

## The prerequisites for QoL of people with intellectual disabilities

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Quality of life (QoL) is seldom described in terms of the essence of what it is. Also, an essential task for the research community is to create space for the voices of people with intellectual disabilities. The aim of the present study was to understand the lived meaning and the essence of QoL in adults with this disability. Using a phenomenological approach, 21 informants living in a Swedish county were interviewed. The interviews were audio taped and analyzed with the empirical phenomenological psychological method. The results indicate that the general essence of QoL consists of well-being and five themes: social adult status, control of life, personal safety, social belonging and self-chosen solitude. The results challenge the stereotype of the informants as passive receivers of support from others. The interrelatedness between the five themes of QoL should be further studied.

**Keywords:** quality of life; intellectual disabilities; adult; phenomenology

### Introduction

Empirical studies describing the essential features of quality of life (QoL) from the perspective of people with intellectual disabilities are scarce. Typically, research on QoL focuses on core domains and indicators (Verdugo et al. 2005) and many reliable and valid quantitative scales are referred to in the literature. Less common are conceptual models and theories of what QoL is, i.e. the essence without which the phenomenon ceases to be what it is. There is a need for theoretical models to advance our understanding of the phenomenon of QoL and to provide informed advice to practitioners (Cummins 2005).

Although there is no consensus definition, QoL always seems to be referred to as something judged as good. Furthermore, QoL is considered a multifaceted concept having both universal- and cultural-bound properties (Jenaro et al. 2005). The IASSID Special Interest Quality of Life Group (SIRG-QoL) suggests that QoL may be conceptualized as a construct that:

- (1) is multidimensional and influenced by personal and environmental factors and their interactions;
- (2) has the same components for all people;
- (3) has both subjective and objective components; and
- (4) is enhanced by self-determination, resources, purpose in life, and a sense of belonging. (Cummins 2005, 700)

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Because of the impairment, people with intellectual disabilities typically have a lifelong need of support in everyday life. They are still a group in society with limited influence on their own life situation (Wehmeyer, Bersani, and Gagne 2000). Furthermore, previous research indicates that, although living in the society like other citizens, people with intellectual disabilities in Sweden have worse living conditions than the population on the whole (Umb-Carlsson and Sonnander 2005). Thus, it may be argued that descriptions of quality of life need to be adapted to the atypical life circumstances of many people with intellectual disabilities (c.f. the necessity of adapting traditional living conditions approach in studies of people with intellectual disabilities, see Tøssebro 1998). In a study that investigated variation in perception, differences between people with intellectual disabilities and other groups (i.e. family members, staff members and residence managers) were identified (Holburn et al. 2008). The authors concluded that an understanding of QoL for people with intellectual disabilities has to include the view of people with intellectual disabilities. Therefore, an essential task for the research community is to create space for the voices of people with intellectual disabilities.

In this study we sought to understand the lived meaning of QoL in adults with intellectual disabilities, even though the individuals are not explicitly aware of these lived meanings. The informants with intellectual disabilities were not required to introspect into their cognitive processes to understand what they experienced. It is assumed that when people experience QoL they grasp its essence. The objective is to trace the general essence of QoL by understanding the structure of the phenomenon from the individual's perspective.

## **Method**

### ***Phenomenology***

To study the essence of the phenomenon of QoL from the perspective of people with intellectual disabilities a qualitative approach inspired by phenomenology was used. Phenomenology, which was founded by Edmund Husserl, is a theoretical philosophical movement dealing with the essences of phenomena as they present themselves in human consciousness. Later Husserl's thoughts were developed as an empirical method to study different phenomena in our life-world (Giorgi 1997; Karlsson 1995; Manen 1997). The aim of phenomenological research is to elucidate the structure and meaning of the phenomenon of interest. The ambition in the present study is to understand QoL as faithfully as possible from the perspective of people with intellectual disabilities.

### ***Informants***

The study was carried out in a Swedish county that included urban as well as rural areas. Informants were selected from the population of individuals with intellectual disabilities born between 1959 and 1974 in Uppsala County and registered at the former Board for Provision and Services for the Mentally Retarded in 1974. A criterion for the selection was that the informant could communicate her or his experiences of life quality to the interviewer. In order to obtain rich descriptions, informants with various life situations (gender, age, functioning limitations, civil status, ethnic background, housing, etc.) were included. Twenty-three adults were

invited of which 21 (11 women and 10 men) agreed to participate (Table 1). The informants were classified during childhood as having moderate or mild intellectual disabilities. The level of intellectual disabilities in adulthood was not assessed. Additional impairments were epilepsy, cerebral palsy, vision impairment and hearing impairment. Half of the group previously experienced living in residential institutions.

**Procedure**

Data collection, in the form of interviews, was carried out by the first author (Öie Umb-Carlson) from February 2007 to June 2007. The informants participated with their informed consent. The study was approved by the Ethical Committee at the Faculty of Medicine at Uppsala University.

