



# Evaluation of the Quality of Life for Parents and Caregivers of Adults with Intellectual Disabilities in the Local Community

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## Abstract

The quality of life is an important component in the development of target interventions related to the inclusion of families in the wider social community. The goal of this research was to test the degree of the quality of life for parents and custodians of adults with intellectual disabilities as a whole and by domains and to check the relationship of the quality of life and socio-demographic features of the participants in this research. Forty parents of adults with intellectual disability took part in the study. A convenience sample from the area of the city of Zagreb and the Zagreb County was used in referential centres and associations caring for adult with intellectual disabilities older than 21 years of age. For the purpose of this study, we have used the Personal Wellbeing Index for the evaluation of the quality of life and welfare of parents and custodians of persons with intellectual disabilities. The results of the research indicate that the perceived quality of life of the parents does not deviate from the values that can be found in the healthy population. Parents have also evaluated the quality of life of their children and the result has shown that they are moderately satisfied. There is a major connection between the evaluation of the quality of life of the parents and their evaluation of the quality of life of their children. The more satisfied parents are with their quality of life, i.e. the better they estimate their personal welfare, the better are the evaluations for the quality of life of their children. The research results point that there is no statistically significant difference in the evaluation of the quality of life between the groups that differ with regard to: gender, inclusion in the physical activity and presence of other disabilities.

**Keywords:** Quality of life; Parents and custodians of adult persons with intellectual disabilities; Predictors of the quality of life

## Introduction

Personal success in the modern society is measured by the contribution to the development of the community. That is precisely one of the important factors in making the families with intellectual disabilities depend on solidarity and personal vision of justice of other members of the community. The quality of life for the families of people with intellectual disabilities is interesting as the subject of many scientific disciplines. The term "quality of life" is a broad concept and subject of various scientific disciplines, including biomedicine and health, based on its multidimensionality [1]. The assessment of the quality of life is founded on individuals' experience, their aspirations, wishes and values, and is determined by a set of individual psychophysiological characteristics and the objective conditions in which they live. The range and quality of interaction with the environment, the flexibility of the individual towards the changes in the physical and social environment, as well as the changes within an organism, are determined by individual cognitive and conative characteristics [2]. The experience of parenthood is undoubtedly one of the most significant changes in everyone's life. There are factors that affect parenthood experience and they include satisfaction / dissatisfaction with their child, satisfaction / dissatisfaction with themselves as parents, the established relationship between themselves as well as the child's developmental achievements [3]. The relations between parenting practices, environmental relations and the child's developmental outcomes are complex, and, indisputably, are different in various developmental periods and different social environments. Naturally, these relations are influenced by culture and ethnicity affecting the ways of raising

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**Table 1:** Overview of basic descriptive indicators for parents of people with intellectual disabilities.

	f	%
<b>GENDER</b>		
Male	14	35
Female	26	65
<b>EDUCATION</b>		
Primary school qualifications	2	5
Secondary school qualifications	22	55
College education	9	23
Two-year post-secondary school qualifications	7	18
<b>MARITAL STATUS</b>		
Single	3	8
Married	20	50
Living with partner	2	5
In a relationship	2	5
Divorced	3	8
Widowed	10	25
<b>SPORTS</b>		
Yes	7	18
No	33	83

children, and also numerous sets of values [4]. Starting from the assumption that raising a child with intellectual disabilities is more stressful than raising a child without special needs, the consequences of that stress were questioned, especially the frequency of physical and mental illness in parents. Studies confirm that, although there are parents who are doing well, there are more of those who experience health problems, a greater degree of depression, anxiety and emotional burden than parents without such problems [5]. Parents of adolescents with developmental disabilities feel isolated and complain about the lack of support during the period of transition from primary to secondary school, as well as the transition period to adulthood [6]. Whether it is a new-born child or an adult member of the family, parents and families are required to know how to properly act to involve the person with special needs in the habilitation and rehabilitation treatments, to be their support and reliance in accepting and adapting to the new situation [7]. The presence of a child with developmental disabilities in a family requires a lot of adjustment from parents and other family members [8]. There are a small number of studies dealing with assessing the quality of life in families with intellectual disabilities who are involved in associations and centers for the rehabilitation of people with intellectual disabilities within the local community. Taking this fact into consideration, the objectives of this study were:

1. To examine the level of the quality of life for parents and caregivers of people with intellectual disabilities, the elderly, in general and by domains,
2. To assess the relation between the quality of life and the socio-demographic characteristics of the participants in this study.

