

## DAY CARE SERVICE FROM THE PERSPECTIVE OF PARENTS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES – LEGISLATION AND PRACTICE \*

UDC 364-53-053.4/.5(497.11 Niš)

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**Abstract.** *The day care service in the social protection system plays a significant role in improving the quality of life of its users, aimed at enabling them to lead an independent life. This service is of particular importance for children with developmental disabilities due to its positive impact on the development of their social, cognitive, and other essential functions. It also provides parents or guardians with additional free time for work and other activities. In this paper, we will first discuss how the position of children with developmental disabilities has changed over time and how the system of social protection has been developing. Furthermore, we will present the normative framework of social protection in our country, as well as social protection services, followed by a detailed analysis of day care as the most significant daily community service. The central part of the paper focuses on research conducted in the form of a questionnaire intended for parents of children with developmental disabilities from the special school “Bubanj” in Niš. The aim of this study is to investigate the prevalence of social protection services, specifically day care, and the impact of this service on the quality of life of children and their parents.*

**Key words:** *Children with developmental disabilities, social protection, day care, normative framework, special school “Bubanj”*

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Received November 2, 2023 / Accepted December 20, 2023

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\* The article is derived from the master thesis “Law regulation and social welfare services in the system of education of children with developmental disabilities”, defended by Jana Mitić in 2023 at the Faculty of Philosophy, University of Niš.

## 1. INTRODUCTION

The position of children with developmental disabilities has evolved throughout history alongside changes in society itself. In the beginning, these children were treated very unfavorably. They were often abandoned, killed, or confined within homes until their deaths. In some periods of the Middle Ages, their conditions were attributed to being “possessed by the devil”, which led to them being seen as a threat and causing fear among people (Petrović 2011). Changes occurred slowly because as undesirable members of society, children with developmental disabilities were not the focus of anyone's attention. However, as medicine developed as a science and as the symptoms of certain conditions began to be alleviated through medication, society began to perceive individuals with developmental disabilities differently. The silver lining in all of this was that their conditions started to be viewed through the lens of medicine and potential “healing”. During the past century in Serbia and many European countries, the approach to children with developmental disabilities was based on what is known as the medical model. This model posits that children with developmental disabilities require treatment and rehabilitation within segregated institutions, and that without these, they cannot be equal members of society. The period of institutionalization lasted for a long time, continuing until the 1950s. By the 1960s, a period of deinstitutionalization had begun, associated with the social model, which aimed to integrate individuals with developmental disabilities into society. Today, there is a prevailing social model that places the children at the center of its focus, just as they are – and it is society that needs to adapt to the needs of children with developmental disabilities so that they can participate in society on an equal basis with others. This shift has been facilitated by the opening of numerous institutions that encourage the independence of these children, rather than their isolation, as well as the development of the regulatory framework of the social protection system, where services targeting children with developmental disabilities are among the most important provisions. What this paper questions is the alignment of the normative and practical framework of one group of services – community-based daily services, with a specific focus on the service of daily care.

## 2. DEVELOPMENT OF SOCIAL PROTECTION

As previously mentioned, “historically, the European social protection system was characterized by the prevalence of residential accommodation over community-based services” (Brkić 2014, 31). This meant that the majority of those who could not contribute to the development and stability of society were placed in institutions, and these were often children, people with disabilities, and the elderly. This was particularly common among individuals with disabilities and those who were mentally ill. The situation began to improve when human rights started to be favored and applied regardless of differences. Instead of institutionalization, deinstitutionalization emerged, promoting the significance of community life. The decentralization and deinstitutionalization of the social protection system are intended to contribute to local communities taking responsibility for meeting the socio-economic needs of their citizens (Brkić 2014).

“In 2000, Serbia initiated reforms off the social protection system, with priority areas including the development of alternative forms of accommodation, the definition of standards for the “gate-keeping” mechanism, the development of community-based services, and the involvement of the non-governmental sector in service provision” (Žegarac 2014, 79). A

significant number of services were developed, targeting, among others, children with developmental disabilities and their families, including numerous community-based day care services. From 2005 onward, a normative framework was also developed, advocating for a child's upbringing in their biological family. The development of community-based services for children and their families played a crucial role in contributing to this objective (Žegarac 2014).

