

# QUALITY OF LIFE IN ADULTS WITH INTELLECTUAL DISABILITY: SELF-ASSESSMENT VERSUS ASSESSMENT BY OTHERS

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## *Abstract*

Researches of quality of life in persons with intellectual disability are affected by the selection of assessment methods and the validity of the obtained data. Neither self-assessment nor assessment by others can exclusively be a measure and an indicator of the objective situation, so commonly both methods are used and gained data are compared.

Research objectives: assessing and comparing the quality of life in adults with intellectual disability from a different residential settings (families, institutions and residential housing units with support), and comparison of self-assessment with assessment by others (parents, professionals from institutions or residential housing units).

The tasks of the research were to determine the differences in the quality of life in adults with intellectual disability from a different residential settings and to determine the differences in self-assessment and assessment by others.

The Quality of life Questionnaire for persons with intellectual disability from Schalock and Keith was a research instrument, and it was answered by 130 adults with mild, moderate and severe intellectual disability.

Most significant results: there is a statistically significant difference in the quality of life in terms of residential status, according to the answers of persons with intellectual disabilities (Kruskal-Wallis H test  $H(2) = 59.218, p < 0.001$ ), and according to the answers obtained from other respondents (Kruskal-Wallis H test  $H(2) = 53.475, p < 0.001$ ). There is a statistically significant difference between self-assessment and assessment by others (T – test  $t(129) = 67.496; p > 0.01$ ).

Conclusions: life in a natural family environment ensures better conditions for quality life, or generally, persons living in smaller community based units have a better quality of life than the institutionalized. Among persons with intellectual disability and respondents from their close environment, there are differences about the same issues, that is, differences between self-assessment and assessment by others.

*Keywords: quality of life, adults with intellectual disabilities, self-assessment, assessment by others*

## **Introduction**

To define the term “quality of life” is very difficult because of the numerous and complex components that the term includes. Various authors have interpreted it in different ways, but generally they all agree that it is a multidimensional concept that includes a significant number of simultaneously objective and subjective factors, and it is influenced by various individual and environmental factors and their mutual relations. Modern knowledge of quality of life says that it is interactive concept (according to Schalock, 2007; Schalock, 2004; Schalock i Verdugo, 2002) which contains many interrelated factors that reflect positive values and life experiences. Although these indicators are sensitive to cultural and social conditions of the community, they generally emphasize the personal well-being and the life satisfaction.

The concept of quality of life in the field of intellectual disability appeared in the 80s of the last century as a sensitive phenomenon and principle according to which the support services for these people started to distribute. It became clear that if an appropriate and individualized support is offered, the quality of life for people with disabilities, their self-determination, independence and inclusion will be significantly improved (Turnbull, A., Brown, I., Turnbull, III HR, 2004).

The quality of life for persons with intellectual disabilities is basically determined by the same or similar indicators that determine the quality of life for the general population, but there are specific characteristics that are associated with the developmental characteristics of these individuals, their position in the society and the interaction with the community. As many authors point out (Schalock, 2007; Schalock and Verdugo, 2002; Schalock and Keith, 2004), the quality of life in these individuals is primarily determined by: emotional well-being, interpersonal relations,

physical and material well-being, personal development, the degree of autonomy and the possibility of self-determination, social inclusion and realization of their rights.

Difficulties always arise in studies of quality of life in persons with intellectual disability. These difficulties are because of the selection of the evaluation instruments and the validity of the received data, especially when dealing with persons with severe and profound intellectual disability and those with communicational difficulties. On the other hand, the validity of responses received by others (people from their close environment) is also questionable. In fact, many studies indicate that there are significant differences about some issues among persons with intellectual disabilities and their parents / professionals or other evaluators from their surroundings (Brown, 2000). For persons with speech and language difficulties, the quality of life is measured by others (a close relative or professional) who knows the person with intellectual disability well and who can respond on his behalf. Many researchers, as well as, Felce and Perry (1995) suggest that the answers provided by others are not sufficiently realistic in terms of how a person with disability really feels. Stancliffe (2000) says that the basic dilemma of this approach is whether the data gained by the mediator would be sufficiently similar to the data that would be obtained directly from the respondents. One of the ways to evaluate the validity of the data is to compare the gained responses from proxies with answers that persons with intellectual disabilities are giving. Because of the mentioned difficulties in these studies, usually, both methods are used, and then the received data are compared. Researchers agree that neither self-assessment or assessment by others, can be an exclusive measure and an indicator of the objective conditions.