## Research Methodology

### Participants

The population defining a number of participants included the parents of people with intellectual disabilities who are beneficiaries of

**Table 2:** Basic descriptive data for people with intellectual disabilities.

	f	%
<b>GENDER</b>		
Male	24	60
Female	16	40
<b>DEGREE OF INTELLECTUAL DISABILITY</b>		
Mild intellectual disability 50-69 (75) mental age 9 - 12 years	16	40
Moderate intellectual disability 35-49 mental age 6 - 9 years	15	38
Severe intellectual disability 20-34 mental age 3 - 6 years	1	2.5
NA	8	20
<b>OTHER DISABILITIES</b>		
Physical disabilities	12	30
Hearing impairment	1	2.5
Visual impairment	8	20
No disabilities	14	35
Physical and hearing impairment	2	5
Hearing and visual impairment	1	2.5
NA	2	5
<b>USING HANDICAP DEVICES</b>		
No	38	95
Yes	1	2.5
NA	1	2.5

rehabilitation centers for people with intellectual disabilities over the age of 21 in Zagreb. The study included 45 parents and caregivers of people with intellectual disabilities. Due to incomplete questionnaires five subjects were excluded in the final data analysis, and the total number of subjects at the end was 40. Of the 40 parents of people with intellectual disabilities who participated in the study, a questionnaire was completed by 14 fathers and 26 mothers. Most parents had secondary school qualifications (55%) and were married (50%).

The average age of parents was 61.8 years (SD = 10.08) with the age range of 34-83 years. Most parents did not engage in any sports activities (82.5%), and 7 participants engaged in some recreational physical activities (Table 1).

In order to more precisely define the sample in this study, we gathered information about children with intellectual disabilities cared for by the studied population. The average age of people with intellectual disabilities cared for by participants, was 34.7 years (SD = 6.76), while the youngest participant was 24-years-old and the oldest 46 (Table 2). Considering the degree of intellectual disability, most children with intellectual disabilities belonged to the category of light, 40%, and moderate intellectual disability (ID), 37.5%. The majority reported no other difficulties (35%), and of those who did, 30% quoted the existence of other problems, most commonly physical problems. Only one participant used a motoric aid daily (Table 2).

### Instruments used in the research

To assess the quality of life in parents of children with intellectual disabilities the Personal Wellbeing Index (PWI) was used. PWI is an integral part of the International Wellbeing Index (IWI) [9], which includes the Personal Wellbeing Index (PWI) and the National Wellbeing Index (NWI). The chosen Personal Wellbeing Index consists of seven items, assessed on the scale from 0 to 10 (0 - I am not satisfied, 5=neither satisfied nor dissatisfied, 10=I am fully satisfied).

The result is multiplied by 10, resulting in an overall score with a range from 0 to 100, with higher scores indicating a higher level of life satisfaction [10].

Previous research confirmed the reliability and validity of this Index for the Croatian population [11]. The reliability of the questionnaire in this study was high, at  $\alpha = 0.9$ . An item was added to this questionnaire, in which parents were asked to assess the quality of life of their child on a scale from 0 to 10 and the results on this scale were also transformed into a number between 0 to 100.

### Data processing

The survey was carried out from the beginning of September 2013 to December 2014. The implementation of the research was approved by the reference centres and associations for the care of people with intellectual disabilities over the age of 21 in the City of Zagreb and the Zagreb County. All subjects were informed about the purpose of the research and all participants voluntarily participated in the research. The guidelines were included at the beginning of the questionnaire. The reasons and the investigative procedure were presented to all subjects. The entire survey was anonymous, guaranteeing the safety of trial subjects. There is ethical consent for the parents and children that participate in the research. The subjects filled in the questionnaire independently and the time necessary for the fulfillment of the questionnaire ranged between 5 and 20 minutes. The draft and the process of research was designed and made in accordance with the general principles of human research.

## Results

### The quality of life and the sense of personal well-being of parents and caregivers of children with intellectual disabilities

To get an insight into the quality of life and a sense of personal well-being of parents and caregivers of children with intellectual disabilities, as well as to compare their assessment with the quality standards that apply to the world's population, we calculated the average value for the entire sample, which is 64.4 (SD=19.65). This suggested that, based on the assessment, the quality of life of parents and caregivers of people with intellectual disabilities did not differ from the values that may be found in the healthy population.

In the total sample the domain of satisfaction with relations in families had the highest value, and the perception and confidence about future had the lowest value of all other domains on average. Table 3 presents average values for each statement from the Personal Wellbeing Index (PWI).

### The relation between the quality of life and the participants' socio-demographic characteristics

In accordance with another set goal, we compared the average value for the assessment of the quality of life with some characteristics of participants, parents of people with intellectual disabilities, to determine their relations.

