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Family Quality of Life from the Perspective of Parents of Children with Intellectual Disabilities

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Research Article

Abstract

Introduction: The quality of life of families (FQoL) with children with intellectual disabilities (ID) has been frequently studied in recent research and there are many factors that influence it. In Croatia, there is still too little research on this topic. The aim of the study was to determine the FQoL with children with ID receiving care at the Centre for Rehabilitation Zagreb.

Methods: The study used the Beach Centre Family Quality of Life Scale (BC-FQoL), which was completed online by parents. Forty-four mothers of children with ID participated in the study.

Results: Mean scores per question showed very acceptable and exemplary scores on all subscales and the overall FQoL. Satisfaction with emotional well-being is significantly lower than satisfaction with other subscales and the overall FQoL. Satisfaction with family interaction, disability-related support and parental care are significantly higher than satisfaction with overall FQoL. Regarding the child's gender, there were statistically significant differences in the family interaction subscale and overall FQoL, with higher satisfaction among mothers of girls. No statistically significant differences were found in the subscales or the total FQoL score in relation to the age of the mothers or the age of the children.

Conclusion: The results of the study show that although the overall FQoL is satisfactory, the families of children with ID need support, especially in terms of emotional well-being. Services for families should include support to reduce stress, provide support for the special needs of all family members and ensure programmes that give family members more time for their own interests. Policy makers and practitioners need to consider the quality of life and well-being of carers alongside child-related goals.

Keywords: family quality of life, intellectual disability, parents, children, support

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1. Introduction

The American Association on Intellectual and Developmental Disabilities (AAIDD) defines intellectual disability (ID) as "a diminished capacity with characteristic limitations in intellectual functioning and adaptive behaviour that are expressed in conceptual, social, and practical skills". The criteria for the end of developmental age were changed from 18 to 22 years, as research indicates that brain development continues into the 20s (Schalock et al., 2021). Many people with ID will need the full support of their parents and health authorities throughout their lives. If this is not the case, quality of life will be affected, leading to social and economic difficulties. The nature of ID means that the quality of life of the whole family needs to be maximised (Brown et al., 2016). According to Murray Bowen's family systems theory, the family should be considered as a whole system, and each family member has an impact on the functioning of the whole family (Guo, 2020). As a unique member of his or her family, a child with disabilities has an impact on other family members, which in turn affects the functioning of the entire family (Samuel et al., 2012). Due to the complex structure of family quality of life (FQoL), there is still no globally accepted definition. However, researchers agree that "FQoL is a multidimensional construct with multiple domains and that FQoL refers to family members' subjective satisfaction with their family life" (Samuel et al., 2012; Guo, 2020). Zuna et al. (2010) (according to Luitwieler et al., 2021) have described four key concepts that influence the FQoL of families of children with ID and other disabilities: "(1) systemic concepts (i.e., systems, policies, and programmes); (2) service concepts (i.e., formal services, supports, and practises); (3) individual family member concepts (i.e., demographic characteristics, traits, and beliefs); and (4) family unit concepts (i.e., family characteristics and family dynamics)". Effective support systems and interventions can only be developed by understanding the predictors of FQoL (Alnahdi & Schwab, 2024). Leutar & Štambuk (2007) state that the families of children with disabilities not only have to cope with their standard family codes but impacts are also made more difficult by the environment in which they live. They are discriminated against, prejudged, shunned, underestimated, etc., which leads to social marginalisation. According to parents, caring for a child with ID is a great challenge and often deprives parents of their own basic personal needs, as they must spend a lot of time, effort and patience to fulfil the high care needs of children with disabilities (Bulić, 2013). Parents of children with developmental disabilities often experience stigmatisation and a lack of understanding from others (Mitter et al., 2018). Their experiences with some of the challenges they face, such as the lack of appropriate services, differ depending on where the family with a disabled child lives, in an urban or rural area (Vaghela & Bodla, 2024). Single mothers in particular face numerous problems, including poverty, stigmatisation and lack of social support (Ramos et al., 2024). Psychological stress affects the FQoL of parents of children with ID in complex ways. Interventions should be developed to help parents of children with disabilities to reduce stress and increase parental engagement (Cheng et al., 2025). According to the Croatian Institute of Public Health (2024), there are 6,922 people with ID aged 0-19 years in the Republic of Croatia. There is little research on the quality of life of families with children with ID in Croatia. The aim of this study is therefore to gain insight into the perception of the quality of life of parents of children with ID regarding some socio-demographic characteristics of the children (age and gender) and the parents (age).

