

UDRUŽENJE ZA PODRŠKU I KREATIVNI RAZVOJ DJECE I MLADIH
EDUKACIJSKO-REHABILITACIJSKI FAKULTET
UNIVERZITETA U TUZLI

**UNAPREĐENJE KVALITETE ŽIVOTA
DJECE I MLADIH**

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PREDGOVOR

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Još od prve konferencije slijedimo naš cilj a to je uputiti poticaj i izazov stručnjacima svih profila koji su na bilo koji način vezani za rad sa djecom i mladima, da pokušaju doprinijeti njihovoj boljoj kvaliteti života.

Zbog velikog broja učesnika ove godine štampana su dva dijela Zbornika, sa istim poglavljima:

- Plenarna izlaganja
- Tema I – Unapređenje kvalitete života djece predškolskog i školskog uzrasta
- Tema II – Unapređenje kvalitete života mladih
- Tema III – Unapređenje kvalitete života djece i mladih s posebnim potrebama
- Slobodne teme

Organizacioni odbor

QUALITY OF LIFE IN PERSONS WITH INTELLECTUAL DISABILITIES IN DAY-CARE CENTERS

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ABSTRACT

Introduction: By assessment of the quality of life we mean examination of the subjective perception and the objective evaluation of the most significant aspects of the life situation of one person. The subjective areas are consisted of the area of pleasure of the individual which is estimated based on the value the individual holds for it. The objective areas are consisted of culturally-relevant measures of the objective well-being. *Goal:* The goal of this research was to estimate the quality of life of the persons with moderate and severe intellectual disability in the day-care centers from a subjective and an objective aspect. Every aspect was analyzed within seven areas: material well-being, health, productivity, intimacy, safety, togetherness and emotional well-being. *Methods:* Within this quantitative research we used a comprehensive psycho-metric scale for assessment of the quality of life of the persons with moderate and severe intellectual disability in the day-care center "Poraka" and a day-care center under the Ministry of labor and social policy, both located in Kumanovo. The psycho-metric scale is multidimensional, it contains objective and subjective components and it gives us normative data. *Results:* The results showed an average accomplishment from 65,75% SM from the objective data. The average scores from the importance and pleasure in each domain showed that the examinees had the highest percentage in the domain of safety (76.20%), and the lowest percentage in the domain-place in society (63.32%). In the domain material well-being the average score was 68.17%, in the domain health the average score was 69,49%, in the domain productivity the average score was 75,53%, in the area of intimacy the average score was 71,25%, and in the area of emotional well-being the average score was 70,84%. There is a small but insignificant difference in favor of the female gender (69,84%) in relation to the examinees that were male (69,44%) regarding the seven domains of the quality of life. Almost half of the examinees were from 20-29 years of age and this was the group that showed the lowest quality of life in relation to the other age groups (66,79%). The lowest quality of life is found in the examinees with a low social status level (62,24%). The lowest quality of life was also found in the examinees whose parents have no education at all (65,53%), and the highest quality of life was found in the examinees whose parents have high education (76,25%). The examinees that have spent less time in the day-care center have a better quality of life (74,07%) than the users of the day care center which have spent more time in the day care centers (66,42%). *Conclusion:* The average scores in the last table showed that the lowest quality of life is found in the area or domain of socialization which means that there has to be a room for improvement of the social inclusion of these persons. It was also

established that the quality of life is not dependant on the sex (gender) or age but it is dependent on the social status, time spent in the institution and the level of education of the parents.

