

## THE ABILITY TO BALANCE PARENTS' WORK AND CARE FOR CHILDREN WITH DISABILITIES: THE EXAMPLE OF THE CITY OF NIŠ

UDC 364.787.224-053.4/.5(497.11 Niš)

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**Abstract.** *By conducting this study, we wanted to ascertain how the use or non-use of the social protection service of personal assistant to a child is associated with the employment of the parents of children with disabilities. Ten parents whose children use and do not use this service were interviewed, and the results were processed by thematic analysis. The key findings of the study show that there is a difference between the parents' employment status, in regard to whether their children use the service of personal assistant to a child, i.e. that the use of this service enables their labor market inclusion. Furthermore, the labor market non-inclusion results in the unfavourable material situation of the family, and the long-term inability to exercise their right to a pension. Based on the results, potential solutions may include: the possibility of reduced working hours, the possibility for parents to be formally employed as a child's personal assistant, and the possibility of using the personal assistant service.*

**Key words:** *social protection, social services, children with disabilities, employment*

### 1. INTRODUCTION

Regardless of the children's needs and traits, and the concern resulting from this, balancing work and parenting can often be challenging for all parents. What is even more challenging for the parents of disabled children, compared to those of children who have no disabilities, is making doctor's and treatment appointments, taking their children to and from school, support in everyday activities (dressing, feeding, moving). According to some estimations, the parents' additional, informal care for disabled children amounts to

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Received July 8, 2023 / Accepted December 10, 2023

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thirty hours per week (Brown and Clark 2017). Moreover, the question of balancing their work and care for children is even more important, since the parents' employment is an important source of income, particularly regarding the high expenses of the activities and overall care for the disabled children, and insufficient systematic support (e.g. available treatments, services or material support).

This paper will discuss the difficulties that parents encounter when managing employment duties and caring for disabled children. It will also be discussed how it is addressed at the national and local levels (on the example of the city of Niš). More specifically, the paper will explain the obstacles in this balancing act for parents whose children require the service of a personal assistant and will compare the experiences of those whose children have gained access to this service and those whose children have been denied access. The aim of this study is to highlight the importance of creating and making social protection services available (in the form of a personal assistant), which are one option for balancing work and caring for disabled children.

## 2. THE PROBLEM OF BALANCING WORK AND FAMILY RESPONSIBILITIES

Parents of children with disabilities face numerous challenges in the field of work. The results of research conducted in Great Britain show the long-term unemployment of parents of children with disabilities. Forty percent of parents who are not involved in the labor market have not worked for more than five years (Working Families, 2018). On the other hand, even those parents who are involved in the labor market encounter difficulties in balancing family and professional life and have to change their career for a better balance of family and business needs. Sometimes working parents do not report increased childcare challenges, so as not to jeopardize their employment (Stefanidis, Strogilos, & Kiriakidou, 2020). In other cases, many parents refuse promotions or accept lower positions and work in positions below their qualifications and skills due to their parental responsibilities (Working Families, 2018).

An overview of the literature on the balance between the business and family life of the parents of children with disabilities and which includes 50 studies shows that there are two types of factors which influence this balance (Brown & Clark, 2017). These are individual and organizational factors. The individual factors are: the number of children, their age, the availability of childcare and services, the type of child's needs, job role perception, and marital status, whereas the organizational factors include: the organizational culture, supervisor's assistance, and formal and informal business policies. Generally speaking, the research shows that employed parents with children with severe disabilities and behavioral problems, without a partner or access to reliable childcare, and with lack of interest for their work have more difficulties achieving a business and family life balance, compared to other parents (Brown and Clark 2017).

The availability of quality childcare is emphasised as a serious challenge that many employed parents face. The so called "service limitations" disables mothers from working or working longer hours (Bourke-Taylor et al. 2011, according to Brown and Clarke 2017). Furthermore, the lack of adequate childcare is related to both parents leaving their jobs (Scott, 2010 according to Brown and Clark 2017).