Each informant chose the time and place for the interview. All interviews but one were conducted in the informants' home. The duration of the interviews which were audiotaped ranged from 0.75h to 1.5h. The informant was encouraged to contact the interviewer after the interview if any particular thoughts were raised by the interview.

The interviews were semi-structured and designed to allow each informant to tell her or his lived experience of QoL. QoL is seen here as a good life. The first question was global, asking the informant to give his or her view of the good life. Subsequent

Table 1. Characteristics of the informants (n = 21).

Characteristics	Women n = 11	Men n = 10
Age (years)		
Mean	39.7	41.9
Range	33–48	36–47
Level of functioning limitations <sup>a</sup>		
Mild	1	6
Moderate	8	2
Severe	2	2
Housing		
Independent living	2	3
Parents home	0	1
Group home	9	6
Occupation		
Sheltered employment	1	
Daily activities <sup>b</sup>	10	9
No occupation		1

<sup>a</sup>Functioning limitations were in adulthood estimated on eight variables: understanding language (verbal, sign or alternative communication), use of language, ability to read/write, ability to tell time, need of assistance at meals, need of assistance with personal care, need of assistance when dressing and need of assistance outside the home.

<sup>b</sup>Daily activities is a service under the Act on support and service for persons with certain functional impairments (SFS 1993:387) and include sensory experiences as well as productive activities such as industrial tasks, handicraft, work at a café or gardening.

questions and probes emanated from the answers, to reveal the subjective views and descriptions of lived QoL as portrayed in the informants' story.

An interview guide was developed in order to elicit wide-ranging and in-depth responses and to make sure that all interviews explored experiences in housing, employment and daily activities, recreation and culture, community participation, social relations and personal safety. Other domains (health, lifestyle and education) were initiated by the informants as essential and hence were included in the analyses.

### **Data analyses**

The interviews were audiotaped and transcribed by the first author (Öie Umb-Carlsson). The analyses were based on examination of the transcripts from 21 interviews. Following the empirical phenomenological psychological method (the EPP method) developed by Gunnar Karlsson (1995), essential themes were identified. The EPP method is composed of five analytic steps: (1) reading through the transcription to gain a good understanding of the text, (2) dividing the text into meaning units, (3) transforming each meaning unit into the language and perspective of the researchers (from the informants' perspective), (4) synthesizing the transformed meaning units into a situated structure (what QoL is), including the process (how QoL is lived), and (5) moving from the situated structure to a general structure in order to reflect on a more abstract level.

Throughout the analytic process, retrospection of the original transcripts were made. In order to be as open as possible to the phenomenon of QoL as it appears to people with intellectual disabilities, an attempt was to eliminate all presuppositions, theories and ideas about QoL (Karlsson 1995). In this study, the two researchers performed all steps individually. Divergent interpretations were discussed until consensus was reached.

## **Results**

### **Description of quality of life**

The transcripts will be referred to using a specific transcription number. The index (W = women or M = men) indicates the gender of the informant. When translating the transcripts, the intention was to catch each individual's way of expressing her- or himself. Thus, some passages may be poorly written and contain numerous errors of grammar, punctuation and word use.

The general structure found in the analysis will be presented and discussed in terms of a general essence (*what*) and five themes (*how*) constituting the essence. The description of QoL as identified in the analyses is depicted in Figure 1.

### **Well-being**

The general essence running through all the interviews is that QoL is to experience emotional, physical and social well-being. Thus, the analyses indicate that subjective well-being is an essential component characterizing QoL. The analyses answer the question *what* is QoL. According to the informants, well-being is closely linked to objective aspects of welfare, particularly living conditions, and applies to the subjective experience of these conditions. However, well-being goes beyond living

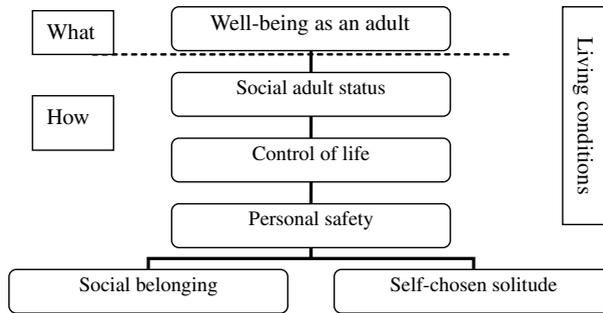


Figure 1. The description of QoL as identified in the analyses.

conditions, encompassing satisfaction with life as a whole, which was expressed in terms of feeling good and the fulfilment of needs in everyday life. As mentioned above, the experience of well-being consists of five themes. These five themes include subjective and objective factors and express themselves in relation to a number of life areas of importance for each individual: housing, employment and daily activities, finance, transportation, recreation and culture, health, lifestyle, education and community participation.

