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# Enhancing the Quality of Life of People with Intellectual Disabilities

From Theory to Practice



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# Chapter 9

## Differences in Variables Influencing the Ratings of Importance and Use of Quality of Life Domains and Indicators by Polish Services Users and Their Parents

Wojciech Otrebski

### Introduction

After 20 years of the socio-economic transformation, community-based services for people with ID in Poland are still in need for further development and improvement. The psychological category of quality of life seems to be one of the best suited for application in the process of building the new service delivery systems for various target groups, including people with ID (Bańka, 2005; Keith & Bonham, 2005; Kowalik, 2001; Oleś, 2002; Wołowicka, 2001). In the context of using the concept of QOL as the basis for developing and providing services for persons with ID, it seems crucial to analyse how service users and their parents evaluate the importance and use of QOL indicators. On one hand, these two groups are the first to benefit from improvements, and on the other hand, they exert an extensive influence on the way the services are provided (Jenaro et al., 2005; Otrebski, 2000, 2005).

### Method

#### *Participants*

The results of this chapter are a part of a larger community-based research project carried out in a range of both rural and urban settings in Poland (villages, major and minor towns) where contacts were made with 67 intellectually disabled service users (53.70% women and 46.30% men) and 73 parents (60.30% women and 39.70% men). The number of parents was bigger than that of intellectually disabled individuals since in six cases both parents filled up the survey questionnaires (Table 9.1).

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**Table 9.1** Demographic characteristics of the service users group

Variables	Frequency (f)	Percentage (P)
<i>Gender</i>		
Female	36	53.70
Male	31	46.30
<i>Age</i>		
16–20	18	26.90
21–25	14	20.90
26–30	16	23.90
31 or more	19	28.30
<i>Level of ID</i>		
Mild	35	52.20
Moderate or lower	32	47.80
<i>Multiple disorders</i>		
Not present	22	32.80
Present	45	67.20
<i>Place of living</i>		
Villages	17	25.40
Small towns	20	29.80
Big cities	30	44.70
<i>Family situation</i>		
Both parents	43	64.20
One parent missing	23	34.3
Married couple	1	1.80
<i>Number of siblings</i>		
No sibling	5	7.50
One	14	20.90
Two	19	28.40
Three or more	18	26.80
Missing data	11	16.40
<i>Economic well-being</i>		
Bad	1	1.50
Average	46	68.70
Good	20	29.90

The individuals with ID were in the age range from 16 to over 31 years. The level of intellectual disability was described as mild in 52.20% and as moderate or higher in 47.80%. The majority of the investigated service users (67.20%), suffered from other co-occurring disorders in addition to their intellectual disability. More than half of them (64.20%) lived with both parents. Approximately, 70% of the subjects described their family economic status as average and the remaining as good (Table 9.1).

Parents of the individuals with intellectually disabilities were aged 38 years and above. Approximately, the half of the parents sample were parents of children

**Table 9.2** Demographic characteristics of the parents group

Variables	Frequency (f)	Percentage (P)
<i>Gender</i>		
Female	44	60.30
Male	29	39.70
<i>Age</i>		
38–50	27	37.00
51–60	29	39.70
61 or more	17	23.30
<i>Level of child's ID</i>		
Mild	39	53.40
Moderate or lower	34	46.60
<i>Level of education</i>		
Primary school	11	15.10
Vocational school	25	34.20
High school	32	43.80
Diploma, undergraduate, or postgraduate	5	6.80
<i>Place of living</i>		
Villages	20	27.40
Small towns	21	27.80
Big cities	32	43.80
<i>Employment status</i>		
Employed	18	24.70
Retired/disability pension	45	61.60
Unemployed	10	13.70
<i>Economic well-being</i>		
Bad	9	12.30
Average	45	61.60
Good	19	26.10

with mild and moderate ID. The parents' education was at high school diploma (43.80%), vocational school (34.20%), primary school (15.10%) and undergraduate and graduate (6.80%) levels (Table 9.2).

### ***Survey Instrument***

The Cross-Cultural Survey on Quality of Life Indicators (Verdugo & Schalock 2001) was translated into Polish by the author. Two types of equivalence were established: conceptual and linguistic. The survey instrument is based on the 24 core indicators and eight QOL domains identified in the international QOL literature (Schalock & Verdugo 2002). For each of the 24 indicators, two sets of questions are asked which address both the importance and the use of a given indicator: (I) "How important is it (the indicator) for people with ID in your country?" And (II) "How

much is it used in services/supports received or delivered". A 4-point Likert scale is used to scale the response dimensions for both sets of questions:

- Importance: not important (1), not very important (2), somewhat important (3), and very important and
- Use: never (1), sometimes (2), frequently (3), always (4).