In different cultures and societies, women, i.e. mothers, are usually recognized as central figures in childcare (Brown and Clark 2017; Working Families 2018; Stefanidis, Strogilos

and Kyriakidou 2020). This is reflected in different spheres of their lives, including the business one. The results of a study conducted in Serbia on a sample of 358 parents of children with disabilities show that less than half of these families has employment income. Based on their gender, 68,2% of women who care for a child, and 48,7% of men, are unemployed (Žegarac, Džamonja Ignajtović & Milanović 2014). The results of a study conducted in the United Kingdom on a sample of 1250 parents of disabled children, show that these parents, mothers in particular, have fewer opportunities for employment than other parents. According to the results, 47% of mothers of children with disabilities were employed, and 64% of other mothers, whereas the gap between the fathers was smaller (72% to 74%) (Working Families 2018).

### 3. THE NATIONAL AND LOCAL SUPPORT CONTEXT

Much has been done, both nationally and internationally, to promote and protect the rights of children with disabilities. The degree of change is most visible in normative contexts. As a result, the Convention on the Rights of Persons with Disabilities was adopted in 2007 (and ratified by the Republic of Serbia in 2009). This Convention served as the foundation for the adoption of new national normative acts, as well as modifications to existing ones, in order to recognize the uniqueness of the situation and improve the degree of support for this group and their families. The improvements should aid in the deinstitutionalization and integration of these children, implying a shift in practice based on the medical model. The advantages of children living with their families and thus preventing the risks of separation from their biological families, have been thoroughly described in the literature, and are achievable only with adequate support to these families with many challenges they may encounter. For parents to respond adequately to the children's developmental needs and encourage their developmental capacities, while performing numerous other roles in family and society, it is important to “possess adequate resources for basic economic stability and psychosocial support, through the network of extended family and friends, the society and wider social systems, thus ensuring higher parenting quality” (Mitić 2011, 80).

The Law on Financial Support for Families with Children, which was adopted in 2017, recognizes the need for additional support for families with children with disabilities. Some of the articles that emphasize these questions are:

- Salary compensation, i.e. salary compensation during maternity leave, work absence due to childcare and special childcare (Article 12). Salary compensation for special childcare can be given until the child reaches five years of age the latest,
- Child allowance is given to a child with developmental disabilities and a child with a disability, for whom the interdepartmental commission issues the opinion, in accordance with the regulations in the field of education, as long as it is included in the educational program and the vocational training program, and for a child whose parental right has been extended up to 26 years at most. (Article 26),
- As an exception to paragraph 1 of this article, the right to child allowance without resubmitting proof of the family's financial situation is exercised by the beneficiary of financial social assistance whose children regularly attend school, and regardless of financial conditions of the family, beneficiary whose child receives the allowance for the assistance and care for another person. (Article 30),

- The amount of the child allowance, determined in paragraph 1 of this article, for single-parent families and guardians, is increased by 30%, and 50% for the parents of a child with developmental disabilities and a disabled child, for whom the opinion of the commission has been issued, and for a child receiving the allowance for the help and care for another person, and does not use accommodation services. (Article 30), and
- Preschool age children with disabilities have the right to compensation for the costs of staying in a preschool institution, that has a permission of the Ministry responsible for the affairs of education about verification, in the amount of the user's participation in the price of the service, that is determined by the decision of the local self-government unit. (Article 35)

These families can also apply for several of the financial assistance programs outlined in the Law on Social Protection (2011), including:

- Cash benefits (specifically for this population, Article 83),
- Assistance and care benefits (Articles 92 and 93),
- Increased assistance and care benefits (Article 94),
- Assistance in vocational training (Article 108), and
- One-time assistance (Article 110).