### 3. THE LEGAL FRAMEWORK OF SOCIAL PROTECTION

The Strategy of Social Protection (2005) defined deinstitutionalization, decentralization, and democratization of social protection services as one of the main goals of reforms. The proposed activities were to be implemented until 2009. The adoption of the Law on Social Protection in 2011 confirmed the direction of reforms outlined in this strategy. After a period in which the dominant form of support was residential care, a pluralism of social protection services was introduced, allowing for the development of services provided within the community or the immediate environment of the beneficiaries. Responsibilities for ensuring social protection were decentralized and divided between central, provincial, and local authorities. A plurality of service providers was introduced, enabling organizations from the private and non-governmental sectors, in addition to public organizations that had been the sole providers of social protection services until then, to become service providers (The Social Protection Strategy of the Republic of Serbia for the period 2019–2025 – Initial version, 2019). The importance of deinstitutionalization is also emphasized in the Deinstitutionalization and Development of Social Protection Services in the Community Strategy for the period from 2022 to 2026. The legal basis for this strategy can be found in Article 38, paragraph 1 of the Law on the Planning System of the Republic of Serbia.

One of the most significant documents currently regulating the social protection system in the Republic of Serbia is the aforementioned Law on Social Protection (2011) and the Regulation on Detailed Conditions and Standards for Providing Social Protection Services (2013).

According to Article 2 of the Law on Social Protection, social protection represents an organized social activity of public interest aimed at providing assistance and empowering individuals and families to lead independent and productive lives in society and preventing social exclusion and its consequences. Every individual and family in need of social assistance and support to overcome social and life difficulties and create conditions for meeting basic life needs has the right to social protection. As per Article 4 of the Law on Social Protection, the rights to social protection are provided through the provision of social protection services and material support. Social protection services include activities that provide assistance and support to improve the quality of life of individuals and families, remove unfavorable living conditions, and create conditions for independent living in society, while the right to material support is realized to secure the existential minimum and support the social inclusion of beneficiaries (Law on Social Protection 2011, Article 5).

#### 4. SOCIAL PROTECTION SERVICES

In the text below, we will list all categories of social protection services and the specified services belonging to them. We will then focus on community-based day services, specifically day care, as one of the significant services for this paper.

According to Article 40 of the Social Protection Law (2011), social protection services can be divided into five categories as follows:

I. Assessment and Planning Services: assessment of the user's condition, needs, strengths, and risks, as well as of other significant persons in their environment; assessment of guardians, foster parents, and adoptive parents; development of an individual or family service plan and measures of legal protection, and other assessments and plans.

II. Community-Based Day Services: day care; home assistance; a day center; and other services that support the user's staying in the family and immediate environment.

III. Independent Living Support Services: supported housing; personal assistance; independent living training, and other types of support necessary for the active participation of the user in society.

IV. Counseling, Therapeutic, and Social-Educational Services: intensive support services for families in crisis; counseling and support for parents, foster parents, and adoptive parents; support for families caring for their child or adult family member with developmental disabilities; family relationship maintenance and reunification; counseling and support in cases of violence; family therapy; mediation; SOS hotlines; activation, and other counseling and educational services and activities.

V. Accommodation Services: placement with a relative, foster, or other family for adults and the elderly; residential care; placement in a shelter; and other types of accommodation.

##### **4.1. Community-Based Daily Services**

According to Article 44 of the Social Protection Law (2011), community-based day services include activities that support the stay of the users within their families and immediate environment. Community-based day services are provided by local self-government units. These services include day care, home help, and day centers. These services are available for a minimum of eight hours a day, five days a week (Regulation on detailed conditions and standards for the provision of social protection services 2013, Article 67).

###### *4.1.1. Day care*

Day care service is available for:

1. Children and youth with physical disabilities or intellectual difficulties who require daily care and supervision, as well as support in maintaining and developing their potential, in a way that does not interfere with their schooling.
2. Adults with physical disabilities or intellectual difficulties who require daily care and supervision, as well as support in maintaining and developing their potential.
3. Children and youth in conflict with the law, parents, school, or the community, in a manner that does not interfere with their schooling or work.
4. Adults and elderly individuals in need of daily care and supervision (Regulation on Detailed Conditions and Standards for Providing Social Protection Services 2013, Article 68).