Two types of reliability were established: Cronbach's alpha coefficients ranged from 0.92 to 0.95 with the average of 0.94 ( $SD = 0.01$ ); split-half coefficients ranged from 0.84 to 0.92 with the average of 0.89 ( $SD = 0.03$ ). These values indicate high reliability, and are consistent with comparable studies (Jenaro et al., 2005).

### ***Survey Procedure***

First, the contacts were made with the respective service users and then their parents were asked to participate in the survey. Both groups were familiarized with the chapter's purpose and procedure. Generally, the groups demonstrated favourable attitudes towards the survey.

### ***Data Analysis***

The following statistical analyses were applied to the data. For the description of the depended variable, mean scores and standard deviations were calculated for each of the eight QOL domains based on the Likert ratings across the indicators for a given domain. These data were analysed through the use of *t*-tests or Mann-Whitney tests, parametric one-way ANOVA, and Kruskal-Wallis ANOVA, as suitable for the variables properties.

## **Results**

### ***Importance***

As shown in Tables 9.3 and 9.5, the evaluations of the importance of eight QOL domains were associated with different sets of variables in the group of the service users and in the group of their parents. The evaluations were significantly higher in the group of individuals with ID than in the parent group.

In the group of service users, the perception of the importance of interpersonal relationships, as indicative of their QOL, were associated with the level of intellectual disability and the place of residence. Subjects with mild ID and those living in big cities perceived this domain as significantly more important than those with moderate or lower levels of ID ( $p \leq 0.01$ ), and those living in villages and small towns ( $p \leq 0.05$ ). The evaluation of the importance of material well-being by the service users was related only to the place of residence, where, again, those living in



Table 9.3 Mean scores and standard deviations obtained by the service users in Cross Cultural Perspective Survey – part I

Table 9.3 Mean scores and standard deviations obtained by the service users in each category																						
Variables	Em. Well. – 2		Int. Rel. – 1		Mat. Well. – 1		Per. Dev. – 1		Phy. Well. – 1		Phy. Well. – 2		Self. Det. – 1		Self. Det. – 2		Soc. Inc. – 1		Right – 1		Right – 2	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
<i>Level of ID</i>																						
Mild			3.70*	0.72			3.61*	0.55	3.65**	0.40	3.16**	0.65	3.54*	0.44	2.77**	0.67	3.47*	0.61	3.63*	0.63		
Moderate or lower			3.30	0.59			3.10	0.72	3.40	0.58	2.84	0.61	2.95	0.81	2.46	0.62	2.95	0.68	3.19	0.83		
<i>Age</i>																						
16–20	24.78**	0.68					38.92**	0.47					43.92**	0.38								
21–25	36.29**	0.72					33.36**	0.53					26.11**	0.72								
26–30	44.56**	0.46					41.09**	0.56					37.34**	0.62								
31 or more	32.16**	0.59					23.84**	0.85					27.61**	0.85								
<i>Level of disability</i>																						
Mild							40.18**	0.62					42.25*	0.53								
Moderate							27.76**	0.74					30.28*	0.73								
Severe							33.63**	0.79					23.13*	0.79								
<i>Place of living</i>																						
Villages	20.76*	0.57	23.03**	0.81	32.50**	0.68			20.74**	0.63												
Small towns	37.35*	0.73	36.70**	0.57	25.00**	0.46			39.25**	0.44												
Big cities	39.27*	0.54	38.42**	0.45	40.85**	0.52			38.02**	0.35												
<i>Family situation</i>																						
Both parents									3.60	0.43												
One parent missing									3.82**	0.23												
<i>Number of siblings</i>																						
One	33.14*	0.39							34.11**	0.29											34.89*	0.68
Two	29.26*	0.48							26.11**	0.34											26.11*	0.59
Three or more	17.00*	0.63							19.58**	0.47											18.97*	0.58

\* $p \leq 0.01$ ; \*\* $p \leq 0.05$ .