Services that enable children to have free access to the process of education, socialization, cultural and other material, and simplify the organization of numerous challenging obligations for their families, in addition to multiple forms of financial support, are also important. According to Article 5 of the 2011 Law on Social Protection, social protection services are activities that provide support and assistance to individuals and families in order to improve or preserve the quality of life, eliminate or mitigate the risks of unfavorable life circumstances, and create the opportunity to live independently in society. Social protection services are provided on an interim, sporadic, or continuous basis, according to the needs and best interests of the users (Article 42). In addition, the Law creates social protection services: assessment and planning services, daily services in the community, support services for independent living, counseling-therapeutic and socio-educational services, and accommodation services (Article 40). Some services are provided by the Republic of Serbia, while some are financed by local self-government. The domestic help service, day care center, personal assistant and other services that support the user's stay in the family and immediate environment could be provided by local self-government organizations, based on the citizens' needs. The Rulebook on Detailed demands and Standards for the Provision of Social Protection Services, issued by the minister responsible for social protection in 2013, contains more detailed requirements and standards for providing and carrying out social protection services.

One of the mentioned services in the community is the personal assistant service. The personal assistant is designed for children with disabilities and offers additional social assistance for children's education and socializing. The service is provided under specific circumstances and in compliance with the Social Protection Act (2011) and other relevant regulations and by-laws. In accordance with statistics from the State Audit Institution's research "Provision of services in the field of social protection - Personal companion of a child" (State Audit Institutions /DRI/ 2020), the service is still inadequately developed in the Republic of Serbia. We can establish the number of people affected by this simply analyzing the data for the City of Niš (DRI 2020). However, the number of persons for whom this service was suggested but not offered has increased (10 proposals in 2017, 24 in 2018, 45 in 2019). There is no data accessible after 2019. Based on all available data on the social protection service of a personal assistant to a child on the territory of the

City of Niš, there is a discrepancy among the children's needs for this service and the material resources allocated for it. Analyzing the City of Niš budget decisions for the year 2017-2022, it was noted that the funds allocated by the city budget have not risen in general or significantly in the past few years, but the number of submitted or unrealized requests increased. As a consequence of the aforementioned difference in financial abilities and service need, the City Commission was established to select users of the personal assistant services, as well as criteria for choosing users of these services. Taking everything into consideration, some percentage of children do not receive this service despite the fact that they need it, and their family members, who are not informed or supported by the system, carry out their responsibilities informally.

#### 4. THE RESEARCH METHODOLOGY

The results presented in this paper are part of a qualitative study that was conducted as part of the public advocacy campaign by the “Nauči me” organization from Niš. Its goal was to generate reliable knowledge about the availability personal assistant services on the territory of the City of Niš.

The central research question in this paper is: in what way is the use or non-use of the social protection service of a child's personal companion related to the work engagement of parents whose children with disabilities?

The study was conducted in December, 2021. Semi-structured interviews were conducted with the parents of children who use and do not use a personal assistant in order to explore in more detail the availability and functioning of this service, as well as the difficulties faced by the families and their needs. Taking into consideration the epidemiological situation caused by the COVID-19, the interviews were conducted over the telephone. The topics included in the interview are: the use of social protection services and other types of support, the need for education, work engagement and child care adjustment, family functioning and the difficulties they face with child care. This paper will present the results related to the balance of work engagement and care for a child with disabilities and developmental delay.

For participation in the qualitative part of the study, verbal consent was obtained from the participants, who were given detailed information about the research objective, the method of data collection, and the presentation of the results. Alongside the consent, the conversation was recorded and transcribed, after which thematic analysis was used to process the data by three researchers, who independently analyzed the transcribed the material (Braun and Clarke, 2006). The method of collecting and processing all data included anonymity, confidentiality, and privacy protection, which were ensured through the encryption of the names of the participants and the removal of all content by which a person could be identified in the data (Craswell 2014). Each participant received a unique code based on their gender (M or F) and the ordinal number of the interview.