As for the parents of children with intellectual disabilities, we compared whether there was a correlation between their age and the assessment of the quality of life by parents ( $r = -0.27$ ;  $p = 0.101$ ) and the assessment of parents for their children's quality of life ( $r = -0.006$ ;  $p = 0.971$ ). We found that the obtained correlations were not statistically significant. A significant correlation was found between the assessment of parents' quality of life and their assessment of the quality of life of their children ( $r = 0.634$ ;  $p = 0.000$ ), indicating that the

**Table 3:** Average values for statements from the Personal Wellbeing Index in a sample of parents of people with intellectual disabilities and the average estimate of perceived quality of life of children.

STATEMENT	Minimum	Maximum	M	SD
Life standard	0	100	60	24
Health	0	100	61	26
Life achievements	0	100	62	22
Family relations	10	100	77	23
Sense of security	0	100	65	28
Belonging to environment	10	100	72	24
Sense of future security	0	100	56	27
IOD	8.57	100	64	20
Assessment of quality of life of children	20	100	61	20

**Table 4:** Average values for the quality of life of parents with regard to gender, educational level, marital status and participation in physical activity and the results of t-test.

	N	M	SD	t	p
<b>GENDER</b>					
Male	14	62.8	16.7	-0.38	0.7
Female	26	65.3	21.3		
<b>EDUCATION*</b>					
SSQ	22	63.9	20.6	-0.26	0.8
CE & PSSQ	16	67.6	17.6		
<b>MARITAL</b>					
<b>STATUS**</b>					
No partner	16	64.5	16.1	0.408	0.69
Have a partner	24	64.3	22		
<b>SPORTS</b>					
Yes	7	60.4	20.7	-0.59	0.7
No	33	65.2	19.7		

\*Due to differences in the number of respondents in each category, from the final analysis subjects with low skills (N=2) were excluded, and the higher and university education are connected in the same category.

\*\*Due to differences in the number of respondents in each category, the category of "no partner" includes participants who live alone, those divorced and widowed, and the category of "have a partner" includes participants who are married, living with a partner or in a relationship.

more parents were satisfied with their quality of life and personal well-being respectively, they tended to give higher estimates of the quality of life of their children.

We checked whether there were differences in the quality of life due to gender, education and marital status, as well as participation in regular physical activity (sports). The results are shown in Table 4.

From the results it is evident that there was no statistically significant difference in the assessment of the quality of life between groups that differ with regard to gender, education, marital status and involvement in physical activities by parents and caregivers of people with intellectual disabilities.

## Discussion

The assessment of the quality of life of parents and caregivers of people with intellectual disabilities and their children is a big challenge for researchers because of the specificity of the population [12]. States those social models in western societies emphasize that

the problems of people with special needs result from the restrictions imposed on them by the society. Society today is still more focused on the personality of people with disabilities rather than their disability. The positive attitude of the community towards people with intellectual disabilities is the basis for the development of the necessary conditions that define the quality of life for these people and their families [13]. According to the results obtained in this study, the quality of life of parents and caregivers of people with intellectual disabilities did not differ from the values that may be found in the healthy population. The evaluation of the personal well-being and the quality of life ranges between 60% to 80% scale maximum, which is under the homeostatic model considered a score within the average accomplished by a healthy person [14]. According to the reviewed studies, the impact of caring for a person with a disability on the quality of family life demonstrates heterogeneous results. On the one hand, there are authors who point out that caring for a disabled family member promotes unity and cohesion within the family, and on the other hand, the authors clearly point out that such care significantly reduces the quality of life for families. When analyzing the quality of life of the parents or the caregivers, the type of disability in a family member should be regarded above all [15].

According to the research results, the parents achieved a relatively high value in the domain of the environment, which may be explained by the fact that their children were involved in the process of rehabilitation and habilitation in centers or associations for people with intellectual disabilities. According to Yau et al. [16], certain prerequisites are required in order to have a positive effect on the family, family members with disabilities and their care: harmonious family relations, high socioeconomic status and life in a community that provides support to such families. This data indicates the fact that the inclusion of people with disabilities is equally important to the individual, their family, as well as the entire community. The analyzed domain of the perception and confidence in future had on average the lowest value in comparison with other analyzed domains which contributes to the fact that the main problem for parents of people with intellectual disabilities is the fact that they do not have enough choices in the context of institutional support for the care of children with intellectual disabilities for the period when they would not be able to care for them or after their death. In any case, this issue is an important factor that the wider community should deal with in the context of community-based rehabilitation, the inclusion of disabled people and the institutional support for parents and children with intellectual disabilities. Parents also evaluated the quality of life of their children by answering the question "How satisfied are you with the life of your child / person with intellectual disabilities you care for?", and the obtained average result suggests that they were moderately satisfied. Nevertheless, attention should be focused on individual differences, because some parents give low estimates for the quality of life of their children, which may indicate problems in some aspects of functioning.