2. Methods

2.1 Study design

The study took place in 2022. The participants, parents of children with ID participating in programmes of the Centre for Rehabilitation Zagreb, received an invitation letter from the Centre for Rehabilitation Zagreb to participate in the study. The study was conducted with the approval of the Ethics Committee of the Centre for Rehabilitation Zagreb (number 738-01-08/02-22-2).

2.2 Participants

Inclusion criteria were parents of children with ID who could speak and understand Croatian. The responses of forty-four mothers of children with ID were analysed. The age of the respondents ranged from 25 to 49 years (M=37.34 years, SD =5.87). The ages of the children with developmental disabilities for whom the questionnaire was completed ranged from 1 year to 9 years (M=3.89 years, SD=1.73), of whom 27 were male and 17 were female. Table 1 shows descriptive statistics for the ages of the children and mothers.

Table 1: Chronological Ages of Children and Mother

Age (years)		n	%
Children	1-4	28	63.6
	5-9	16	36.4
Mothers	25-35	16	36.4
	36-49	28	63.6

Note: *n=number of participants*

2.3 Instrument

The Beach Centre Family Quality of Life Scale (BC-FQoL) was used in the study. The BC-FQoL assesses the family's perceived satisfaction with various aspects of the family's quality of life. The BC-FQoL contains five subscales: family interaction (6 items), parenting (6 items), emotional well-being (4 items), physical/material well-being (5 items) and disability-related support (4 items) (FQoL, 2015). The answers were rated on a Likert scale from 1 - very dissatisfied to 5 - very satisfied. Užarević et al (2025) found that the Croatian version of the BC-FQoL has good validity, reliability and factor structure for measuring the quality of life of families in Croatian-speaking families. The questionnaire is publicly available and was translated into Croatian for the purposes of the study. The online version of the questionnaire was sent to the addresses of 80 families of children with ID who use the services of the Centre for Rehabilitation Zagreb. The questionnaire was completed anonymously, and respondents were informed that the results would be analysed at group level. However, of the 58 respondents who started filling out the online questionnaire, we only analysed the complete cases without missing values. As only four fathers responded, we did not use their responses. Finally, we analysed the responses of forty-four respondents, all of them mothers.

In our study, the reliability analysis of the 5 subscales of the BC-FQoL showed very good internal consistency with Cronbach's alpha 0.901. The overall reliability coefficient for the BC-FQoL scale was 0.953, indicating impressive reliability. The Cronbach's α coefficients for the subscales of the BC-FQoL scale ranged from 0.758, indicating adequate reliability, to 0.932 for the family interaction subscale, indicating excellent reliability. The Cronbach's α-coefficients of the scale and subscales are shown in Table 2.

Table 2: Cronbach's α coefficients for the BC-FQOL subscales and the overall scale

BC-FQoL scales	Number of items	Cronbach's α
Family Interaction	6	0.932
Parenting	6	0.879
Emotional Well-being	4	0.805
Physical / Material Well-being	5	0.758
Disability-Related Support	4	0.832
Overall FQoL	25	0.953
BC-FQoL scales	5	0.901

2.4 Data processing methods

The results were processed using descriptive statistics. As the BC-FQOL scale does not provide for a scoring method, the BC-FQoL scores were interpreted according to the classification offered by Raphael et al. (1996, after McFelea & Raver, 2012): "<1.37=very problematic, 1.37 to 2.11 = problematic; 2.12 to 2.86 = adequate, 2.87 to 3.61 very acceptable, and >3.61=exemplary". As the Shapiro-Wilk test did not confirm the normality of the distribution of scores or all respondents in the subscales of the BC-FQoL, as shown in Table 3, the Mann-Whitney test was used to determine the differences between the groups.

