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SUPPORT FOR PARENTS OF CHILDREN WITH NEURODEVELOPMENTAL DISORDERS^a

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SUMMARY

Parents of children with neurodevelopmental disorders often lack support for raising their child. Problems that they face are numerous and include emotional, social, psychological and financial difficulties and limitations. The aim of the paper is focused on presenting available and relevant researches that consider various problems faced by parents of children with neurodevelopmental disorders (autism spectrum disorder and intellectual disability), as well as the types of support intended for them. Some types of support are: spousal support, support from relatives and friends, financial support, support from various services, social support, online social support and the like. In the paper, it is pointed out to specific problems that occur to parents of children with autism spectrum disorder and children with intellectual disabilities. Specificities for mentioned types of support for parents of these two groups were discussed.

Key words: support, parents, autism spectrum disorder, intellectual disability, problems

INTRODUCTION

The birth of a child with developmental disabilities brings many difficulties, primarily for parents. They go through different stages of coping with the reality they find themselves in, in order to be able to accept the situation in the best possible way and help their child develop maximum potential. Along that path they encounter various emotional, social, psychological and financial difficulties and limitations. Raising a child with disabilities affects the overall quality of life of the family and all its members. The source of possible difficulties in lives of these parents refers to a lack of support. Families with children with neurodevelopmental disorders (ND) face many challenges that affect different aspects of their lives (Davis & Gavidia-Payne, 2009).

Dimitrijević accentuates research findings that point to the problem families with a child with ND face. The predominant problems are difficulties in accepting the disorder, parental unemployment, chronic stress and fatigue due to continuous care for the child, reduced parental leisure opportunities, as well as worry and fear regarding the child's future (Dimitrijević, 2013). Milačić-Vidojević concludes in his research that one of the possible sources of problems for parents is the lack of support services (Milačić-Vidojević, 2008).

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Some of the problems that parents also encounter are: insufficient awareness of the facilities and services available and how to reach them, understanding of the roles of different professional staff profiles, problems originating from experts in understanding the situation of family and parents, and understanding their needs (Slopper, Greco, Beecham, & Webb, 2005).

In literature, other factors that influence the level of family difficulties of parents are cited and include the child's irregular sleep, behavioral problems, financial status of the family, employment of parents, lack of social support, failure to meet the needs of parents and the child by various services and parents stress coping strategies. The authors point to a high rate of poverty in families with a child with ND in the UK, up to 55%. These families have financial problems due to the fact that one of the parents, most often the mother, is unemployed due to the care of the child (Sloper & Beresford, 2006).

According to the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, 5th ed.) effective from 2013, the ND group includes:

- intellectual development disorder/intellectual disability (ID) (mild, moderate, severe and profound),
- communication disorders (language disorder, speech disorder, childhood fluency disorder, pragmatic communication disorder, unspecified communication disorder),
- autism spectrum disorder (ASD),
- attention deficit hyperactivity disorder (ADHD),
- specific learning disorders (reading disorder, writing disorder, calculation disorder, i.e. math related disorder),
- motor disorders (developmental coordination disorder, stereotyped movement disorder, tics) and
- other neurodevelopmental disorders (other specified neurodevelopmental disorder and unspecified neurodevelopmental disorder) (American Psychiatric Association, 2013).

Neurodevelopmental disorders include significant intellectual, motor, language, and social disabilities that arise during the developmental period. They are most often manifested and detected in early development before the child goes to school (American Psychiatric Association, 2013). Complexity in deficits ranges from very specific learning disabilities (such as spelling difficulties in which consonants and vowels are replaced during writing) to overarching difficulties in social or intellectual ability. These disorders often occur in comorbidity (i.e. people with ASD often also have ID). The importance of comorbid conditions is that they can determine the further course of treatment, the frequency and intensity of complications, type of education, as well as academic and health outcomes (Polyak, Kubina, & Girirajan, 2015).