**Table 9.4** Mean scores and standard deviations obtained by the service users in Cross Cultural Perspective Survey – part II

	I		II		III		IV		V		VI		VII		VIII	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
<i>Gender</i>																
Female	29.63	2.09							38.58*	2.03						
Male	39.08*	2.47							28.68	1.83						
<i>Level of ID</i>																
Mild			29.21	2.22					40.07**	2.02						
Moderate or lower			39.23*	1.97					27.36	1.74						
<i>Age</i>																
16–20																
21–25																
26–30																
31 or more																
<i>Multiple disorders</i>																
Not present					25.91*	2.43										
Present					37.96*	2.30										
<i>Place of living</i>																
Villages			44.00*	2.35												
Small towns			32.75*	1.74												
Big cities			29.17*	2.27												
<i>Level of disability</i>																
Mild									41.21*	2.06						
Moderate									27.09*	1.65						
Severe									32.71*	2.02						
<i>Family situation</i>																
Both parents																
One parent missing																
<i>Number of siblings</i>																
One					35.25**	1.65			17.43*	1.44	22.96*	1.70				
Two					26.37**	1.92			28.84*	2.08	33.61*	2.65				
Three or more					18.42**	2.22			29.67*	2.04	20.33*	2.71				

\*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$ .



**Table 9.5** Mean scores and standard deviations obtained by the parents in Cross Cultural Perspective Survey – part I

Variables	Em. Well. – 2		Int. Rel. – 2		Mat. Well. – 2		Self. Det. – 1		Right – 1	
	M	SD	M	SD	M	SD	M	SD	M	SD
<i>Gender</i>										
Female					2.45	0.77				
Male					2.84*	0.61				
<i>Level of the child's ID</i>										
Mild	3.26**	0.58	3.19*	0.63	2.76*	0.71	3.37*	0.59	3.49**	0.65
Moderate or lower	2.77	0.63	2.80	0.66	2.37	0.75	3.04	0.73	2.79	0.98

\* $p \leq 0.05$ ; \*\* $p \leq 0.01$ .

big cities assessed this domain as significantly more important than did those living in villages and small towns ( $p \leq 0.05$ ).

The possibility of personal development was evaluated as significantly more important for the description of QOL by the service users with mild levels of ID than by those with moderate or lower levels of ID ( $p \leq 0.001$ ). Similarly, this QOL domain assessed as significantly more important by the service users in the age range between 26 and 30 years as compared with the subjects from other ranges ( $p \leq 0.05$ ), and for those with mild levels of disability as compared with individuals with greater levels of disability<sup>1</sup> (moderate or severe) ( $p \leq 0.05$ ). The evaluation of the importance of physical well-being by the service users was again associated with the level of intellectual disability and place of residence but additionally with the familial situation and the number of siblings. For those who had mild levels of ID, lived in small towns, stayed with only one parent and had only one sibling this domain was significantly more important than for the others ( $p \leq 0.05$ ).

The differences in self-determination were found related only to three demographic variables characterizing service users: the level of ID, age and level of disability. For the service users with the mild levels of ID as well as for those with mild levels of disability this domain was significantly more important than for those with lower levels of ID and disability ( $p \leq 0.01$ ). A similar difference was observed between the service users in the age range of 16–20 and those from other age ranges ( $p \leq 0.05$ ). The evaluation of the importance of social inclusion and rights in the group of subjects with ID differed significantly with regard to only one demographic characteristic: the level of ID. Those individuals with mild ID assess them as more important than did the others ( $p \leq 0.01$ ).

<sup>1</sup> In Poland there are different classifications for levels of ID and for level of disability. In regards to levels of ID, Poland follows DSM-IV. Level of disability is assessed based on an individual's ability to live an independent life. Thus, although the names of the levels are the same (mild, moderate, severe), the constructs are measuring different criteria.

With regards to the evaluation of the importance of QOL domains for the parents group, only two of the domains were found to be associated with one demographic characteristic: the level of child's ID. For the parents of the children with mild levels of ID, self-determination and rights were significantly more important QOL domains than for the parents of children with greater levels of ID ( $p \leq 0.05$  and  $p \leq 0.01$ , respectively).

## *Use*

As presented in Tables 9.3 and 9.5, the service users and their parents' evaluations of the use were less differentiated than for the importance regarding their demographic characteristics. Differences were found in six domains for the individuals with ID and in three domains in the parents groups.

In the group of service users, the differences in the emotional well-being as an indicator of their QOL were associated with age ( $p \leq 0.05$ ), place of residence ( $p \leq 0.01$ ) and number of siblings ( $p \leq 0.05$ ). For those who were between 26 and 30 years of age, for those living in big cities, and for those who had one sibling, this domain was significantly more useful than for other groups of responders.

