personal strength and the sense of their family's consolidation. Strong mothers that were confident about their efficiency, but experienced instability in the family and voiced their concern about the lack of social support, tended to see the early intervention personnel as a substitute of the family, saying: "I have found a new family."

Mothers lacking self-confidence but living in a consolidated family did not look for a "new family", but expressed their satisfaction with the family support programme, saying: "They help me believe that I can help my child" (Margalit et al., 2006). According to Victor Florian and Tamar Krulik (1991), the parents' sense of social isolation can be another factor that impacts the level of satisfaction with social support. Their research reveals a negative correlation between the accessibility of social support and the sense of abandonment among mothers.

## Conclusion

In conclusion, parenthood is a significant factor that gives the sense of safety to a young person and defines his/her status in the family system and in society (Ziemska, 1973, 1979). By performing the parental role, men and women can satisfy their own needs, e.g. recognition, respect or self-development, and the children's needs, e.g. conveying values and knowledge, catering for their development and preparing them to function in society (Rostowska, 2009). On the other hand, the birth of a child with Down syndrome is a difficult situation, often unexpected and described as a trauma (e.g. Będkowska-Heine, 2003; Kościelska, 1998; Liberska and Matuszewska, 2011; Żyta, 2004). When referring to parents of intellectually disabled children, it is more adequate to define the role acceptance

process as a multi-staged adaptation to the parental role (Będkowska-Heine, 2003; Emde, Brown, 1978; Kościelska, 1998).

Since 1980, researchers have been modifying their perception of Down syndrome as the cause of psychopathology in a family by introducing the concept of the child's disability as the stress factor within the family system (Gath, 1977; Hodapp, 2003, Kościelska, 1998; Kulik and Otrębski, 2011; Liberska, Matuszewska, 2011). In line with this change of perspective, the child's intellectual disability as the stress factor in the family may lead to serious negative effects for the parents, such as mental stress, depression, somatic ailments as well as separation or divorce of the spouses (Cummings et al., 1966; Friedrich and Friedrich, 1981). On the other hand, the child's intellectual disability can reinforce the parents by giving meaning to their parenthood, which is also reflected in other aspects of the family life, e.g. the family's consolidation level, positive communication between parents or benefiting from social support (Będkowska-Heine, 2003; Greenberg et al., 2004; Hodapp et al., 2007; Kościelska, 1998; Liberska and Matuszewska, 2011; Żyta, 2004).

Parental stress seems to result from the combination of enlarged care-related needs of the child with retarded or irregular development and the emotional reactions of the family to the fact of disability (Saloviita, 2003). The choice of the coping strategy can improve the parents' cognitive abilities and competences of emotional and behavioural control and it also facilitates a more positive assessment of their intellectually disabled child (Turnbull et al., 1993). By analogy, if parents are able choose a more beneficial, task-focused coping strategy, adaptation to the parental role proceeds more fluently and more adequately (Abery, 2006; Lackaye and Margalit, 2006; Van Riper, 2003).

In general, the process of adaptation to the role of a parent of a child with Down syndrome is difficult, multi-staged and stressful for both the mother and the father. Coping with parental stress is a constant challenge for mothers and fathers of a child with Down syndrome and it increases the significance of different types of social support. Social support is vital for the adaptation process of

a parent of a child with Down syndrome to the parental role, since it develops the sense of being cared for, the sense of belonging to a community of people with similar problems, the sense that someone listens and understands and of being able to give support to other people with similar experiences (Dunst, Trivette and Deal, 1988).

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