In order to identify and overcome the problems that families face, it is necessary to understand the importance of the role of the family in the child's development and to understand the impact of the environment on family functioning. The foregoing refers primarily to professional and social support (Davis & Gavidia-Payne, 2009). Social support is multidimensional support that includes not only parents but also the wider family, friends and various types of services. White and Hastings indicate

that it is important to recognize the significance of the role of social support on family functioning. This implies the need to improve the availability of support networks and identify the key types of support that the family needs. Most research focuses on broader family functioning, not social support itself (White & Hastings, 2004). Mitchell points out that members of the wider family (grandparents) can be a significant source of support, which can help improve family functioning. They can also be an additional source of stress, primarily due to the fact that they will go through the stages of adjusting to difficulties of a child's ND, same as child's parents. A misunderstanding of the child's difficulties and needs may also occur, which affects the quality of support they will provide. This can further lead to disagreements within the wider family, which then only contribute to stress for parents and poor family functioning. Despite these allegations, the study shows that members of the wider family (grandparents) are an important source of support, both financially and emotionally (Mitchell, 2006).

Researches are rarely focused on assessing the availability of different types of support. Small number of studies address the assessment of interaction between support provided and the positive outcomes of parents and the whole family, but the data available suggest that there is a connection (White & Hastings, 2004). This paper will attempt to fuse some of the findings regarding the problems of parents of children with ASD and ID and the support available to them.

The aim of the paper

The aim of the paper is to present available and relevant research that takes into the account various problems faced by parents of children with ND (ASD and ID), as well as the types of support they may receive.

METHOD

An overview of the relevant literature was made through a review of the electronic databases available through the Consortium of Libraries of Serbia for Unified Acquisition (KOBSON) as well as Google Scholar Advanced Search. Searches were made through the following search engines: ScienceDirect, Ebscohost, SpringerLink and WileyInterScience. The following keywords were used in the search: ID, ASD, parents, support, need for support, types of support, family support, family strengths, family activities and family assistance. Papers were collected and analyzed, in which the problems encountered by parents of children with ND are discussed, as well as papers describing possible support.

Review of the research

Basic parental problems and possible forms of support

Functioning, quality of life, expectations and outcomes in families with a child with ND depend not only on the severity of the disability, the child's characteristics and needs, but also on the characteristics of the whole family, the experiences of family

members and the resources available to them (Thomas & Dykes, 2013). The prevailing belief is that families with a child with ND need different support across a number of areas (Oluremi, 2015).

Parents of children with ND more often socially isolate themselves than parents of children of the typical population (Oluremi, 2015). Domestic research indicates that parents feel they have no time for anything but a child with ND. Their child requires all-day supervision and care, and they do not have much time left for their careers, non-child care responsibilities, rest, socializing, relaxation and personal interests. Parents also find that they do not devote sufficient time to their other children (Žegarac, Džamonja-Ignjatović, Milanović, 2013).

One study shows that the level of stress in a parent of a child with ND is associated with the **level of support a parent receives from their partner** and the level of satisfaction with the marital relationship (White & Hastings, 2004). It has been noted that parents of children with ND have more marital problems than parents of children of the typical population. Some findings indicate that there is a high incidence of marital disputes and divorce among parents of children with Down Syndrome (Aldosari & Pufpaff, 2014). Mihić and his associates also talk about broken partnerships between spouses who have children with ND (Mihić, Rajić, Krstić, Divljan, Lukić, 2016).

Informal support is very important for parents, i.e. the support they receive from their relatives and friends, and most of all the support from their parents. Research shows that parents of children with ND, especially mothers, express greater satisfaction and lower levels of stress when receiving informal support from their relatives and friends and when interacting with them regularly (Aldosari & Pufpaff, 2014). This type of support has proven to be an excellent stress regulator in parents of these children (Kwai-sang Yau & Li-Tsang, 1999). In certain families, grandparents are the ones who take upon themselves the care of a child with ND for various reasons (so that the child's parents can work, if the child's parents have passed away, or have health problems, or they have lost parental rights due to neglecting the child). Research shows that, most often, grandmother takes the role of child caregiver, their age being 50 to 60 years old (Neely-Barnes & Dia, 2008).

Parents of this population often have financial problems. Payment for medication, special equipment, therapists, transportation, etc. is required for a child with ND, and parents often need **financial support**. For these reasons, parents are often forced to change their diet and reduce their spending on recreation, rest, relaxation and clothing. Numerous studies point out that fathers are the ones who stay in their jobs, continue to build careers, or are often focused on finding better paying jobs. On the other hand, mothers most often lose their jobs, or do not search for work, so that they can look after the child (Oluremi, 2015). Research in our country indicates that only 9.8% of families with a child with ND have both parents employed (Dimitrijević, 2013). Comparative studies show that mothers of children with ND, compared to mothers of children of the typical population, work fewer hours and are paid less for their jobs (Neely-Barnes & Dia, 2008). Research results show that parents who do not have financial difficulties exhibit higher levels of satisfaction with their lives and their parenting role (Davis & Gavidia-Payne, 2009). Research in our country shows that the most common sources of income in families with children with ND are state aid for help and care of another