The differences in physical well-being and self-determination were found to be related to only one demographic variable characterizing the service users: level of ID ( $p \leq 0.05$  and  $p \leq 0.05$ ). Those with mild levels of ID perceived this domain as of significantly more use in service delivery than did those with moderate or lower levels of ID. For two other domains, social inclusion and rights, the associations were observed only with the number of siblings. These domains were seen as significantly more useful by those service users who had one sibling than by those with more siblings.

With regard to the evaluation of the use of QOL domains among the parents, three of the domains were found to be associated with the level of the child's ID, and one of these three domains was additionally associated with the parent's gender. Emotional well-being ( $p \leq 0.01$ ), interpersonal relationship ( $p \leq 0.05$ ) and material well-being ( $p \leq 0.05$ ) were rated as being of significantly more use by the parents of children with mild ID than for by the parents of children with moderate or lower levels of ID. Additionally, the last mentioned domain was rated by males as being used significantly more often as compared with females ( $p \leq 0.05$ ).

## *Ranks*

As a part of the Survey, each participant was asked to rank the eight domains with respect to their importance for the description of QOL for persons with ID (Tables 9.4 and 9.6). The findings from the service users indicated that:

- emotional well-being was ranked as significantly more important by male than female responders ( $p \leq 0.05$ ),

**Table 9.6** Mean scores and standard deviation obtained by the parents in Cross Cultural Perspective Survey – part II

	Emotional well-being		Interpersonal relationship		Material well-being		Personal development		Social inclusion	
	M	SD	M	SD	M	SD	M	SD	M	SD
<i>Gender</i>										
Female							30.44	2.06		
Male							46.95*	2.05		
<i>Level of child's ID</i>										
Mild					40.55*	2.26			40.88*	2.23
Moderate or lower					27.78	2.22			27.35	2.09
<i>Employment status</i>										
Employed			40.14**	4.22						
Retired/ disability pension	16.89**	3.11	28.74	2.98			17.31*	4.51		
Unemployed	10.20	1.80					9.45	3.00		
<i>Economical well-being</i>										
Average									35.56**	2.18
Good/very good									25.26	2.25

\* $p \leq 0.01$ ; \*\* $p \leq 0.05$ .

- interpersonal relationships were ranked as significantly more important by those with moderate or lower levels of ID ( $p \leq 0.05$ ) and by those living in villages ( $p \leq 0.05$ ) as compared with those with mild levels of ID and living in non-rural areas,
- the service users with multiple disorders gave higher ranks to the material well-being domain than those without ( $p \leq 0.05$ ), additionally, the highest ranks were ascribed to this domain by those having one sibling and the lowest ranks by those having three or more siblings ( $p \leq 0.05$ ),
- physical well-being was the domain associated with the biggest number of variables: the female service users, those with the mild levels of ID and disability, and those with two or three siblings evaluated this domain as more important than, respectively, the males ( $p \leq 0.01$ ), those with lower levels of ID ( $p \leq 0.01$ ) and disability ( $p \leq 0.05$ ), and those having one sibling ( $p \leq 0.05$ ),
- the service users having two siblings assessed the self-determination domain as more important than did the others (with one or three siblings) ( $p \leq 0.05$ ).

There were less statistically significant associations between the demographic characteristics and the domains ranks among the parents. The findings from the parents indicated that:



- emotional well-being was perceived as the domain most important for the evaluation of QOL in person with ID significantly more frequently by those parents who were retired or lived on disability pension than those who were unemployed ( $p \leq 0.05$ ),
- interpersonal relationships were viewed as important for QOL evaluation significantly more frequent by the employed parents than by those retired or living on disability pension ( $p \leq 0.05$ ),
- material well-being and social inclusion were two domains which were perceived as important for the evaluation of QOL in person with ID significantly more frequently by the parents of children with lower levels of ID ( $p \leq 0.01$ ); additionally, the importance of the second of these domains was associated also with the parents' economic status, were those who reported average financial conditions viewing this domain as more important than those who reported good or very good financial condition ( $p \leq 0.01$ ),
- personal development was the last domain whose rankings showed significant differences as a function of such variables as the parents' gender and employment status. The fathers and the parents who were retired or lived on disability pension perceived this domain as important for the evaluation of QOL in persons with ID more frequently than the mothers ( $p \leq 0.01$ ) and unemployed parents ( $p \leq 0.01$ ).