The Wilcoxon Signed Ranks Test was performed to analyse the internal differences between the five subscales of the BC-FQoL.

Table 3: Shapiro-Wilk test of normality BC-FQoL

BC-FQoL scales	W	df	p
Family Interaction	0.873	44	<0.001
Parenting	0.810	44	<0.001
Emotional Well-being	0.949	44	0.052
Physical / Material Well-being	0.831	44	<0.001
Disability-Related Support	0.833	44	<0.001
Overall FQoL	0.881	44	<0.001

Table 4: Average score per question of the overall scale and the five subscales BC-FQoL

BC-FQoL scales	M	SD
Family Interaction	4.08	0.882
Parenting	4.05	0.776
Emotional Well-being	3.22	0.943
Physical / Material Well-being	3.97	0.699
Disability-Related Support	4.08	0.773
Overall FQoL	3.88	0.692

Note: *M=mean, SD=standard deviation*

Table 5: Internal differences among five sub-scales of BC-FQoL

		n	Mean Rank	Sum of Ranks	z	p
Parenting < Family Interaction	Negative Ranks	22	19.23	423.00	-0.762	0.446
	Positive Ranks	16	19.88	318.00		
	Ties	6				
Emotional Well-being < Family Interaction	Negative Ranks	37	23.26	860.50	-5.116	**<0.001**
	Positive Ranks	5	8.50	42.50		
	Ties	2				
Physical / Material Well-being < Family Interaction	Negative Ranks	28	17.70	495.50	-1.473	0.141
	Positive Ranks	11	25.86	284.50		
	Ties	5				
Disability-Related Support < Family Interaction	Negative Ranks	15	21.13	317.00	-0.033	0.974
	Positive Ranks	20	15.65	313.00		
	Ties	9				
Emotional Well-being < Parenting	Negative Ranks	35	23.97	839.00	-4.846	**<0.001**
	Positive Ranks	7	9.14	64.00		
	Ties	2				
Physical / Material Well-being < Parenting	Negative Ranks	19	20.39	387.50	-1.551	0.121
	Positive Ranks	15	13.83	207.50		
	Ties	10				
Disability-Related Support > Parenting	Negative Ranks	15	23.13	347.00	-0.341	0.733
	Positive Ranks	23	17.13	394.00		
	Ties	6				
Physical / Material Well-being > Emotional Well-being	Negative Ranks	7	9.43	66.00	-4.915	**<0.001**
	Positive Ranks	36	24.44	880.00		
	Ties	1				
Disability-Related Support > Emotional Well-being	Negative Ranks	4	9.63	38.50	-5.014	**<0.001**
	Positive Ranks	36	21.71	781.50		
	Ties	4				
Disability-Related Support > Physical / Material Well-being	Negative Ranks	13	20.81	270.50	-1.452	0.147
	Positive Ranks	25	18.82	470.50		
	Ties	6				
Overall FQoL < Family Interaction	Negative Ranks	33	22.95	757.50	-3.435	**<0.001**
	Positive Ranks	10	18.85	188.50		
	Ties	1				
Overall FQoL < Parenting	Negative Ranks	29	24.19	701.50	-2.759	**0.006**
	Positive Ranks	14	17.46	244.50		
	Ties	1				
Overall FQoL > Emotional Well-being	Negative Ranks	5	7.40	37.00	-5.265	**<0.001**
	Positive Ranks	38	23.92	909.00		
	Ties	1				
Overall FQoL < Physical / Material Well-being	Negative Ranks	24	23.98	575.50	-1.238	0.216
	Positive Ranks	19	19.50	370.50		
	Ties	1				
Overall FQoL < Disability-Related Support	Negative Ranks	32	22.45	718.50	-2.964	**0.003**
	Positive Ranks	11	20.68	227.50		
	Ties	1				

Note: *n= number of participants, z=z-score, p=statistical significance*

3. Results

Table 4 shows the average values per question of the overall scale and the five BC-FQoL subscales.