Key words: quality of life, persons with moderate and severe intellectual disability, day-care centers

INTRODUCTION

For each and every one of us, the life course is a fascinating and complex personal journey, and for those of us who work therapeutically with others it provides a robust framework that helps divide complicated concepts into smaller, logically related and more manageable chunks (Wright & Sugarman, 2009). Quality of life is a term that has been used for several decades, but it has come into its own in the last 15 years. A great deal has been written about it, and a considerable amount of research has been carried out concerning aspects of people's lives and their environments that are associated with quality of life. Quality of life is a term that is recognized and used today in a variety of ways. When we talk about positive quality of life, we are talking about having a life that is very meaningful to individuals and that provides them with resources. People have their own ideas about what is most meaningful for them, what fits their self-images best, and what adds richness to their lives. Assisting people to exercise choices that reflect these ideas empowers them to improve their own lives and to develop positive self-images that reflect their own needs, wishes and values (Brown & Brown, 2004). Much of what we know today about quality of life for individuals with disabilities, however, has been developed within the field of intellectual disability. Over the past 2 decades, the concept of quality of life has increasingly been applied to persons with intellectual disabilities. Yet in the growing body of literature in this area, people with profound intellectual and multiple disabilities (PIMD) have received only limited attention. People with disabilities live with their disabilities every moment of their lives. Everything they do in life, large or small, has to accommodate these disabilities. If people with disabilities are to improve or maintain their quality of life, it is imperative that non-disabled people understand, to the fullest extent they can, the experience of disability. The ways other people, and society as a whole, view disability has a strong influence on how people with disabilities can enjoy an effective quality of life. Family members, friends, professionals and other caring people have helped many people with disabilities to have better lives by carrying out effective practices (Schalock, 1997). Service systems within which professionals and other practitioners work are one part of the environment that can have a considerable impact on personal quality of life. A number of factors – training and education of professionals, the policies that guide professional activities and behaviour, and the procedures of professional systems – can help people develop improved quality of life or can hinder them from doing so. Practitioners who work with people who have disabilities need a core set of skills

to carry out their work effectively. In most countries of the world, even those with the best services, the funding and personnel made available do not meet all the needs of all the people with disabilities (Goode, 1988). In practical work with people who have disabilities, two principles sometimes pull in opposite directions: providing appropriate care, and enhancing self-care and independence. Family members, other informal support people, community groups, agencies and government funders all assume some responsibility, to varying degrees, for ensuring that care is provided. At the same time, people with disabilities strive for independence in their lives and usually welcome it, provided that it is accompanied by an ease of being able to carry out the activities of life of their choosing. Practitioners recognize that, if desired by the individual, providing care and enhancing independence can each improve quality of life. The difficulty is that most people with disabilities require both care and independence, and the two contradict each other to a considerable degree (Schalock, 2002). In the limited number of studies that have evaluated more specific aspects of the life situation of people with PIMD in day care and residential services, similar problem areas have emerged. First of all, staff/client interactions are often characterised by neutral affection and instructions, resulting in a lack of connectedness and value or in social distance between staff and clients (De Waele & Van Hove, 2005). Staff are said to be insufficiently responsive to clients' individual needs and to take inadequate account of clients' capacities and perspectives (De Waele & Van Hove, 2005). A second problem pertains to the limited number and lack of variation in developmental and leisure activities, resulting in boredom and repetitive routines (Zijlstra & Vlaskamp, 2005). People with PIMD have only limited opportunities to participate in everyday activities, and only a small proportion of their leisure time is spent away from the living unit (Campo, Sharpton, Thompson, & Sexton, 1997; Zijlstra & Vlaskamp, 2005). In addition, their preferences, interests and capacities are not sufficiently taken into account when designing programs and selecting activities. A third problem involves the limited opportunities for choice. Several studies have demonstrated that people with PIMD lack control over their life situation (Carnaby & Cambridge, 2002; De Waele & Van Hove, 2005), and have few opportunities to make choices regarding everyday activities and major life events. Finally, people with PIMD have limited social networks, which mostly include professionals, co-residents and family members (Brown & Brown, 2004). The concept of quality of life has potential to allow a new perspective on intellectual disability and to be a positive influence on those who work in the field. It offers a new way of looking at issues of disability and is a useful paradigm that can contribute to identification, development, and evaluation of supports, services, and policies for individuals with intellectual disabilities.