The sample was criterion-referenced (Creswell 2013). The chosen criteria were that the parents have children who need personal companion service and that they live on the territory of the City of Niš. The sample consisted of 10 parents (9 mothers and 1 fathers), 5 whose children use and 5 whose children do not use the service of a personal assistant. The parents who participated in the study were recruited in two ways Parents whose children use the service were recruited in cooperation with the Center for Defectology Artemida from Niš, which was the service provider during that period, while contact with parents who do not use

the service was established in cooperation with representatives of the elementary schools where the children go. Before the interview, a telephone contact was established with the parents, in which the purpose and goal of the research were explained to them.

#### 4.1. Parents' employment status

Of the 10 parents who participated in the study, 5 are employed, and 5 are not. There is a significant difference in the employment status of parents whose children use or do not use the personal assistant service. Among the parents whose children use the personal assistant service, 4 are employed, and 1 is unemployed. In the group of interviewees whose children do not use the service, 4 are unemployed, and 1 is.

#### 4.2. Parents' employment status and childcare (balance and difficulties)

Employed parents whose children use the personal assistant service acknowledge the fact that the service facilitates their work situation, i.e., it is directly related to their ability to remain employed.

*“Well, it makes things a lot easier. I mean, if it weren't for the personal assistant service, me or my husband wouldn't be able to work. I mean, one of us has to be here, for him and for our two other children.” F9*

*“For me, this service makes everything easier when it comes to my work, because I know that my child is fine.” F8*

When they talk about the understanding of their employers in regard to the responsibilities arising from their care of a child with disabilities, the employed participants have different experiences, but mostly positive ones. It should also be mentioned that employees at work are sometimes reluctant to share the details of their family life and the need for additional childcare.

*“At my previous job, people weren't very understanding, but now they are fantastic. They're really great, some of them have similar problems in their own families and know what it's like, and they support me.” F8*

*“People weren't that understanding. But I also didn't go into it very much. I don't think they are aware how big of a problem it is. It was wobbly in the beginning, but I could leave to take my child to the doctor. During that period, I got transferred from Niš to another place, but I adapted. That's when I stepped out of my comfort zone and it helped me snap out of it. I don't want to blame them.” F7*

As mentioned, within the group of parents whose children use the service, only one is currently unemployed. It is important to note that the family in question is a single-parent household, and unemployment in this case is largely the result of caregiving responsibilities for a disabled child and other children in the family.

*“Well, I'm not employed. Haven't even had a job. I've been alone for two years, with three children. I wanted to work somewhere, but my youngest daughter didn't go to kindergarten, she is 6 now. So I'm devoted to the oldest daughter. Well, it's difficult for me to work and take care of a child, when she's like this, when she has surgeries and then recovery. When we go to Russia, she has 10 surgeries in 7 months over there. So she takes up 100% of my time.” M1*

In the group of interviewees whose children do not use the personal assistant to a child service, four of them are not employed. The participant who is, states that she will resign from her job in the following period due to the inability to adjust child care and business responsibilities.

*“Take us for example, my husband is self-employed and he works from home, but I'm gonna work till the end of the month, and that's it. Because we have to stay with him at school. I'm gonna have to give up my job. It's one salary less in the house. And there are a lot of us, we also have one little child who'll be three soon. It's a lot for us, even it's not that much money nowadays, 35 000 RSD, but still, it's a loss.” F5*

In another case, a child's mother already resigned from her workplace so that she could devote herself to childcare.

*“I quit my job two years ago so that I could be completely devoted to him.” F1*

From the other participants, one of them receives a disability pension, whereas two of them have never been employed, which is related to childcare.

*“I've never worked, and now that seems impossible to me. It's difficult anyways for a woman to balance all her responsibilities, and when they hear that you have a child with something like this, I don't think anyone would welcome me with open arms.” F3*

*“Well I don't think I'd be able to also balance work. I wouldn't be able to do that because he needs me to be with him all the time. I mean, I'm not avoiding work, I just don't think I could manage all of that.” F10*

Based on these examples from parents whose children do not use a personal assistant service, it can be noted that when someone in the family has to stay out of the labor market to take care of the child, it is the woman. In addition, in accordance with traditional roles, they take informal care not only of the children, but also of other family members when needed.

