



FAMILY AND MOTHER LEISURE OF CHILDREN WITH DISABILITY SLOBODNO VRIJEME MAJKI DJECE S TEŠKOĆAMA U RAZVOJU

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ABSTRACT

Leisure is often associate with quality of life of an individual. Objective leisure definitions are used by economic, business and recreational researchers, and focused on behaviors that we can observe. Subjective definitions are more concerned with scientists who are focused on the microsphere of an individual. Modern families are under great stress and that through different family activities the reduction of stress can be achieved and also increase feel of family well-being. Family leisure is considered as very important component of family life. It often shows as idealized, constantly happy time in which everyone enjoys together, time that is pleasure for all family members as individuals and also for the whole family. During family leisure mothers usually have mixed roles of caring for children and caring for the household, thus disrupting their sense of freedom and enjoyment. Many roles that parents of children with disabilities need to take over creates a time pressure that does not occur to parents of children without disabilities. That time pressure is reflected on psychological and physical health of the parents, affecting simultaneously the lack of time for different activities such as going to work, leisure activities, personal care and social interactions. Research has shown that mothers of children with disabilities generally have much less time for themselves and family activities than when it comes to mothers of children without disabilities, no matter what type and level of disability is about.

Key words: leisure, family, mothers of children with disabilities

SAŽETAK

Pojam slobodnog vremena uglavnom vežemo uz kvalitetu života pojedinca. Objektivne definicije slobodnog vremena uglavnom koriste znanstvenici koji su usmjereni na ekonomiju i rekreaciju, a u fokusu su im ponašanja koja možemo opservirati. Subjektivnim definicijama slobodnog vremena više se bave znanstvenici koji su usmjereni na mikrosvijet pojedinca.

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Današnje obitelji izložene su velikom stresu, a kroz različite obiteljske aktivnosti može se poboljšati kvaliteta života obitelji smanjujući utjecaj stresa. Slobodno vrijeme obitelji smatra se vrlo važnom komponentom obiteljskog života. Međutim, često se to vrijeme idealizira, prikazujući ga kao vrijeme u kojem svi uživaju i osjećaju se sretno, kao vrijeme koje je ugodno za sve članove obitelji. Tijekom obiteljskog slobodnog vremena majke uglavnom imaju još niz popratnih obaveza poput brige o djeci i kućanstvu, što narušava njihov osjećaj slobode i ugone. Roditelji djece s teškoćama u razvoju primorani su preuzeti životne uloge koje same po sebi stvaraju dodatni vremenski pritisak, a s kojim se ne susreću roditelji djece bez teškoća u razvoju. Sve to odražava se na psihičko i fizičko zdravlje roditelja, utječući istodobno i na manjak vremena za različite aktivnosti poput odlaska na posao, organizacije slobodnog vremena, brige o sebi i socijalne interakcije. Istraživanja su pokazala da majke djece s teškoćama u razvoju generalno imaju mnogo manje vremena za sebe i obiteljske aktivnosti u odnosu na majke djece bez teškoća u razvoju, bez obzira o kojoj vrsti i stupnju teškoće u razvoju je riječ.

Ključne riječi: slobodno vrijeme, obitelj, majke djece s teškoćama u razvoju

INTRODUCTION

A few decades ago, there was not so much thought about the impact of social support and family leisure in everyday parental functioning, their psychological well-being and stress level. Over time, they began to develop support programs like early intervention program. These programs were primary directed on child development, but indirectly they effect on wider context in which child is rising up. More preciously, they were affecting on expanding the network of family social support of child and increasing opportunities for including family in social and leisure activities. By conducting research it has been concluded that the effectiveness of social support and family leisure, depend of level of connection with family microsystem (relation parent-child). That mean if there is positive connection between social support and family leisure with parenting, parents are feeling pleasure, parental stress as also negatives parental feelings is reduce. As we can see theoretical premises and empirical research are connecting family functioning and family involvement in leisure activities (Roggman, Moe, Hart & Forthun, 1994).