person (58.2%) and state financial aid for a child (42.5%). Less than half of families (42.2%) have salaries (Žegarac et al., 2013). Research shows that if the family has no financial problems, family relationships, interaction with the child with ND, and marital relationships are good, of good quality and with little or no difficulty (Meral & Cavcaytar, 2012). When assessing the quality of life of families with a child with ND, assessment of family income could be considered to identify the appropriate type of support that the family needs (Davis & Gavidia-Payne, 2009).

One source of problems for parents is dissatisfaction, or misunderstanding of their needs by **various support services** (Jones & Passey, 2004). Research shows that parents think that they do not receive satisfactory support from the educational and healthcare institutions that are helping them to care for their children. The most common indicator of poor quality of cooperation with these institutions is the rare involvement of parents in decision-making regarding the child and the parents feeling that the overall family functioning is not taken into consideration. Research shows that professionals often perceive parents as too demanding, overprotective, overwhelmed by feelings (Mihic et al., 2016), while parents often feel only as passive participants in decision making which concerns their child (Thomas & Dykes, 2013). Sources of difficulty for parents are aspects of the services they receive, such as the length of a particular program, the location of the service, or the venue of the program, as well as the frequency of contact with professionals (Davis & Gavidia-Payne, 2009). The services provided to the families of children with ND in our country are being carried out within the framework of social protection programs and most often represent an instrumental type of support (nutrition, therapy, care, etc.), they are not of a lasting nature and are usually available only to parents in major cities (Mihic et al., 2016).

Parents often experience trauma and stress due to a lack of information about the disorders that have been diagnosed, what to do next and to which institutions and services should they addressed to, so they could best meet their child's needs. Due to lack of information, parents often resort to alternative treatments, causing them to spend more money and sometimes those treatments even harm the health of the child. It is considered necessary to create more quality intervention programs for children with ND and their families. Primarily, there is a need for different forms of counseling, family education, skills training and different social services (Oluremi, 2015).

The support that parents often need most is help with **babysitting**. This kind of support allows parents to have time for themselves, relaxation and fun. There are childcare services in Ireland and the UK, which are regulated and intended for families with children with ND. In the United States, there are also services designed exclusively for children with developmental disabilities and children with chronic illnesses (Sung & Park, 2012).

Parents should be involved in an early intervention program so they can, with the help of a specialist, identify the services that can provide the type of support that best meets the child's needs at that moment (Jacob, Olisaemenka, & Edozie, 2015).

Early intervention programs in our country are still not being implemented satisfactorily. Parents find that they are not sufficiently involved and informed in one of the most critical times for their child and their entire family. They also think that education about the disorder that has been diagnosed, as well as information about

the implications of the diagnosis on the child's development and the functioning of the whole family, should be organized. They also state that it is necessary to provide them with psychological support in dealing with conflicts, stressful situations and difficulties they encounter (Mihic et al., 2016). The same research done in our country indicates that few parents use any form of support directly addressed to them. The most common difficulties are inadequate time of conducting a program, lack of free time due to constant child care and lack of information about the existence of support programs (Mihic et al., 2016). Parents in our country believe that greater support from all levels of government is needed in order to improve the network of different services in our country (Žegarac et al., 2013).

Problems and support to parents of children with ASD

Parents of children with ASD face difficult challenges to cope with the grief they feel, concerns about the future, and difficulties of finding the appropriate support services their child needs (Anderson & Smith, 2014). One of the most significant periods in the lives of families with children with ASD is the diagnosis. Parents of children with ASD experience the whole process of diagnosis as stressful (Kalash & Olson, 2012). It takes a long time to get a diagnosis. Procedures from the detection of early ASD symptoms to diagnosis are different between countries, but in most states, families wait at least one year until the end of this segment (Mereoiu, Bland, Dobbins, & Niemeyer, 2015). Some authors think that the first reaction of parents, when a child is diagnosed, is to seek information about what is that specific disorder that has been diagnosed, what the implications and prognosis are, and practical advices (Murphy & Tierney, 2005). Parents often wonder what the reason for their child's diagnosis of ASD is, and whether they have contributed in any way to the development of the disorder, so they feel guilty about it. Also, some of them want to master the facts about this disorder so that they can help their child (Anderson & Smith, 2014). On the other hand, one of the sources of frustration is the lack of information coming from different institutions and services (Murphy & Tierney, 2005).