*“I'm the one who takes care of all the family members. I'm the one who took care of my husband's grandmother up to six month ago. She was bed-ridden for two years. Partly because of her and the child, and also because of my father and mother-in-law, I couldn't work. The entire house was on my shoulders.” F5*

For parents whose children do not use a personal assistant service, it is impossible to balance their business responsibilities and childcare. As a consequence, they are excluded from the labor market (they are currently unemployed, have never been employed, or have resigned from their jobs because of this role). The long-term consequence of this is not being able to achieve the minimum number of years of service that ensures retirement, which is one of the elements of concern for parents when they talk about the future.

*“We are supposed to have some sort of pension, after all. Then I think about how, if I don't work, I won't have enough years of service, I won't be able to support my children.” F5*

Furthermore, the unfavorable material situation and financial difficulties are one of the consequences of the inability to coordinate work and childcare, as well as the high costs of various treatments intended for the child (psychological, speech therapy, defectology). It is recognized that parents often bear the costs of various forms of child support themselves, but

that the level of support depends on the financial situation of the family (*“Supporting children mostly depends on how much the parents can bear themselves.”*, F8).

#### 4.3. Potential solutions

Unemployed parents were asked what would help them balance their work obligations and childcare. Those whose children do not use the service personal assistant see the potential solution in a few different ways:

- The possibility of reduced working hours (*“Reduced working hours would be really, really awesome. I tried to do that with my previous company or to find a job like that, but didn't manage. I didn't find something like that in Niš.”* F7)
- The possibility of being formally employed as a child's personal assistant (*“It would be best for us if I could formally be my child's personal assistant. I really don't understand why that's not possible. It would help us a lot and make our functioning easier.”* F3)
- The possibility of using the personal assistant service (*“If I used this service, I could keep my job... I am used to working, I am used to being useful.”* F5)

The parent whose child uses a personal assistant service do not see the possibility of balancing work commitments and childcare.

## 5. RESULTS, DISCUSSION, AND CONCLUSION

The results indicate a difference in the employment status between parents whose children use the personal assistant service and parents whose children do not use this service. In the group of parents whose children use the service, all except one are employed, while in the other group, whose children do not use the service, non-employment predominates.

Parents whose children do not use the service are unable to balance work and childcare and do not participate in the labor market. The consequences of this are noticeable within the family's financial situation, and long-term in the parents' not receiving a pension, because of insufficient years of service. It is also evident that gender-based ideas about work and informal care still prevail, which reproduces patriarchal patterns – men are in charge of the public sphere, and women are in charge of the private-family sphere. When the child does not receive the child's personal escort service, the mothers are the ones who take on the informal performance of this role and are excluded from the labor market, which can have multiple consequences on their individual and family functioning.

Other researchers also acknowledge the importance of parents' employment. Mothers who did not work showed the need for employment for financial reasons, as well as frustration due to the impossibility of using their skills and the lack of a sense of identity provided by work (Shearn & Todd 2000, according to Brown & Clark 2017). In addition to the consequences that are of a financial nature for the family itself and the impossibility of self-realization through work, the wider consequences for society can also be seen considering that the parents' potential for contributing to society through engagement at work is lost. Moreover, many studies show that engagement at work has a 'break' effect on people (Brown & Clark 2017). This may be particularly important for preventing the burnout syndrome that can occur in long-term informal care.

There are several ways in which the improvement of the parents' employment and work and the balance of work and childcare can be facilitated.