METHODOLOGY

The goal of this research was to estimate the quality of life of the persons with moderate and severe intellectual disability in the day-care centers from a subjective

and an objective aspect. Every aspect was analyzed within seven areas: material well-being, health, productivity, intimacy, safety, togetherness and emotional well-being. Within this quantitative research we used a comprehensive psycho-metric scale for assessment of the quality of life of the persons with moderate and severe intellectual disability in the day-care center "Poraka" and a day-care center under the Ministry of labor and social policy, both located in Kumanovo. The psycho-metric scale is multidimensional, it contains objective and subjective components and it gives us normative data. The questionnaires' were consisted of three parts. Each part was consisted of seven domains which were stated above. The first part was answered by the examinee with the help of his guardian if there was a need for that. Those were objective data. The second and third parts were answered by the guardians but in behalf of the examinee (they were put in their position. In the second part we examined the importance of certain domains and in the third the pleasure in all of them. The data was analyzed in accordance to the following variables: sex, age, social status, education of parents and the time spent in the day-care center.

Hypothesis:

X0 – Persons with moderate and severe intellectual disabilities have a positive subjective perception regarding their quality of life in relation to the objective conditions.

X1 – Persons with moderate and severe intellectual disability have a more positive perception of the aspects – material well-being, intimacy and productivity than the real objective condition while they have a more negative perception of the aspects – safety, health, togetherness and emotional wellbeing than the real objective state.

X2 – The females have better quality of life than males with moderate and severe intellectual disabilities.

X3 – The older users of day-care centers have a better quality of life than the younger ones.

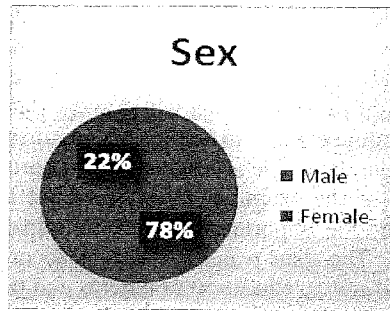
X4 – The social status of the persons with moderate and severe ID influences the quality of life of the examinees.

X5 – The level of education of the parents or caregivers of persons with moderate and severe ID does not influence the quality of life.

X6 – The time spent in day-care centers enhances the quality of life of the persons with moderate and severe intellectual disability.

ANALYSES OF DATA

Analyses of data in relation to gender



Picture 1. Sex ratio of the examinees

In relation to the variable sex, from the total of 32 examinees, 25 were male and 7 were female.

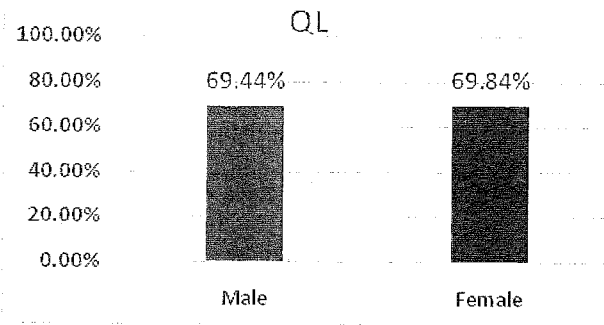
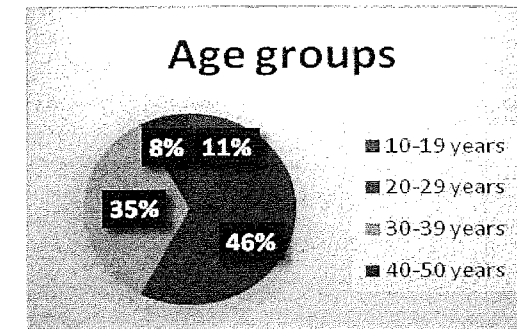


Table 1. Quality of life in relation to sex

The results gained in this research showed a small but insignificant difference in favor of the female gender (69,84%) in relation to the examines that were male (69,44%). We can conclude that there is no difference in the quality of life perception between the male and female examinees in all areas of the research.