LEISURE

Leisure is the term that is not so simple to explain and not easy to define also. We often associate it with quality of life of an individual. Kaplan (1961 toward Unger, Kernan, 1983) categorizes definitions of leisure on objective and subjective definitions. Objective leisure definitions are used by economic, business and recreational researchers, and focused on behaviors that we can observe. Subjective definitions are more concerned with scientists who are focused on the microsphere of an individual. To be precise, subjective definitions are directed to the state of mind and psychological experiences, the more we engage in the quality of life.

Frequently, in the discussion leisure is comparing with concepts like free time, recreation and play (Miller and Robinson, 1963 toward Unger, Kernan, 1983), time and psychological state (Russel, 2004 toward Boyd Hegarty, 2009). Some author's states that leisure is the same as play but the term of leisure is used for adult age, while play is used for child's age (Berlyne, 1969 toward Unger, Kernan, 1983; Roggman, Moe, Hart & Forthun, 1994). It is about non obligate activities, activities that reduce stress level and encourage personal development (Roggman, Moe, Hart & Forthun, 1994). Over time, researchers came to the conclusion that leisure has some components, and that these components include free choice, intrinsic motivation, enjoy, relaxation, role interactions, personal involvement and self-expression (Henderson, Bialeschki, Shaw & Freysinger, 1989 toward Henderson & Allen, 1991). Neulinger (1974 toward Esteve, San Martin, Lopez, 1999) states that the sense of freedom is crucial to the perception of certain activities as leisure activities.

FAMILY LEISURE

Family cohesion is an individual characteristic of every family. Research has shown that family cohesion is higher in two-parent families (only husband and wife) than in families with children. The reason for this is in fact that when child is born the family must adapt to new situations and challenges that distort the previously established family cohesion (Dansie, Brian Hill, 2014).

Family leisure often shows as idealized, constantly happy time in which everyone enjoys together, time that is pleasure for all family members as individuals and also for the whole family. All that has been accompanied by mass media and popular culture that promote positive family interactions and the common pursuit of leisure in which everyone enjoys (Shaw, 1992). Accordingly, various family leisure programs was developed in the community that encourage families to participate in activities such as going to picnics, running and cycling. The main idea was that modern families are under great stress and that through different family activities the reduction of stress can be achieved and also increase feel of family well-being (Harper, 1986 toward Shaw, 1992). Although it is undeniable that family leisure activities are enjoyable and family members have benefit from them, it is not all so unidimensional. As Shaw (1992) points out, we cannot work on family homogeneity, and ignore family members as individuals.

FAMILY LEISURE AND WOMAN

Depersonalization often happens to woman or to mothers in the family. One of the reasons for that is the gender role of the woman which is imposed to her by society. The role that woman is expected from others to care for (Miller, 1986 toward Henderson & Allen, 1991), and to be primarily a mother if there are children (Chodorow, 1978; Deem, 1986 toward Henderson & Allen, 1991). That is in some way affecting the freedom of choice which is one of the components of leisure. Wimbush and Talbot (1988 toward Henderson & Allen, 1991) state that the autonomy of women is limited when it is comes to enjoying personal leisure time due to the overall environment in which woman lives.

Bella (1986; 1989 toward Henderson & Allen, 1991) agrees, stating that sometime it happens that the woman actually has no time for nonobligatory activities because of gender roles imposed to her. Therefore she does not have opportunity to satisfy her leisure needs. Family leisure is considered as very important component of family life (Holman & Epperson, 1984; Orthner & Mancini, 1990 toward Larson, Gillman & Richards, 1997). Despite the fact that different authors confirm that family leisure is very important for family and family cohesion, often family leisure equates with woman leisure (Bella 1987 toward Henderson & Allen, 1991). During family leisure mothers usually have mixed roles of caring for children and caring for the household, thus disrupting their sense of freedom and enjoyment (Henderson, 1990, 1991; Shaw, 1992 toward Larson, Gillman & Richards, 1997). As an example we can take a going to a vacation that does not necessarily have to be leisure for a woman because in those situations she cannot spend her time freely and stop caring about children (Bella 1987 toward Henderson & Allen, 1991).

Research has shown that mothers spend much more time in caring about family and doing housework compared to fathers (Pleck, 1985; Thompson & Walker, 1989 toward Larson, Gillman & Richards, 1997), and in addition, mothers are more likely to neglect their leisure interests and take on their role of mother (Freysinger, 1995; Shaw, 1992 toward Larson, Gillman & Richards, 1997). With time there is developed opinion about family leisure as an oxymoron for women (Hunter & Whitson, 1991 toward Larson, Gillman & Richards, 1997) because women are much less enjoying family leisure, neglecting their leisure needs.