The lowest average score per question was determined on the scale for emotional well-being, for overall FQoL and for physical/material well-being. The highest average score per question was for satisfaction with family interaction, disability-related support and parenting.

The Wilcoxon Signed Ranks Test was conducted to analyse the internal differences between the five subscales of the BC-FQoL. The results are shown in Table 5.

Satisfaction with emotional well-being is significantly lower than satisfaction with family interaction (z=-5.116, p=<0.001), parenting (z=-4.846, p=<0.001), material well-being (z=-4.915, p=<0.001), disability-related support (z=-5.014, p=<0.001) and overall FQoL (z=-5.265, p=<0.001).

Satisfaction with overall FQoL is significantly lower than satisfaction with family interaction (z=-3.435, p=<0.001), satisfaction with parenting (z=-2.759, p=0.006) and disability-related support (z=-2.964, p=0.003).

The difference in satisfaction between other pairs of subscales is not statistically significant.

The Mann-Whitney test was used to determine differences in the results depending on the gender and age of the children and the age of the mothers.

No statistically significant differences were found in the subscales of the questionnaire or the BC-FQoL total score depending on the age of the children (Table 6).

Table 6: Difference in BC-FQOL depending on the age of the children

BC-FQOL Scale	*Age of the child (years)*	*n*	*Mean Rank*	*Sum of Ranks*	*z*	*p*
Family Interaction	*1-4*	*28*	*22.39*	*627.00*	*-0.074*	*0.941*
	5-9	*16*	*22.69*	*363.00*		
Parenting	*1-4*	*28*	*22.48*	*629.50*	*-0.012*	*0.990*
	5-9	*16*	*22.53*	*360.50*		
Emotional Well-being	*1-4*	*28*	*24.55*	*687.50*	*-1.409*	*0.159*
	5-9	*16*	*18.91*	*302.50*		
Physical / Material Well-being	*1-4*	*28*	*24.88*	*696.50*	*-1.638*	*0.101*
	5-9	*16*	*18.34*	*293.50*		
Disability-Related Support	*1-4*	*28*	*22.05*	*617.50*	*-0.313*	*0.754*
	5-9	*16*	*23.28*	*372.50*		
Overall FQoL	*1-4*	*28*	*23.55*	*659.50*	*-0.720*	*0.472*
	5-9	*16*	*20.66*	*330.50*		

Note: *n= number of participants, z=z-score, p=statistical significance*

Table 7 shows that a statistically significant difference was found in the family interaction subscale (z=-2.998, p=0.003) and in the overall FQoL (z=-2.088, p=0.037) depending on the child's gender, with the FQoL of mothers of girls being better.

Table 7: Differences in the BC-FQoL scale depending on the gender of the children

BC-FQOL Scale	*Gender of the child*	*n*	*Mean Rank*	*Sum of Ranks*	*z*	*p*
Family Interaction	*Boys*	*27*	*17.93*	*484.00*	*-2.998*	***0.003***
	Girls	*17*	*29.76*	*506.00*		
Parenting	*Boys*	*27*	*19.83*	*535.50*	*-1.748*	*0.08*
	Girls	*17*	*26.74*	*454.50*		
Emotional Well-being	*Boys*	*27*	*20.98*	*566.50*	*-0.993*	*0.321*
	Girls	*17*	*24.91*	*423.50*		
Physical / Material Well-being	*Boys*	*27*	*20.02*	*540.50*	*-1.63*	*0.103*
	Girls	*17*	*26.44*	*449.50*		
Disability-Related Support	*Boys*	*27*	*21.17*	*571.50*	*-0.891*	*0.373*
	Girls	*17*	*24.62*	*418.50*		
Overall FQoL	*Boys*	*27*	*19.30*	*521.00*	*-2.088*	***0.037***
	Girls	*17*	*27.59*	*469.00*		

Note: *n= number of participants, z=z-score, p=statistical significance*

No statistically significant differences were found in the subscales or the overall FQoL score in relation to maternal age, as shown in Table 8.