Analyses of data in relation to age



Picture 2. Age of examinees

Regarding the age of the examinees, 11% of the examinees from the age group 10-19 years old, 46% were from 20-29 years old, 35% were on the age from 30-39 years and 8% were from 40-50 years old.

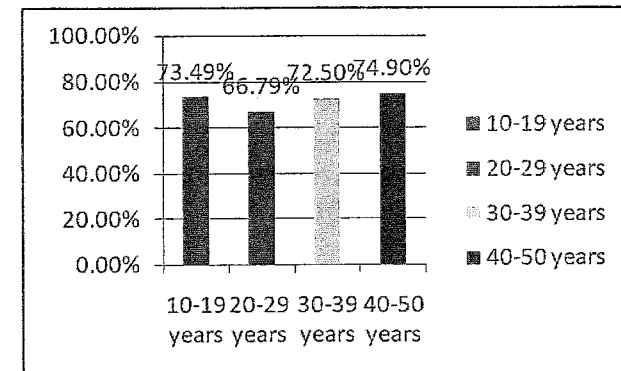
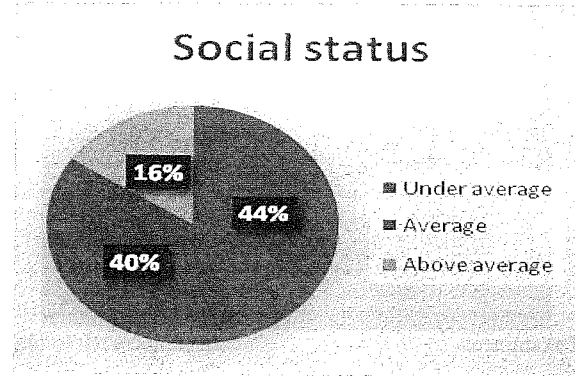


Table 2. Quality of life in relation to age of examinees

Regarding the second variable-age of examinees we were trying to determine whether the perception of the quality of life depends on the age of the examined persons with moderate and severe intellectual disability. Almost half of the examinees were from 20-29 years of age and this was the group that showed the lowest quality of life in relation to the other age groups (66,79%). But the general results showed that there is no direct correlation between the age and quality of life-the group from 10-19 years of age showed 73,49% of satisfaction of the quality of life, the group from 30-39 years old showed 72,50% of satisfaction from the

quality of life and the last group or the oldest ones (from 40-50 years old) showed 74,90% of satisfaction from the quality of life. This was the highest score.

Analyses of data in relation to social status



Picture 3. Social status of examinees

Regarding the social status we divided the examinees in three groups: under average (low) social status, average social status and above average (high) social status. 44% of the examinees were coming from families with a low social status, 40% of the examinees were coming from families with an average social status and 16% of the examinees were coming from families with an above average social status. The social status was determined by the social workers and many parameters were taken into consideration (income, place of living, social structure and social roles).

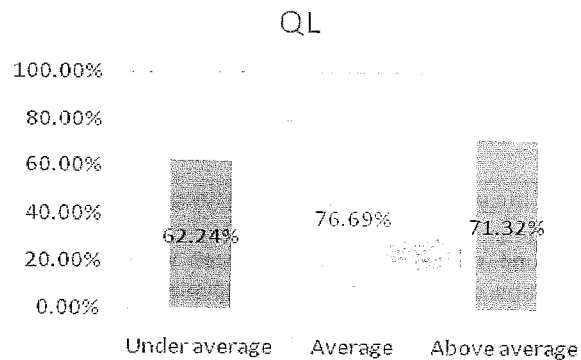
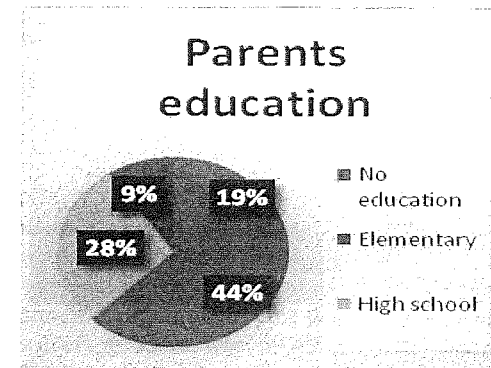