The research carried out by Larson, Gillman & Richards (1997) confirms the fact that mothers are much less intrinsically motivated than the fathers when we are talking about family leisure. Fathers often have more negative experiences at work than mothers, so family leisure is for fathers usually a departure from hard work (Freysinger, 1995 toward Larson, Gillman & Richards, 1997). On the other hand, mothers does not experience family leisure so pleasant as fathers, because they cannot so easily move away from the role of the mother who is expecting to care for the family members and to lead the family (Freysinger & Flannery, 1992 toward Larson, Gillman & Richards, 1997). Mothers have shorter leisure periods than fathers, and if they want to have leisure in the true sense of the word (without interruption and without making compromise) they mostly have to be away from the family (Larson, Gillman & Richards, 1997).

Research by Bittman & Wajcman (2000 toward Crettender, 2008) confirms that the leisure time that parents have is reduced, especially when we talk about women. After the birth of a child, it was confirmed that women are likely to spend their leisure time much less quality in relation to husbands, and that a woman's leisure is focused on the family. In addition, their leisure time is also more likely to be interrupted in relation to fathers.

FAMILY LEISURE AND CHILDREN WITH DISABILITIES

It's not necessary to emphasize in particular how important the role of parents is in raising a child, but when we are talking about child with disabilities, parents role becomes even greater.

They are a constant in the child's life and must be considered as partner and cooperator, but for successful co-operation it is important to have understanding for the parents. The life of parents that have child with disabilities is often accompanied by numerous uncertainties and concerns about the future of their child (Bujas Petković, Frey Škrinjar i sur., 2010). When we are talking about families of children with disabilities, it is clear that they are going through much greater stress and face more developmental challenges than those families without children with disabilities, and that the required level of parental care depends on the type and child's disabilities degree (McCann et al., 2012).

Parents play an important role in all segments of professional work with their child and they must be part of the whole process of encouraging child development. However often it happens that the parents of child with disabilities turn into a professional and forget to be parents. The new situations, in which they are found, become very stressful and painful. Therefore, one of the tasks of professional is not only to stimulate the development of a child, but also to encourage the personal development of parents as individuals and as partners (Bujas Petković, Frey Škrinjar i sur., 2010).

Many roles that parents of children with disabilities need to take over creates a time pressure that does not occur to parents of children without disabilities. That time pressure is reflected on psychological and physical health of the parents, affecting simultaneously the lack of time for different activities such as going to work, leisure activities, personal care and social interactions (McCann, Bull & Winzenberg, 2012). This lack of time for all these different activities directly affects the sense of control over their own life (Brandon, 2007 toward McCann, Bull & Winzenberg, 2012).

The possibility to spend free time is very important for parents of children with disabilities because of the high level of stress they face every day (Baker-Ericzén et al., 2005). It is often the case that parents of children with disabilities are prevented from continuing their leisure activities after the birth of a child. The disability of the child can also affect the choice of leisure activities. The reason for this may be cognitive and physical skills that make the child unable to participate in activities that are pleasant to parents. This inability to participate in activities that are pleasant to parents can effect on physical and social activity of parents, which indirectly affect the level of satisfaction and happiness of parents (Myers & Diener, 1995).

Studies show that the need for child care decreases with the child's age (Crowe and Michael, 2011). It has been shown that provision of basic care for the child with severe disabilities has a very significant impact on the everyday life of the parents of that child (Tadema and Vlaskamp, 2010), and greatly affects the quality of family life (Summers et al., 2005). The research conducted by Axelsson and Wilder (2014) confirmed that families of children with severe disabilities had much less free time than families of children without disabilities. Parents of children with disabilities allocate about 1 and a half hour less time for leisure activities than parents of children without disabilities. That is a big difference because that time they could spend in one of the leisure activities (Luijkx, van der Putten & Vlaskamp, 2017).