The purpose of the day care service is to improve the quality of life of the beneficiaries in their own social environment by maintaining and developing their social, psychological, and physical functions and skills, with the aim of enabling them to live as independently as possible (Article 69, paragraph 1 of the Regulation on Detailed Conditions and Standards for Providing Social Protection Services). Through the day care service, beneficiaries meet their developmental needs, acquire and develop life skills, personal and social responsibility for the development of independence, social, cognitive, and other important functions, all while under necessary supervision (Article 69, paragraph 2 of the Regulation on Detailed Conditions and Standards for Providing Social Protection Services). The day care service provides a positive and constructive experience of being outside the family, and it allows family members to have free time for work and other activities (Article 69, paragraph 3 of the Regulation on Detailed Conditions and Standards for Providing Social Protection Services). The day care service is implemented through well-designed programs, in planned and limited time periods (Article 69, paragraph 4 of the Regulation on Detailed Conditions and Standards for Providing Social Protection Services).

The activities of the day care service are aimed at developing and preserving the potential of the beneficiaries and preparing them for sustainable independent living. These activities are carried out in accordance with the purpose of the service, the characteristics of the user group, the capacities of the users, the individual plan, and, in line with the assessment of user needs, include one or more of the following activities:

1. Support in building and maintaining positive relationships with adults and children.
2. Support in learning, maintaining, and developing contacts with the relevant authorities of the local government.
3. Organizing occupational or educational activities that promote the development of new knowledge and skills.
4. Developing working methods that encourage user participation in community activities.
5. Organizing leisure time according to the needs and interests of the users.
6. Organizing appropriate cultural and entertainment activities within the day care or enabling users to attend community activities.
7. Developing problem recognition and solving skills.
8. Developing communication skills.
9. Developing self-protection skills.
10. Developing skills and knowledge necessary for living in the community.
11. Rehabilitation and therapeutic activities.
12. Program activities of a child's personal caregiver in accordance with the provisions of this regulation (Article 70 of the Regulation on Detailed Conditions and Standards for Providing Social Protection Services).

The minimum number of professional workers and collaborators directly involved in working with users of the day care service is defined as follows:

1. For children and youth with physical disabilities and intellectual difficulties – two professional workers and one collaborator for up to ten users, and one professional worker for every additional five users, or one collaborator for every additional ten users.
2. For children and youth in conflict with the law, parents, school, or the community – two professional workers for up to ten users, and one professional worker for every additional five users.

3. For adults with physical disabilities and intellectual difficulties – one professional worker and two collaborators for up to ten users, and one collaborator for every additional five users, or one professional worker for every additional ten users (Article 71 of the Regulation on Detailed Conditions and Standards for Providing Social Protection Services).

“The concept of day care activities involves supporting each child with the aim of achieving the highest level of individual independence in practicing everyday skills. This approach is based on the philosophy of recognizing strengths, building capacities, creating a supportive environment, and organizing activities that focus on the person in need of support” (Dakić 2013, 53).

#### *4.1.2. Assistance at home*

The help at home service or “Assistance at home” is available to children, adults, and the elderly who have physical or psychological limitations that prevent them from living independently in their homes without regular assistance with daily activities, care, and supervision, especially when family support is insufficient or unavailable. The purpose of Help at Home is to support users in meeting their daily life needs to enhance or maintain their quality of life (Article 74 of the Regulation on Detailed Conditions and Standards for Providing Social Protection Services).

#### *4.1.3. Shelter*

The shelter service is available to children, young people, adults, and the elderly who live or work on the streets and voluntarily request or agree to the service (Article 77 of the Regulation on Detailed Conditions and Standards for Providing Social Protection Services). The purpose of the shelter service is to provide temporary or occasional interventions and meet the immediate needs of the users, as well as to mediate in ensuring the availability of other services in the community (Article 78 of the Regulation on Detailed Conditions and Standards for Providing Social Protection Services).

In addition to the previously mentioned daily community services, the services most commonly provided in the community also include services to support independent living (supported housing, personal assistance, training for independent living, and other forms of support necessary for active participation of users in society), as well as the service of a child's personal companion and respite care service.