Table 3. Quality of life in relation to social status

The results from the research showed that the lowest quality of life is found in the examinees with a low social status level (62,24%). The examinees that come from families with an average social status had the highest quality of life-76,69% and the examinees that come from above average social status families had a score of 71,32%. The difference between the examinees with average and above average social status is not significantly big, which leads to the conclusion that there is a positive correlation between the social status and the quality of life of the examinees.

Analyses of data in relation to education of parents



Picture 4. Level of education of parents

Regarding the fourth variable, education of the parents of the examinees with moderate and severe intellectual disability, we divided them in four groups. 19% of the parents of the examinees had no education, 44% of the parents had only finished primary education, 28% of the parents of the examinees had finished secondary education, and only 9% of the parents had high education.

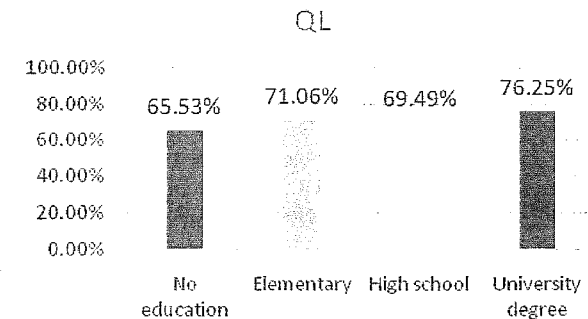
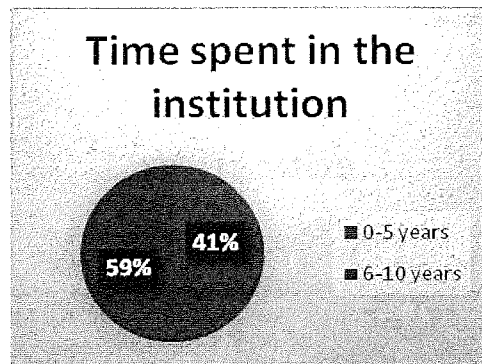


Table 4. Quality of life in relation to education of parents

Regarding the fourth variable, the results showed that the lowest quality of life was found in the examinees whose parents have no education at all (65,53%), and the highest quality of life was found in the examinees whose parents have high education (76,25%) which points out to the fact that the quality of life is in a positive correlation with the degree of education of the parents of the examinees.

Analyses of data in relation to time spent in day-care centers



Picture 5. Time spent in a day care center

For this variable we divided the examinees in two groups and we got the following results. 41% of the examinees have spent from 0-5 years in the day care center and 59% have spent 6-10 years in the day-care center.

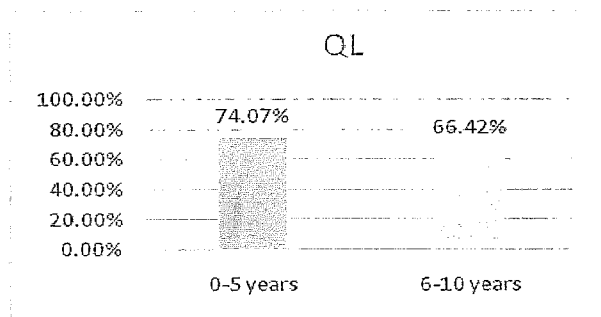


Table 5. Quality of life in relation to the time spent in the day-care center

The results showed that the examinees that have spent less time in the day-care center have a better quality of life (74,07%) than the users of the day care center which have spent more time in the day care centers (66,42%). This points out to a

negative correlation between the quality of life and the time spent in the day care centers.