## **Methodology:**

### Goals of the research:

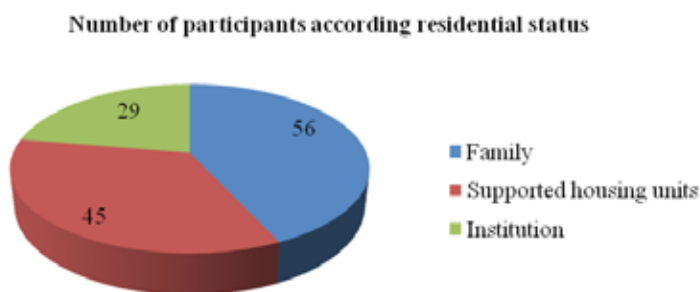
- assessing and comparing the quality of life in adults with intellectual disability in different settings (family, institution and community-based supported housing units);
- comparison of the self-assessment (gained from participants with intellectual disability them self) with the assessment by others (acquired from parents, family members, professionals from institutions and supported housing units).

### Objectives of the research:

- determining the differences in quality of life among adults with intellectual disabilities from different settings (family, institution and community-based supported housing units) according to self-assessment;
- determining the differences in quality of life among adults with intellectual disabilities from different settings (family, institution and community-based supported housing units) according to assessment by others;
- determining the difference between self-evaluation and evaluation by others.

A Quality of life Questionnaire for persons with intellectual disabilities from authors Schalock and Keith (since 1993, revision 2004) was used as an instrument of the survey. The questionnaire consists of 40 questions divided into 4 domains: Satisfaction, Competence/Productivity, Empowerment/Independence and Social belonging/Community integration. Higher scores indicate greater satisfaction, more competence/productivity, greater empowerment/independence and greater social integration/participation in the community, or in general, high total score indicates better quality of life. Self-evaluation was conducted first, and the assessment by other persons (other evaluators) second.

The sample consisted of 130 adults with mild, moderate and severe intellectual disability and 130 other evaluators. The number of participants with intellectual disability by residential status is shown in Figure 1. Most of the participants live with their families (56), 45 of all respondents are from supported living units and some respondents were institutionalized (29).



**Figure 1.** Number of participants by residential status

The analysis of the gained data began by creating a database in the statistical software SPSS. Kruskal-Wallis test was used to determine the statistical differences in the quality of life among participants according to self-assessment and assessment by others, because the distribution of data was not normal (Gaussian), and this test does not need the normal distribution as a premise. For determining the differences between self-assessment and assessment by others the one-sample t-test was used.

## Results with discussion

Table 1. *Data from the self-assessment*

Residential status	Number of respondents (n)	Arithmetic mean (m)	Standard deviation (s)	Standard error	95% Trustworthiness interval of the average		Min.	Max.
					Lower limit	Upper limit		
<b>Families</b>	56	<b>80.04</b>	7.65	1.02	77.99	82.08	69	107
<b>Supported living units</b>	45	<b>73.76</b>	10.40	1.55	70.63	76.88	57	99
<b>Institution</b>	29	<b>58.10</b>	9.24	1.72	54.59	61.62	44	75
<b>Total</b>	130	72.97	12.33	1.08	70.83	75.11	44	107

From Table 1, we can see that according to the average values obtained by self-assessment of the questionnaire for quality of life, respondents from families achieved the highest average score (80.04), followed by the respondents from supported living units (73.76), while institutionalized participants have the lowest average score (58.10).

Table 2. *Kruskal-Wallis test according to the self-assessment*

	Amount
<b>Kruskal-Wallis test (KW)</b>	<b>59.218</b>
<b>Degree of freedom (df)</b>	2
<b>Asymptotic significance</b>	0.000

The result from Kruskal-Wallis test ( $KW(2)=59.218$ ,  $r<0.001$ ) shows that according to self-assessment, there is a statistically significant difference in the quality of life between persons with intellectual disabilities, in terms of residential status.

*Table 3. Data from the assessment by others*

Residential status	Number of respondents (n)	Arithmetic mean (m)	Standard deviation (s)	Standard error	95% Trustworthiness interval of the average		Min.	Max.
					Lower limit	Upper limit		
<b>Families</b>	56	<b>74.86</b>	8.624	1.152	72.55	77.17	60	103
<b>Supported living units</b>	45	<b>76.76</b>	10.564	1.575	73.58	79.93	53	106
<b>Institution</b>	29	<b>60.21</b>	5.247	0.974	58.21	62.20	49	69
<b>Total</b>	130	72.25	10.881	0.954	70.36	74.13	49	106

From Table 3 it is obvious that according to the average values obtained by assessment by others of the questionnaire for quality of life, participants from supported living units have the highest average score (76.76), than respondents that live in their families (74.86), and institutionalized participants have lowest average score (60.21).