## 5. METHODOLOGY

The research was conducted in September 2023 at the “Bubanj” special school with student residence in Niš. The method used in this study was the survey as a quantitative technique for data collection, and the instrument utilized was the questionnaire. The questionnaire comprised pre-prepared closed and open-ended questions and their combinations. Additionally, the questionnaire included statements for which the respondents were required to indicate their levels of agreement using a five-point Likert scale, in the following way: 1 – strongly disagree; 2 – disagree; 3 – undecided; 4 – agree; 5 – strongly agree. The service under consideration in this study is a day care center. Parents were asked to use the scale to assess the positive impact of this service on both their child and themselves. The research involved the participation of 40 parents of children

with developmental disabilities. However, this study has certain limitations reflected in the insufficiently representative sample, given that out of 40 participants, 15% of them (which numerically amounts to 6 participants) utilize the day care service. Therefore, these results cannot be generalized to a broader population.

## 6. RESULTS AND DISCUSSION

The majority of the respondents were female, aged between 31 and 40, living in urban areas, with a completed secondary education, and not currently employed. Most of them were mothers or fathers of the children, and the children were mostly between the ages of 11 and 20, male, with combined disabilities. A significant portion of the parents (80%) had sought information about their rights and services available within the social protection system, and they generally rated their level of awareness as very good (42.5%). Those who did not seek information cited reasons such as lack of time and resources.

Out of the 40 parents, 13 of them (32.5%) are currently using some form of social protection services, while only 6 parents indicated that their child is using a day care service, which corresponds to 15% of the parents.

Table 1 below presents statements with which parents were supposed to express their levels of agreement. As mentioned, it was necessary to assess to what extent the day care service positively affects various aspects of a child's life, and subsequently, the parents', using a five-point scale (in the tables, users of the day care service will be a separate group – represented as 100%).

Based on the responses, it can be concluded that parents/guardians believe that the day care service has had a positive impact on their child. Parents especially rated the positive impact of the day care service on their child's sociability, reduced dependency on parents/guardians, and school performance. Such responses justify the role of day care, as its goals are based on improving various aspects of the child's life. This kind of statistical outcome is somewhat expected since social protection services, among other things, exist to ease and enhance different aspects of the users' lives.

**Table 1** The day care service has had a positive impact on:

	Strongly disagree	Somewhat disagree	Undecided	Somewhat agree	Strongly agree
The child's quality of life	/	/	/	66.7% (4)	33.3% (2)
The child's sense of satisfaction	/	/	/	33.3% (2)	66.7% (4)
The child's socialization and activity	/	/	/	16.7% (1)	83.3% (5)
The development of the child's capacities	/	/	/	50.0% (3)	50.0% (3)
Improving communication with the environment	/	/	/	16.7% (1)	83.3% (5)
The child's self-confidence	/	/	/	33.3% (2)	66.7% (4)
Acquiring new knowledge and skills (speech, drawing, writing, hygiene)	/	/	/	16.7% (1)	83.3% (5)
The child's sociability	/	/	/	/	100.0% (6)
Reduced dependence on parents/guardians	/	/	/	/	100.0% (6)
Progress in school	/	/	/	/	100.0% (6)

Right after assessing the impact of the service on various aspects of their child's life, parents were asked to evaluate the impact of the service on various aspects of their own lives. In Table 2, you can see their responses. Parents have positively evaluated the impact of the day care service on themselves as well. They showed strong agreement in statements that the service had a positive influence on their free time, improved parenting competencies, and reduced stress. Besides its purpose to enhance all aspects of the child's life, the day care service is meant to give parents more free time for their daily activities, which justifies its purpose in this sense too. The parents' responses are an indisputable sign of the indirect influence of the service on those who do not directly use it. Because they can share the responsibility of taking care of the child with professionals in the field, caregivers, or other experts, parents have more free time for their own activities. Their parenting competencies are enhanced because they can see how professionals educated in caring for children with developmental disabilities work with them, which allows them to acquire new knowledge and skills and gain advice. Reduced stress for parents results from knowing that, even when they are not with their children, they are safe, and parents do not have to take care of them around the clock. Taking care of school-age children can be challenging, especially when it comes to children with developmental disabilities because they go through the same phases as other children, but children with disabilities might have difficulty understanding themselves and what is happening to them, which can pose an even greater challenge to parents.