Table 8: Differences in the BC-FQoL scale according to maternal age

BC-FQoL Scale	*Age of the mothers (years)*	*n*	*Mean Rank*	*Sum of Ranks*	*z*	*p*
Family Interaction	*25-35*	*16*	*22.00*	*352.00*	*-0.197*	*0.844*
	36-49	*28*	*22.79*	*638.00*		
Parenting	*25-35*	*16*	*21.63*	*346.00*	*-0.344*	*0.731*
	36-49	*28*	*23.00*	*644.00*		
Emotional Well-being	*25-35*	*16*	*23.09*	*369.50*	*-0.233*	*0.816*
	36-49	*28*	*22.16*	*620.50*		
Physical / Material Well-being	*25-35*	*16*	*23.44*	*375.00*	*-0.369*	*0.712*
	36-49	*28*	*21.96*	*615.00*		
Disability-Related Support	*25-35*	*16*	*22.03*	*352.50*	*-0.188*	*0.851*
	36-49	*28*	*22.77*	*637.50*		
Overall FQoL	*25-35*	*16*	*22.28*	*356.50*	*-0.086*	*0.932*
	36-49	*28*	*22.63*	*633.50*		

Note: *n= number of participants, z = z-score, p = statistical significance*

4. Discussion

The aim of the study is to gain an insight into the perception of the quality of life of parents of children with ID regarding some socio-demographic characteristics of the children and the mothers.

The mean values per question show very acceptable and exemplary scores on all subscales and the overall FQoL. The scores for overall FQoL in our study (M=3.88) differ from the Turkish sample in the study by Meral et al. (2013) (M=3.65) and the American sample (M=3.99) (Boehm & Carter, 2019). The lowest mean values per question of the BC-FQoL were determined for satisfaction with emotional well-being, overall FQoL and physical/material well-being.

The results show that satisfaction with emotional well-being is significantly lower than satisfaction with other subscales and overall FQoL.

The low score for emotional well-being is in line with other findings in different cultures (Boehm, 2017, Borilli et al., 2022, Lahaije et al., 2023) and points to the crucial importance of emotional factors for quality of life in different cultures and social contexts. Existing services should be broader and provided by specialised professionals such as psychologists and educational rehabilitators as individual and group support for parents and carers.

Barratt et al (2025) found that parents of children with moderate to severe ID had lower FQoL and more physical and psychological problems. Social support, especially when it comes from multiple sources, significantly reduces emotional distress, facilitates the acceptance process, and promotes personal and family growth. Tarleton & Ward (2007) found that parents can be enabled to develop self-confidence, support each other and interact more positively with the professionals and systems responsible for their children's wellbeing when they receive appropriate help from services. Caples & Sweeney (2011) found that parents who receive support can continue in this caring role and improve their quality of life. Beadle-Brown et al (2016) found that in many countries there are services for people with mild ID, but fewer for people with more severe ID and that most care is left to families.

In our study, the highest mean scores were for satisfaction with family interaction, disability-related support and parental care, and scores on these scales are significantly higher than satisfaction with overall FQoL.

As ours was a random sample in which all families were supported by the Centre for Rehabilitation Zagreb, this could explain the higher scores for disability-related support. The higher scores in the areas of family interaction and parenting can be explained by the fact that the family in Croatia is considered the main actor providing goods and services for the well-being of people with disabilities. These results are similar to the results of the study conducted in Brazil (Borilli et al., 2022).

Regarding the gender of the child, our results show a statistically significant difference in the family interaction subscale and in the overall FQoL, with higher satisfaction in mothers of girls. Dizdarevic et al. (2020) also found that families who had daughters with ID reported higher FQoL than families with sons. Miezah et al. (2024) reported the opposite. Finding only these two studies with these results, we accepted the explanation of Dizdarevic et al. that the differences between boys and girls were due to differences in the severity of behavioural difficulties leading to the differences in FQoL scores, but that cultural influences must also play a role.