Numerous difficulties found in a child, such as challenging behavior that is often present in children with ASD, eating problems, sleep problems, or tantrums, affect the daily life of the entire family, relationships among members, and lead to chronic fatigue (Anderson & Smith, 2014). Parents express concerns regarding their child behavior when they are visiting someone, since destroying the furniture, objects and unacceptable behavior can occur, and for that reason visiting is avoided. One study found that the severity of ASD symptomatology positively correlates with the level of stress in parents, that is, more severe symptoms lead to higher levels of stress and greater dissatisfaction (Brown, 2014).

The diagnosis is followed by one of the most important periods in the life of a child with ASD during which the basis for further development is laid. It is a period of early intervention. Early treatment and family involvement in this system are very important for any child with ASD. Some parents are satisfied with this program, they feel that they are sufficiently involved in decision making, that support services are flexible, that they are adequately supported and that they have access to various resources. They state

that they are satisfied with the established social support network that allows them to interact with other parents of children with ASD and to learn different intervention strategies to improve the child's communication and social skills and play. There are those parents who are not satisfied with this type of program. Their dissatisfaction most often relates to the cost of services and the time they have to wait to receive a particular service (Coogle, Guerette & Hanline, 2013). Many parents of children with ASD, despite the importance of early treatment, do not have enough time, energy, or resources to participate in it (Mereoiu et al., 2015).

Experts play a very important role in the lives of families with children with ASD. They should provide families with emotional support, encouragement, information support, identify the child's needs and how to meet them (Mereoiu et al., 2015; Shu, 2009).

Sometimes the source of frustration for the parents are the experts themselves. Parents object to the emergence of differences of opinion among professionals regarding adequate treatment. Different providers are sometimes perceived as not organized, not flexible, not responsible and lacking in knowledge to meet the child's needs, as well as not providing sufficient information, support and understanding to families (Shu, 2009). Parents conclude how the experts do not take into account their worries, doubts and suggestion (Mereoiu et al., 2015).

Parents of children with ASD experience more stress than parents of children with other ND (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). There is evidence that parents of children with ASD experience the most stress compared to parents of children with ID and parents of children with chronic illness (Anderson & Smith, 2014). Some of these problems are related to increased negative health outcomes, marital dissatisfaction, disputes and conflicts, as well as anxiety (Dunn et al., 2001; Rivard, Terroux, Parent-Boursier, & Mercier, 2014). Mothers of adolescents with ASD report that they face more problems as parents and as a family, compared to mothers of adolescents with ID (Dunn et al., 2001). Research shows that the level of stress that occurs in parents of children with ASD is associated with the level of the child's social skills, behavioral problems, and worsening of the clinical picture (Wang & West, 2016).

These parents are at greater risk for marital issues and divorce, problems in relationships with other people and social isolation, than parents of the typical population (Dunn et al., 2001). Most often, mothers quit their jobs and quit their careers. Gray interviewed 32 families who had a child with ASD and came up with information that the mothers had plans to find a job at some point, or to return to their jobs that they left, but most often, it did not happen. Mothers who stay in their jobs, or get a job at some point, report that they often do not work full time, often have to be absent from work, or do not do their full potential because they are too tired (Gray, 2003). Milačić-Vidojević confirms a similar situation regarding Serbia. Fathers rarely leave their jobs to stay home and take care of the child, while mothers fully devote themselves to the child (Milačić-Vidojević, 2008).

Research shows that, in relation to fathers, mothers most often seek support and assistance from their partners, friends, relatives, other parents, and professional services and experts (Gray, 2003).

The best strategy to cope with the various difficulties and stress for parents of children with ASD is thought to be social support (Brown, 2014). However, social support can also be a source of various problems. Parents of children with ASD often have the problem of not being informed about the various services available, the financial problem of paying for these services or treatment, or the problem of establishing adequate communication and collaboration with service providers (Mandell & Salzer, 2007). These parents are often members of different social support groups, which gives them a sense of belonging within a circle of people in a similar situation (Brown, 2014).

Online social support is increasingly popular today. Research shows that this type of support is also used by parents of children with ASD. It allows them to receive the emotional support they lack from their family, relatives, or friends. Also, in this way, they can get the information they need, or that could be helpful from the people facing similar or same difficulties (Reinke & Solheim, 2015).