*Table 4. Kruskal-Wallis test according to the assessment by others*

	Amount
<b>Kruskal-Wallis test (KW)</b>	<b>53.475</b>
<b>Degree of freedom (df)</b>	2
<b>Asymptotic significance</b>	0.000

The result from the Kruskal-Wallis test ( $KW(2)=53.475$ ,  $r<0.001$ ) shows that according to assessment by others, there is a statistically significant difference in the quality of life between persons with intellectual disabilities, in terms of residential status.

Table 5. One-sample statistics for self-assessment versus assessment by others

	Number of respondents (n)	Arithmetic mean (M)	Standard deviation (s)	Standard error of the arithmetic mean
Self-assessment	130	72.969	12.326	1.081
Assessment by others	130	72.246	10.881	0.954

Table 5 shows that the average rating of the quality of life is higher in case of self-assessment (72.969) compared with the average score obtained from other estimators (72.246).

Table 6. One-sample t-test

	t-distribution	Degree of freedom (df)	Significance (bilateral)	Average difference	Difference in standard error	
					Low range	Upper range
Self-assessment	67.496	129	0.000	72.969	70.830	75.108
Assessment by others	75.706	129	0.000	72.246	70.358	74.134

The result from the t-test ( $t(129)=67.496$ ,  $r>0.01$ ) shows that there is a statistically significant difference between the assessment by the persons with intellectual disabilities and the assessment acquired from proxies.



**Figure 2.** *Relation between average assessments of quality of life*

Figure 2 shows that there is a statistical difference between the self-assessment and the assessment by proxies in terms of residential status.

Similar to our results were obtained by Bratkovic (2002) from Croatia in the survey on 100 adults with moderate and severe intellectual disability, of which 50 were living with their families, and 50 in an institution, and sample of other estimators (50 parents of participants and 50 experts from institutions). Statistically significant differences in self-assessment and evaluation by others were found, and as well statistically significant differences in the quality of life of institutionalized persons and those living in families were found.

Researches by other authors (Schalock, Verdugo Alonso, 2002), as well as analysis of studies for deinstitutionalization into smaller residential living settings in the community, indicate that intellectually disabled persons that live in smaller community based units have overall better quality of life than those that are institutionalised. The following positive results are observed: improved interpersonal relationships, improved material well-being, productivity, improved adaptive behaviors and competence, greater autonomy, more opportunities for choice and decisions making, wider social network, facilitated access to community, generally greater social participation and higher degree of satisfaction. Life in the family provides a better quality of life, particularly in terms of psychological and emotional well-being, independence development, social integration, community participation



and self-determination. Life of those persons that live in institutions is restricted and very tied to institutional programs on which they dependent on.

Schwartz and Rabinovitz (2003) examined the life satisfaction among 93 people with intellectual disabilities living in supported living houses, and they took into account the assessment by the respondents themselves, as well as the assessment by their parents and professional staff. Results indicate a generally positive picture, although there were some differences between the answers provided by intellectually disabled persons and professionals who care for them, while no differences were found in the results of the respondents and their parents.

Also in Maryland, US, within the “Ask Me!” project, 5125 participants, adults with disabilities, of which 27% were persons with severe and profound intellectual disabilities, were involved. Three quarters of the respondents answered questions about their quality of life on their own. Those who answered the questions on their own gave different answers than those gained by professionals who have answered the questions on their behalf (Schalock, Gardner, Bradley, 2007).

Rapley, Ridgway and Beyer (1998) compared data of examination of the quality of life obtained from the professional staff and from persons with intellectual disabilities and found that the results have a low correlation and matching, and the professionals overestimated the independence and the autonomy of the intellectually disabled. In this context, Lefort and Fraser (2002) pointed out that the responses of the professionals should not be taken as a substitute for information that can be obtained on the first hand.

## Conclusions

According to self-assessment the best quality of life have intellectually disabled persons who live with their families (with average score 80.04), while according to the assessment by others, best quality of life have those intellectually disabled persons who live in community-based supported housing units (their average score is 76.76). The obtained results from the assessment by others are due to the fact that parents give lower evaluation of the quality of life to people with intellectual disabilities living in their families than they give themselves, because they always think that they could contribute more for better quality of the life of their child. Compared to them, experts

from supported housing units or institutions, consider that they provide higher quality of life than the persons with intellectual disabilities think they receive.