No statistically significant differences were found in the subscales or the total FQoL score in relation to the age of the mother or the age of the children. In the study by Meral et al. (2013), FQoL did not depend on the age of the mother, but Alnahdi & Schwab (2024) found that younger mothers had higher FQoL. In the study by Boehm and Carter (2019), the age of the child did not correlate with FQoL.

Compared to parents of children without disabilities in Croatia (Užarević et al., 2025), the satisfaction of mothers of children with ID in our study is lower on all subscales and in overall FQoL. This was also shown by the results of an earlier study in Croatia (Kovač Mišura & Memišević, 2017) and Bosnia and Herzegovina (Dizdarevic et al., 2020).

The results of our study show that families of children with ID need additional support, especially emotional support. Although there are programmes in Croatia, the results show that they need to be strengthened.

All families who participated in our study received continuous support from the Centre for Rehabilitation Zagreb. By providing complex rehabilitation that focuses on the child and their family, with a holistic approach and team-coordinated support through family-oriented programmes, the Centre for Rehabilitation Zagreb offers the child the opportunity to achieve optimal developmental outcomes.

Counselling and involving parents in the interaction with the child strengthens parental competences to optimally support the child's development through daily routines and activities and to raise awareness of their strengths and needs (Matijaš & Bulić, 2021). The Centre runs the "Break from Care" project, which offers carers a break from the emotional and physical demands of daily care and support for children with developmental disabilities and/or people with ID. Support programmes for children with ID and their parents are also carried out in Croatia within the framework of associations of people with disabilities. The state supports families of children with ID through the Social Assistance Act, the possibility of obtaining caregiver parent status, partial integration programmes and the right to early intervention, but does not provide guidelines for monitoring the family's quality of life.

In many countries, service providers are encouraged to consider not only the goals for the client but also for their family members to ensure better FQoL outcomes (Wang and Brown, 2009; Bhopti et al, 2022). However, the 2023 indicator for inclusion in European countries shows that “many people with ID and their families also lack access to good services for people with disabilities.

Family members serve as supporters of people with disabilities, rather than simply being a family” (Inclusion Europe, 2023). As Mr Pinomaa, President of Inclusion Europe and father of two sons with severe disabilities, explained in an interview (Šveřepa, 2021): “We need proper support for families so that they don’t have to “choose” between devoting all their energy to one member or placing them in an institution. With the right support, families can be just that – families. Not full-time carers, therapists, administrators, organisers. There are no universal solutions – but there are universal principles: People are looking for human relationships, for stability. This must be the guiding principle of any support system. Independence and inclusion are achieved by respecting the needs of each individual and providing a range of personalised support”.

Our findings can guide policy makers and practitioners to consider the quality of life and well-being of carers alongside child-related goals, and that a good FQoL should be one of the goals.

4.1 Limitations of the Study

As the study was only conducted in a single institution, the data cannot be generalised. There is also the possibility of bias due to self-reporting and institutional recruitment. Furthermore, the data was only collected from one family member, the mother, as is the case in most other studies in this area. In addition, the study did not use data on the degree of ID and other socio-demographic data of the parents (such as education, employment, marital status, material income, etc.), which should also be considered in future studies.

4.2 Future Directions

Future research on FQoL of children with ID should also consider parents' stress levels and the impact of family relationships on other family members, coping mechanisms, intersectionality or the systemic policy context. Furthermore, the impact on practise might be limited to certain cultural contexts. Therefore, it is important to investigate how cultural differences affect FQoL, and a comparison of results between regions with similar and different cultural backgrounds could be considered in the future. Future research could use regression or mixed methods to identify the predictors of FQoL more robustly.

5. Conclusion

Although the overall quality of life is satisfactory, families of children with ID need support, especially regarding emotional well-being. Existing support programmes for parents of children with ID need to be intensified, involving all family members of a person with ID and thus ensuring the best possible quality of life for the family. FQoL should be one of the factors measured along with outcomes for the child. Service providers need to enable better inclusion and participation and work towards an inclusive society.

Conflict of interests

The authors have no conflicts of interest to declare.

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