### ***Cross-Group Analyses: Importance, Use and Ranks***

Comparisons between the assessments of the eight QOL domains made by the service users and their parents revealed several significant differences (Tables 9.7 and 9.8). When evaluating the *importance* of the domains, the group of service users perceived two of them – material well-being and physical well-being – as significantly more important than the group of parents ( $p \leq 0.01$  and  $p \leq 0.05$ , respectively). With regard to the evaluations of the *use* of the domains by the service providers, social inclusion and rights were the two which service users perceived as significantly more important than their parents ( $p \leq 0.05$  and  $p \leq 0.01$ , respectively).

The analysis of the QOL domains *ranking* showed that there was only one significant difference between evaluations of the service users and their parents (Table 9.9).

**Table 9.7** Mean scores and standard deviations obtained by the service users and their parent in Cross Cultural Perspective Survey – part I (importance) and differences between the groups

	Em. Well.	Int. Rel.	Mat. Well.		Per. Dev.		Phy. Well.	Self. Det.		Soc. Inc.	Right	
	M	M	M	SD	M	SD	M	M	SD	M	SD	M
Parents	66.14	66.82	2.60	0.76	3.26	0.65	64.23	3.21	0.66	3.21	0.63	65.30
Service users	75.25	74.51	3.35*	0.57	3.37	0.68	77.34**	3.26	0.71	3.22	0.70	76.16

\* $p \leq 0.01$ ; \*\* $p \leq 0.05$ .

**Table 9.8** Mean scores and standard deviations obtained by the service users and their parents in Cross Cultural Perspective Survey – part I (use) and differences between the groups

	Em. Well.		Int. Rel.		Mat. Well.		Per. Dev.		Phy. Well.		Self. Det.		Soc. Inc.		Right	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
Parents	3.04	0.64	3.02	0.66	2.60	0.74	2.90	0.75	2.95	0.71	2.68	0.61	2.78	0.63	2.76	0.80
Service users	3.13	0.60	3.12	0.70	2.65	0.76	3.06	0.58	3.01	0.65	2.62	0.66	3.05*	0.71	3.11**	0.70

\*  $p \leq 0.05$ ; \*\*  $p \leq 0.01$ .

**Table 9.9** Mean scores and standard deviations obtained by the service users and their parents in Cross Cultural Perspective Survey – part II and differences between the groups

	Em. Well. M	Int. Rel. M	Mat. Well. M	Per. Dev. M	Phy. Well. M	Self. Det. M	Soc. Inc. M	Right M
Parents	68.73	71.92	65.97	67.84	69.67	69.56	63.64	73.98
Service users	72.43	68.96	75.43	73.40	71.40	71.52	77.98*	67.49

\* $p \leq 0.05$ .

The group of service users ranked the domain of social inclusion significantly higher in evaluating QOL in persons with ID than their parents did ( $p \leq 0.05$ ).

## Discussion

According to Schalock (2004), what we know and will continue to learn about QOL, specifically about its application to people with ID, can make a difference in both peoples' lives and in policies and practices that impact those lives. The results of the current chapter presented above may extend our knowledge about QOL. The results indicate that demographic variables play a significant role in differentiating the perception of the importance and use of some QOL domains among service users and their parents. This chapter also yielded a finding that there are certain differences between these two groups in this aspect.

All those who deliver the services/support to the individuals with ID and their families should be aware that perception of the importance and use of QOL domains may vary depending on such personal characteristics as: the level of ID, age, level of disability; and on such social characteristics as: place of residence, family situation, number of siblings. Among the parents of the individuals with ID, this variation appears to be associated with such variables as gender and the level of the child's ID.

Second, it would be useful for service providers to remember that ratings of the QOL domains among service users and their parents also fluctuate depending on demographic characteristics. For the persons with ID it may be gender, level of ID, multiple disorders, level of disability – as personal characteristics – and place of living and number of siblings – as social characteristics. In contrast, for the parents, it is only gender out of personal characteristics, and the level of the child's ID, employment status and economical well-being out of social variables that are associated with QOL domains ratings.

With regard to the well-known common wisdom that differences between generations always exist, we partially obtained empirical confirmation for this in the field of QOL. The differences between the service users and their parents were revealed with respect to two QOL domains in the case of the perception of importance and use of QOL domains, and with respect to one QOL domain in the case of ranking.



It may safely be concluded that the presented results of this chapter, similarly to the previously published work by Keith and Bonham (2005) enrich our knowledge about the possibilities of the application of QOL concepts into organizations that provide services for people with ID and their families.

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