**Table 2** The day care service has positively affected me (parent/caregiver) in the following aspects:

	Strongly disagree	Somewhat disagree	Undecided	Somewhat agree	Strongly agree
Quality of life	/	/	/	50.0% (3)	50.0% (3)
More free time	/	/	/	16.7% (1)	83.3% (5)
Feeling relieved	/	/	/	33.3% (2)	66.7% (4)
Improved family relationships	/	/	/	33.3% (2)	66.7% (4)
Improvement of parental competences	/	/	/	16.7% (1)	83.3% (5)
Sharing experiences with other parents	/	/	/	33.3% (2)	66.7% (4)
Networking and community integration	/	/	/	50.0% (3)	50.0% (3)
Less stress	/	/	/	16.7% (1)	83.3% (5)

Children with developmental disabilities are one of the common categories of users of social protection services. They, as well as their parents/guardians, often need assistance in meeting their daily needs and activities, and they may not be in a financially stable situation to cover all the medical expenses associated with caring for a child with developmental disabilities. They may also lack sufficient time and support and constantly spend time with their child. This situation can limit the parents' ability to work/seek employment (restricting job choices), engage in leisure activities, and meet personal, social, health, family, and other needs. "In addition to these, other negative implications can be identified in connection with this issue: the emergence of physical and psychological health problems in parents, lower incomes, neglect of the developmental needs of healthy children (if they have more than one child), increased stress, the possibility of parents' divorce or separate lives, anxiety, uncertainty, lack of sleep" (Brkić, Stanković & Žegarac 2013, 214). For these reasons, it was of great importance to gather information about how informed parents are about the content of social protection services, whether they are accessing the rights and

services prescribed by the Law on Social Protection, and to what extent they are (dis)satisfied. Their opinions on the alignment of the law and practice can serve as a basis for possible reforms. It is also important to rely on some other formal source of support, rather than just informal support. Because in addition to being able to share the care of the child with someone else, the child can improve various aspects of their life and be in an environment that encourages their growth and development. Professionals, educators, or experts in these fields have more competence to work with children with developmental disabilities, among other things because their professional title implies that they are educated to work with this category of children, which is an undeniable advantage compared to informal support systems.

A similar study can be seen in the publication “Kada nam nedelja dolazi sredom” [“When Sunday Comes on Wednesday”] (Žegarac, Džamonja-Ignjatović, & Milanović 2014), where some of the primary research objectives include investigating the benefits of social protection services for children with developmental disabilities and their families and how these improve their quality of life. The study investigated user satisfaction at the beginning of service utilization and after one year of service use. The results indicated that the majority of parents were satisfied with the services, particularly with the staff's attitude toward both the children and themselves. Areas where they were less satisfied (but not dissatisfied) included working hours, participation in needs assessment and service planning, the ability to choose the manner of service utilization, and the adaptability of services to the needs of the child and family. After a year of using the service, the user satisfaction level remains high (95% of users are either completely or mostly satisfied, while 5% are dissatisfied). The order of satisfaction levels is similar to that at the beginning of using the service, indicating that users continue to be satisfied with what they initially experienced, or less satisfied/dissatisfied. We can observe a similarity between this and our study – users positively evaluated the services. The only difference is that in our study, parents slightly rate the impact of services on their child more positively than on themselves, while in the mentioned study, the situation is reversed.

Parents of children with developmental disabilities often face challenges due to a lack of free time, arising from the need for constant supervision of their child. One study that compared the daily activities of mothers with children with developmental disabilities and those with typically developing children is “Engagement of Mothers of Children with Developmental Disabilities in Everyday Activities” (Bulić, Joković-Oreb, & Nikolić 2012). The research results showed that mothers of children with disabilities are significantly more engaged in their everyday life activities. In this context, it is important to mention the results of our study. Parents particularly positively evaluated the beneficial impact of the day care service on having more free time, improving parenting skills, and experiencing less stress. This undoubtedly emphasizes the importance of the service in terms of sharing the responsibility for caring for the child with the formal support system, resulting in more free time for parents. In connection with that, we will mention the paper “Community-Based Services as Support for Parents in Providing Long-Term Care for Children and Youth with Disabilities” (Dimitrijević 2013). This paper focused on highlighting the significance of community-based services for children with disabilities in providing support to parents who care for them. It also discussed their contribution and positive impact on both children and parents, aligning with the results of our study, given that all the mentioned aspects of the lives of children and parents were positively evaluated.