The results obtained in this study indicate that the parents who were satisfied with their quality of life and personal well-being tended to give higher estimates about the quality of life of their children. This information supports the fact that the parent or the caregiver of a person with intellectual disabilities is the most important prerequisite in ensuring and determining what the quality of life of the child would be. This information is an important destination point for future research. In the families of people with intellectual disabilities, the parent is the one who provides methods and terms

for the child's quality of life, and if his self-assessment of the quality of life is satisfactory, that would directly and indirectly affect the quality of life of their child. Poljan [17] indicates that the adjustment of the child to its condition and the ability to cope with everyday stress, as well as to integrate with the environment, mostly depend on the parental acceptance of the child. In a study on the quality of life of adults with intellectual disabilities and their families authors [18] found a significant correlation between the estimated quality of life of parents and their assessment of the quality of life of their children, which is consistent with the results obtained in this study. In this study there were no significant differences in the assessment of the quality of life of parents and caregivers of people with intellectual disabilities between the groups that differ with regard to gender, education, marital status and involvement in physical activity. Most parents are not engaged in any form of organized sports activities, which is understandable because the study included middle-aged and elderly people in the standard population, who also practice sedentary lifestyles. The socio-demographic characteristics of the parents and caregivers of people with intellectual disabilities in our study did not prove significant in terms of their self-assessment of the quality of life, and the investigation should be expanded to include some personality traits or the assessment of marital relations that were shown as significant in the previously mentioned studies.

#### **Methodological disadvantages and possible directions for future research**

The discussed research demonstrated the importance of developing effective methods for assessing the quality of life for families of people with intellectual disabilities and gives guidelines for future research related to the population of people with intellectual disabilities. The practical value of this work is the specificity of the sample, that is, parents in the population of the middle-aged and elderly. In Croatia, there are a very few studies on the quality of life of this population. This research points to the importance of developing targeted interventions related to the inclusion and participation of their families in the community, as well as developing habilitation and rehabilitation models of intervention, with the ultimate goal of achieving a better quality of life for people with intellectual disabilities and their families. Special attention should be paid to systematic planning to ensure adequate care for children after their parents' death. Considering the specific selection of subjects and the sample size, any generalization of the results is not possible. In order for the sample to represent the entire population of Croatia, it would be necessary to conduct a study involving a larger number of subjects who represent a population of parents and caregivers of people with intellectual disabilities. It would also be required to generalize the results to a wider area in the Republic of Croatia and include families of people with intellectual disabilities who live in non-urban areas. All collected information was based on self-assessments and does not necessarily reflect objective results, which presents a methodological problem in the interpretation of the data.

Conducting a longitudinal research would allow monitoring of factors that affect the quality of life for families of people with intellectual disabilities and the changes these families experience. The PWI questionnaire was reliable, but did not examine in detail the quality of life and this may be the reason that there was no deviation from the norm of the healthy population. It is necessary to compare the quality of life of parents and caregivers depending on the inclusion of people with intellectual disabilities in different models of care where the population participates. In future studies, apart from the self-

assessment of the quality of life for families of people with intellectual disabilities, other variables should be examined, such as personality traits of people with intellectual disabilities, strategies for dealing with stress, the level of perceived support and the socioeconomic status.

## Conclusion

In accordance with the set objectives, this study showed that the perceived quality of life of parents did not deviate from the values that may be found in the healthy population. Parents also evaluated the quality of life of their children, and the result showed that they were moderately satisfied. A significant correlation was found between the assessment of the quality of life of parents and their assessment of the quality of life of their children, which indicates that when the parents were satisfied with their quality of life and personal well-being, they tended to estimate of the quality of life of their children higher. The results of this study indicate that parents of people with intellectual disabilities were most concerned about the sense of security in the future, and believed that a sense of belonging to the environment and relations with neighbors contributed mostly to their quality of life.

These results indicate that the main strategy of working with families of people with intellectual disabilities should focus precisely on these test domains. The inclusion of people with disabilities in the community at all levels is a right, not a problem, and as such is a reliable indicator of the society's attainment in its democratization. For families of people with intellectual disabilities the quality of life should be the ultimate outcome of the evaluation instrument for the rehabilitation and habilitation processes in this population.

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