According to researches, family leisure has own benefits for families of children with disabilities. Benefits are: being together, sharing child's daily experiences and providing learning opportunities (Segal, 1999). In the research about quality of life, family of children with disabilities express dissatisfaction with the support from their family, friends and neighbors, and the dissatisfaction with the opportunities offered to them for spending leisure time as family (Summers et al., 2005).

By birth of a child with disabilities, the pressure on both parents increases, which can lead to changes in family structure (Cummins, 2001 toward Crettender, 2008). Parents have to start balancing between common family responsibilities with the new additional responsibilities that occur in the birth of children with disabilities. As mentioned earlier, all this leads to a rise in the level of family stress (Bruce & Schultz, 2001 toward Crettender, 2008), especially when it comes to mothers whose primary role in family is mainly caring for children and even for the child with disabilities (Cummins, 2001).

Research has shown that mothers of children with disabilities generally have much less time for themselves and family activities than when it comes to mothers of children without disabilities, no matter what type and level of disability is about (Lucca & Settles, 1981 toward Crettender, 2008). In addition to the mentioned mothers of children with disabilities spend much less time in free activities (Crowe & Florez, 2006). Johnson & Deitz (1985 toward Rassafiani et. al., 2012) compared the time it takes to care for child with disabilities and without disabilities. It was found that mothers of child with disabilities spend much more time for child care, and spend much less time with their child in out-home activities.

Many researches, including Breslau's (1983 to Crowe, 1993) research confirms that mothers of children with disabilities spend much more time with their child in activities than mothers of children without disabilities. The same research has shown that mothers of children with disabilities spend much more time in household activities than mothers of children without disabilities, but no differences in the time they spend on child care have been established. However, when we are talking only about mothers of children with disabilities, differences have been observed with regard to the type and level of disabilities child has. Mothers of children with severe disabilities spend much more time in child care activities than mothers of children with mild disabilities, as well as in child-related activities. Another finding that has been made in this research is that there are no differences between mothers of children without disabilities and mothers of children with various disabilities when it is about time spent in recreational activities. But it has been shown that mothers of children without disabilities are more involved in socialization activities than mothers of children with disabilities. Regardless of the less time spent in socialization activities compared to mothers of children without disabilities, all mothers spend much more leisure time in socialization activities than in recreational activities as physical activities (cycling, running) (Crowe, 1993). Rassafiani et al. (2012) state that most mothers spend their leisure time in passive activities such as watching TV. The research carried out by Crowe & Florez (2006) included 30 mothers of children with various disabilities and 30 mothers of children without disabilities between the ages of 3 and 14. They also confirmed the differences in the time that mothers spend on child care and spend on leisure activities.

This was confirmed by the research carried out by Rassafiani et al. (2012). They had included mothers of children with cerebral palsy and mothers of children without disabilities in the study. As expected mothers of children with cerebral palsy spend much less time on leisure activities, which is consistent with the results of research conducted by Sawyer et al. (2011). They noticed that mothers of children with cerebral palsy spend much more time on child care, and much less time on some other activities. That misbalance in everyday activities can lead to physical and emotional stress and affect the mental health of the mother of a child with cerebral palsy (Sawyer et al., 2011).

CONCLUSION

If we think about Bronfenbrenner's ecological system theory, we are clear about how important is developmental environments of individual, whether it is about a child or an adult male or a woman.

Like any other parent, parent of child with disabilities need systematic support from their environment to continue development as an individual and after the child's birth. We must not allow parents of children with disabilities to lose their personality neglecting their needs. Special emphasis needs to be on mothers who often come to situations that put needs of other members of their family in front of their own personal needs. Women should certainly be free in choosing the way they want to spend their time and leisure.

We must not ignore either family leisure that contributes to family cohesion that is often disturbed in families of child with disabilities, but we must not equalize it with leisure time of mothers. However, we must not ignore fathers either. There is no enough findings about the leisure time of fathers of children with disabilities and that would be interesting to explore.

One of the tasks for professionals is that through early intervention programs emphasize not only the treatment of a child with disabilities, but to focus on parents self-awareness with the aim to prevent the development of burnout and lead them to the top of Maslow pyramid of needs – to self-realization. That process of support for parents should be constant as well as for their children, since we can never safely say what will happen to the new developmental phase in which a child with disabilities enters and whether it will effect on family cohesion and on self-realization of each of the parents.

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