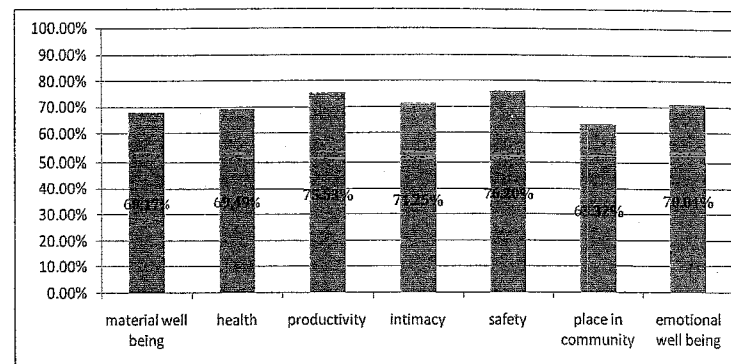


Table 6. Average results from the importance and pleasure from each domain

The results showed an average accomplishment from 65,75% SM from the objective data. The average scores from the importance and pleasure in each domain showed that the examinees had the highest percentage in the domain of safety (76.20%), and the lowest percentage in the domain-place in society (63.32%). In the domain material well-being the average score was 68.17%, in the domain health the average score was 69.49%, in the domain productivity the average score was 75.53%, in the area of intimacy the average score was 71.25%, and in the area of emotional well-being the average score was 70.84%.

DISCUSSION

Regarding the first hypothesis the research showed that the persons with moderate and severe intellectual disability have a more positive perception regarding their quality of life. Regarding the second hypothesis the examinees showed the highest percentage in the domain of safety (76.20%), and the lowest percentage in the domain-place in society (63.32%). The research showed that the three most positive domains are the domains of productivity, safety and intimacy. Still the results don't vary in such a manner and the difference is not so significant. Regarding the second hypothesis we can conclude that there is no difference in the quality of life perception between the male and female examinees in all areas of the research. This hypothesis was rejected. Regarding the third hypothesis the general results showed that there is no direct correlation between the age and quality of life-the group from 10-19 years of age showed 73,49% of satisfaction of the quality of life, the group from 30-39 years old showed 72,50% of satisfaction from the quality of life and the last group or the oldest ones (from 40-50 years old) showed 74,90% of satisfaction from the quality of life. This was the highest score. With these results, the third hypothesis was also rejected. Regarding the fourth

hypothesis, the results showed that the examinees that come from families with an average social status had the highest quality of life-76,69% and the examinees that come from above average social status families had a score of 71,32%. The difference between the examinees with average and above average social status is not significantly big, which leads to the conclusion that there is a positive correlation between the social status and the quality of life of the examinees. This proves our fourth hypothesis. The results regarding the fifth hypothesis showed that the lowest quality of life was found in the examinees whose parents have no education at all (65,53%), and the highest quality of life was found in the examinees whose parents have high education (76,25%) which points out to the fact that the quality of life is in a positive correlation with the degree of education of the parents of the examinees. This proves our fifth hypothesis. Regarding the last hypothesis, the examinees that have spent less time in the day-care center have a better quality of life (74,07%) than the users of the day care center which have spent more time in the day care centers (66,42%). This points out to a negative correlation between the quality of life and the time spent in the day care centers. This leads to rejection of the last hypothesis.

CONCLUSION

The average scores in the last table showed that the lowest quality of life is found in the area or domain of socialization which means that there has to be a room for improvement of the social inclusion of these persons. It was also established that the quality of life is not dependant on the sex (gender) or age but it is dependent on the social status, time spent in the institution and the level of education of the parents. It is a fact that the quality of life depends on a variety of variables. It is also very difficult to measure the quality of life in individuals with moderate and severe intellectual disabilities because of their condition and cognitive status. But this questionnaire gives us valid data regarding their objective and subjective perception of their life conditions and their views on them.

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