## 7. RECOMMENDATIONS

The day care service, in addition to helping children, also significantly eases the burden on parents. Firstly, it instills confidence in parents that their children are in a safe environment. On the other hand, children make progress in various aspects. Based on the respondents' answers, the positive impact of the day care service is evident. It would be truly meaningful for more children and parents to avail themselves of this service. Therefore, one of the recommendations would be to inform parents more frequently about the rights they and their children have within the social protection system, given that a very small number of respondents are currently using this service. What is most important is to find an adequate way of informing parents, and this should become a mandatory practice. Considering that every special school has a social worker, as the most competent person and expert in social protection, they should provide parents with all information about their rights and services within the social protection system at the beginning of each school year. This can be done on a group level as well. Additionally, teachers at the school can also assist in providing information. Day care services should be promoted more, and their number should be increased. Due to the legal foundation of this service, it should exist in every city to ensure equal access for all citizens. If this were to happen, it would be essential to ensure the sustainability of services by constantly developing and improving them, which would undoubtedly have positive effects on the users.

## 8. CONCLUSION

The position of children with developmental disabilities has been changing slowly. As time has progressed, gradual improvements have occurred, influenced by advancements in various scientific fields and societal progress. Today, children with developmental disabilities are in a much better position than before. Many laws have been enacted to benefit individuals with disabilities, and their education has become possible in both mainstream and special schools. Their participation and status in society have significantly improved, and they are no longer considered undesirable members. The social protection system has expanded the range of its services. From a legal perspective, it can be said that the system is at a satisfactory level today, providing a greater number of services for individuals with disabilities, including various forms of material support. Day care is one of the basic services to support families caring for a child or an adult with a disability. It involves not only satisfying basic human needs but also providing opportunities for education, job training, socialization, and quality time during the day (Matković 2009). The day care service provides a positive and constructive experience outside the family, allowing family members to have free time for work and other activities. The purpose of social protection services is indeed to assist their beneficiaries, a fact confirmed by results on the positively assessed impact of the day care service. According to respondents, the primary effects of the service include increased sociability of the child, reduced dependence on parents, and academic progress. The positive impact on parents is evident through having more free time, improved parenting skills, and experiencing less stress. The essence of parental perception of rights and services lies in the fact that they know what is most needed for them and their children because, in addition to the direct impact, the influence of the service can also be indirect, as we could notice. Based on this, we can conclude that the impact of social

protection services is positive and beneficial, and the alignment of the normative and practical framework in this regard is indeed satisfying.

However, what we do not know is how users of social protection services would evaluate the Social Protection Law (2011) and whether they would suggest any changes. If they would suggest anything, would it involve an increase in social protection services, additional material support, or the introduction of entirely new regulations. This could serve as a stimulus for further research on this topic. Additionally, it would be instructive to explore whether there are opportunities to increase the number of day care services at the level of the Republic of Serbia and make them equally accessible to users in both smaller and larger cities.

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## USLUGA DNEVNI BORAVAK IZ PERSPEKTIVE RODITELJA DECE SA SMETNJAMA U RAZVOJU – NORMATIVA I PRAKSA

*Usluga dnevnog boravka u sistemu socijalne zaštite ima veliku ulogu u unapređenju kvaliteta života korisnika u cilju njihovog osposobljavanja za samostalan život. Ova usluga ima poseban značaj za decu sa smetnjama u razvoju, zbog pozitivnog uticaja na razvoj njihovih socijalnih, saznanjnih i drugih važnih funkcija, ali i za njihove roditelje/staratelje, jer im pruža dodatno slobodno vreme za radne i druge aktivnosti. U radu će se, najpre, biti reči o tome kako se menjao položaj dece sa smetnjama u razvoju i kako se razvijao sistem socijalne zaštite. Zatim, biće predstavljen normativni okvir socijalne zaštite u našoj zemlji, kao i usluga socijalne zaštite, nakog čega će uslediti detaljna analiza dnevnog boravka kao*

*najznačajnije dnevne usluge u zajednici. Centralni deo rada odnosi se na istraživanje sprovedeno u formi upitnika namenjenog roditeljima dece sa smetnjama u razvoju specijalne škole "Bubanj" u Nišu, sa ciljem da se ispita zastupljenost usluga socijalne zaštite, konkretno dnevnog boravka, kao i uticaj ove usluge na kvalitet života dece, odnosno njihovih roditelja.*

*Ključne reči: deca sa smetnjama u razvoju, socijalna zaštita, dnevni boravak, normativni okvir, specijalna škola "Bubanj".*