We confirmed the results obtained in other studies that life in the natural family environment ensures better conditions for quality life, or those persons with intellectual disability who live in smaller communities have overall better quality of life than the institutionalized.

We also confirm the conclusion of many other studies which indicates that among persons with intellectual disability and persons in their surroundings there may be differences about same issues. The gained data shows that there is a statistical difference between self-assessment versus assessment by others.

In the last three decades, in the most highly developed countries, services for people with intellectually disabled have changed from residential care to supported living in the community that contributed to improving the quality of life of these people. Today's opinion is that people with intellectual disabilities have better and more quality life within their families, where they receive the necessary support. However, risks may arise if we fully turn to support these people in their families, rather than providing services, assistance and support for themselves as individuals. Because of the economic rationalization and the need for costs reduction, the personal requirements and desires can be neglected. Also, the families themselves are very different in their ability to provide adequate care, a stimulating environment and help. It is therefore, necessary to carefully analyze the overall family quality of life and the extent to which it can be implemented.

To improve the quality of life of persons with intellectual disabilities they need to be allowed to participate in social life through activities and to have social contacts outside the place they live or work, or use their leisure time. They need to be accepted by the general population as equal citizens in our society. To realize this, the society should change the attitudes and raise the awareness about these people, and help them through self-advocacy and autonomy to make decisions and choices, actively participate in finding their place in the society as valuable members.

The society should be more aware and it should take action to contribute to the improvement of care and support for these individuals and humanization of their living conditions by promoting quality services, programs and strategies in the current educational and rehabilitation practice. The change in the social relations and social policy towards people with intellectual disabilities would improve their integration

and inclusion in the community. The concept of quality of life transformed into a rehabilitative model emphasizes the need for improvement of the independence, productivity and inclusion, along with the implementation of supported living and supported employment of adults with intellectual disabilities. The responsibilities and the tasks of individuals and of the society as a whole, is to create conditions for a satisfactory quality of life of these people, stressing that all persons with disabilities have the right to a better quality of life.

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## **КВАЛИТЕТ НА ЖИВОТ КАЈ ВОЗРАСНИ ЛИЦА СО ИНТЕЛЕКТУАЛНА ПОПРЕЧЕНОСТ: САМОПРОЦЕНКА НАСПРОТИ ПРОЦЕНКА ОД ДРУГИ**

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### *Анстракт*

Во истражувањата на квалитетот на живеење кај лица со интелектуална попреченост се јавуваат тешкотии во врска со изборот на методи за испитување, како и со валидноста на добиените податоци. Ниту самопроценката ниту проценката од други лица не можат да бидат исклучително мерило и показател на објективната состојба, па затоа најчесто се користат обете методи и се врши споредба на добиените податоци.

Цели на истражувањето се проценување и споредување на квалитетот на живот кај возрастните лица со интелектуална попреченост во различни животни услови (семејни, институционални и станбени единици за домување со поддршка) и компарација на самопроценката со проценката од страна на други (родители, стручни лица од институциите или станбените зедници).

Задачи на истражувањето се утврдување на разликите во квалитетот на живот кај возрастните лица со интелектуална попреченост во различни животни услови и утврдување на разликите во самопроценката и проценката од други лица.

Инструмент во истражувањето е Прашалникот за квалитет на животот кај лица со интелектуална попреченост од Шалок и Кејт, на кој одговараа 130 возрастни лица со лесна, умерена и тешка интелектуална попреченост.

Најзначајни резултати: постои статистички значајна разлика во квалитетот на живот во однос на резиденцијалниот статус, според одговорите на самите лица со интелектуална попреченост (Kruskal-Wallis H тест  $H(2) = 59,218$ ,  $p < 0,001$ ), и според одговорите на другите (Kruskal-Wallis H тест  $H(2) = 53,475$ ,  $p < 0,001$ ). Постои статистички значајна разлика помеѓу самопроценката и проценката од други (T – test  $t(129) = 67,496$ ,  $p > 0,01$ ).

Заклучоци: Животот во природна семејна средина обезбедува подобри предуслови за квалитетен живот, односно, генерално, подобар квалитет на живот имаат лицата кои живеат во помали заедници отколку институционализираните лица. Помеѓу самите лица со интелектуална попреченост и лицата од нивната околина постојат разлики во поглед на исти прашања, односно постои разлика меѓу самопроценката наспроти проценката од други.

*Клучни зборови: квалитет на живот, возрастни лица со интелектуална попреченост, самопроценка, проценка од други лица*