*The possibility of reduced working hours.* Although it is officially recognized in the national Labor Law (part-time work, Article 39, work from home, Article 50, redistribution of working time, Article 57, flexible working time, Article 55), in reality it is not sufficiently practiced as a form of support to care about children with disabilities, and additional awareness and information on this topic is needed for both parents and employers. Research shows that flexible working hours and the workplace allow both meeting the needs of the child (e.g. if medical examinations are scheduled during working hours) and the possibility of staying at work (Rosenzweig et al. 2002, according to Brown & Clark 2017). Some authors consider this flexibility as key to managing work and childcare. However, the research shows that these parents are often reluctant to ask for the flexibility they need, especially if it is seen as a benefit rather than a right. This is especially noticeable in situations with insecure jobs (Lewis, Kagan & Heaton 2000). This highlights the importance of empowering parents to seek the support they need in order to adequately balance their work and childcare. Of course, it should be emphasized that formal policies at the workplace as well as the informal practice of adjusting work and parenting are important for all parents, but that we should be especially sensitive to parents of children with disabilities.

*The possibility of being formally employed as a child's personal assistant.* National legislation does not recognize that parents can formally take on the role of a personal assistant and be compensated for it. However, some parents in this study see it as a way of addressing their unemployment issue. Accordingly, the launching of an advocacy campaign to change regulations at the national level and allow parents who wish (with assessment and training) to formally act as personal assistants for their children should be considered.

*The possibility of using the personal assistant service.* For some unemployed parents in this study, the opportunity to use the child's personal assistant service could be a means of improving their employment status and achieving work and childcare balance. Also, the employed parents in this study recognize that using the personal assistant service is one factor which enabled them to balance work and childcare ("service makes everything easier"). In order to allow a larger number of children to use the service at the local level, it is necessary to adjust the financial resources for the implementation of the personal escort service with the recommendations of the Interdepartmental Commission, to meet the needs of all children in the area. In addition to the service of a child's personal assistant, other services in the community that contribute to more adequate childcare and the quality of life of families (e.g., home assistance – help at home) should be developed or improved. The development of these services can be a step towards the inclusion of unemployed parents in the labor market and towards balancing work and childcare.

In the end, it is crucial to emphasize that the population of children with disabilities and their families is diverse, and all the suggested solutions and support should be customized to suit the child's and family's specific circumstances and needs. Also, it is important to emphasize the need to include the people in question in the creation of local and national policies in this area.

### **Limitations and further studies**

The main limitation of this study is that the sample is not representative. The results provide initial insights into the state of affairs in this area and can serve as a basis for conducting research that would include a larger number of parents, both at the local and national level.

**Acknowledgment.** *The article was prepared with the support program in the field of public advocacy "Investigate – Empower" launched by the Trag Foundation with the financial support of the Government of the United Kingdom. The public advocacy campaign was implemented by the "Nauči me" organization from Niš.*

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## **USKLAĐIVANJE RADA RODITELJA I BRIGE O DETETU SA SMETNJAMA I TEŠKOĆAMA U RAZVOJU: PRIMER GRADA NIŠA**

*Sprovođenjem ovog istraživanja želeli smo da utvrdimo kako je korišćenje ili nekorisćenje usluge socijalne zaštite, lični pratilac deteta, povezano sa zapošljavanjem roditelja dece sa teškoćama u razvoju i/ili invaliditetom. Intervjuisano je deset roditelja čija deca koriste i ne koriste ovu uslugu, a rezultati su obrađeni tematskom analizom. Ključni nalazi istraživanja pokazuju da postoji razlika između radnog statusa roditelja u pogledu toga da li njihova deca koriste uslugu ličnog pratioca, odnosno da korišćenje ove usluge omogućava njihovo uključivanje na tržište rada. Takođe, neuključenost na tržište rada rezultira nepovoljnom materijalnom situacijom porodice, a dugoročno i nemogućnošću ostvarivanja prava na penziju. Na osnovu rezultata, potencijalna rešenja mogu uključivati: mogućnost skraćenog radnog vremena, mogućnost da se roditelji formalno zaposle kao lični pratilac deteta i mogućnost korišćenja usluge personalnog asistenta.*

**Ključne reči:** *socijalna zaštita, usluge Sistema socijalne zaštite, deca sa teškoćama u razvoju i/ili invaliditetom, zapošljavanje.*