In recent years, an increasing number of projects, programs and interventions have been organized aimed at learning about and enhancing the knowledge about the ASD, understanding the needs of these individuals and their families, and enhancing the child's capabilities and skills (Mereoiu et al., 2015). One of the ways that parents of children with ASD can be assisted is by teaching them the methods that can enhance their child's development and improve their behavioral characteristics. It also extends teaching methods that can help parents themselves adequately cope with the difficulties and stress they encounter (Anderson & Smith, 2014).

Problems and support for parents of children with ID

The moment of getting the diagnosis is accompanied by feelings of sadness, hopelessness, loss and resentment for the parents of children with ID (Aldosari & Pupaff, 2014). As parents of children with ASD, the parents of children with ID go through several stages, after finding out their child's diagnosis. There are five such phases in the literature: 1) shock and negation; 2) anger and resentment; 3) negotiation; 4) depression and hopelessness and 5) acceptance and adjustment (Cavkaytar, Ceyhan, Adıgüzel, & Uysal, 2012).

According to the studies, the impact of the clinical picture of ID on parents is different. In one study, 55.38% of parents stated that they thought their child with ID had a positive effect on the whole family. Parents stated that having a child with ID led them to develop patience, tolerance, empathy, sensitivity and that their marital relationship improved (Indla, Indla, & Singh, 2008, according to Aldosari & Pufpaff, 2014). Some parents feel that, thanks to their child with ID, they have begun to appreciate the little things they once took for granted (Aldosari & Pufpaff, 2014). Other research supports the fact that parents of children with ID have more negative than positive parenting experiences and that the stress that comes from caring for a child with ID can affect the physical, cognitive and emotional aspects of all family members (Azar & Badr, 2010).

Sources of difficulties for parents of children with ID are complex, interrelated and influenced by a number of factors. Parents of children with ID cite challenging behaviors and changes in their child's sleep, social isolation, inner family disputes, and financial problems as sources of difficulty (Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009).

Children with ID often need hospitalization, medical care, special development services, and more specific care than children of the typical population. These requirements can be a great source of difficulties for parents of children with IDs in terms of financial problems, time constraints, and parents' doubts about their ability to meet their child's specific needs (Gerstein, Crnic, Blacher, & Baker, 2009; Nachshen, Garcin, & Minnes, 2005).

Parents of children with ID have poor social network (van Asselt-Goverts, Embregts, & Hendriks, 2015). Research shows that these parents often have marital problems, and that the mutual support between spouses is very poor. A child with ID affects the functioning of the whole family as well as siblings (Aldosari & Pufpaff, 2014). Parents of children with ID, same as parents of children with ASD, have an unequal distribution of child-related responsibilities, and thus the mother most often plays a dominant role in the care of the child (Azar & Badr, 2006). The support they receive from their partners is very important for parents of children with ID, and when that support exists, it helps them to more adequately cope with various difficulties (Kilic, Gencdogan, Bag, & Arıcan, 2013; Wieland, & Baker, 2010).

Numerous authors believe that it is necessary to collect information on the needs of the entire family who have a child with ID in order to identify appropriate support services that will improve their quality of life (Cavkaytar et al., 2012). If the support provided is not adequate, parents are very dissatisfied and stressed (White & Hastings, 2004). One study state that different support services often do not take into account the needs of a family with a child with ID and are not sensitive to the problems these families face (Nachshen, 2005).

The type of support is important for the parents' adaptation process and the level of their satisfaction with the support. The results indicate that informal support is most effective and that this type of support can compensate for parental dissatisfaction arising from the influence of experts, professional office and services (Hastings, Allen, McDermott & Still, 2002). Parents of children with ID state that they need emotional support from close people in their environment, professional help in dealing with various psychological problems, and different resources of social support (Cavkaytar et al., 2012).

INSTEAD OF A CONCLUSION

A quality support program for parents would include: accessibility in all local communities, not just in major cities; education on ND and the impact of diagnosis on child development; redefining parental role and quality child care with ND.

When planning support, it is necessary to identify and describe the type and intensity of support needed, and to include in the support process those services that will mitigate or eliminate the differences that exist between the individual level of functioning of the child with ND, the parents' problems and the demands of the setting environment. In our country, more support from all levels of government is needed in order to improve the network of different services.

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