### ***Social adult status***

Although the informants had their own unique social living situation, they expressed that being viewed as an adult is a determining prerequisite for the experience of well-being. The attitude of staff personnel and family members was particularly important. According to the informants, it was important to carry out everyday matters and coming up to their own expectations as well as to those of staff and family members:

- W01: ... as far as possible one should manage by one's own.  
 I: Hmm  
 W01: If not, you aren't looked upon as anybody. Failing managing anything I would not like to live here. All my life, I would not like to live with my mother.  
 I: No?  
 W01: Before, before my mother does not exist anymore, I would like to manage as much as possible by my own.

The analyses indicated that social adult status requires objective living conditions typical for adults, such as having a job and earning an income and practicing age-adequate recreational activities. Having a home of one's own and the possibility of co-habiting with a partner are other ways of fulfilling the role as an adult. Furthermore, the informants spoke about subjective experiences, including being regarded as a citizen equal to other adults:

- M01: ... he is my cousin, he is a listener, one can talk to him, he is glad and positive to me. He told me: you are an ordinary man.  
 I: Yes?  
 M01: That is good to hear. Yes, you are an ordinary man, you too, M01.

I: What is it like to be an ordinary man?

M01: One feels glad. Happy, happy.

To be treated as an adult increased self-confidence. A woman exemplified her experience of being viewed as an adult by her involvement as storekeeper in a sports team:

W02: And we are in the players' box [during league matches]. I have been in the box this year. They call out my name because we are leaders, we storekeepers. And Rolf and Arne are leaders for the team, telling the players how to play. So, we don't handle that, but water and all that stuff and medical articles if someone gets hurt.

I: I see.

W02: and we use to help, we help, they give they say I have a good hand and I am really praised.

In contrast to this experience of being on equal terms with other leaders of the team, the woman experienced injustice and inequality in working life. Whereas her fellow workers had paid employment, her main sources of income were a disability pension and housing allowance from the social insurance system. Although being praised for her working performance, differences in sources of income and level of income indicated that she was not fully included in the staff community and thus not equal to other adults in the workplace. This decreased her experience of well-being in working life.

The analysis indicate that to have a social adult status requires control on everyday matters and a possibility of choosing one's own life course:

I: What is good about that [having a social adult status].

W03: It is [pause], it is the thing itself. Yes [pause], I can decide for myself.

### *Control of life*

According to informants QoL is to experience control of life, i.e. to be master of the everyday life and to live a life according to one's own values and preferences. It has to do with deciding and acting in everyday life. For example, a prerequisite of control of life is to have the possibility to act if being treated with disrespect by staff members:

I: Hmm. Why did you move to another group home?

W05: They [staff] talked rubbish and harped on me.

For example, control of life is the opportunity to choose to engage in activities where one requires assistance:

I: Did they accompany you when you travelled by air?

W03: Yes.

I: I see.

W03: Myself I cannot manage.

I: Hmm.

W03: And when going by train and all that.

I: Hmm. There is someone accompanying you when are going somewhere?

W03: Yes.

When travelling, the woman relies upon others but she emphasizes that it is her decision whether she can manage without help or not.

Environmental factors may both facilitate and hamper the ability to choose leisure and cultural activities. Informants emphasize that such activities contribute to QoL. One man argued that politicians made a show of expensive public buildings for cultural events at the sacrifice of people with disabilities:

M02: And I believe that they raised the price of mobility service partly and to build that [a new concert hall].

Increased expenses for everyday life (mobility service, technical aids, the apartment in a group home, pharmaceuticals, etc.) prevented him from participating in social activities and thus decreased his experience of QoL. The man wanted to discuss with politicians financial and other environmental barriers for community participation of people with disabilities but limited self-efficacy and lack of support prevented him from contacting these people:

M02: I don't know if I dare that, but I need someone supporting me. I don't dare to phone a politician without having support.

Further, to be dependent on others may inhibit participation in social activities with friends. With Easter approaching, a man wanted to join his fellow workers for lunch. Because he had no cash, he wanted to withdraw some money from his bank account. However, he had not access to the bank account himself but was obliged to ask his trustee for permission and help in making bank transactions. With only a couple of days before Easter, he still had not succeeded in contacting his trustee, and consequently, was anxious about not being able to participate in the lunch. Lack of control and no opportunity to act decreased the experience of QoL.

In concordance with previous research (Lachapelle et al. 2005; Bertelli and Brown 2006), informants considered self-determination to be a condition of control of life and highly related to QoL. Wehmeyer and colleagues (2000) reasoned that skills and opportunities are equally important in achieving self-determination and emphasized the need to listen to people with intellectual disabilities when determining what is or is not self-determination. In the current study a difference in meaning of self-determination was identified in the transcripts. Some informants put self-determination in relation to the entire life situation and life course, whereas others confined self-determination to everyday matters. In addition, when choices are to be made, some informants experienced self-determination when staff members and parents presented a few alternatives, whereas others argued that self-determination implies having knowledge of all possible alternatives.

### ***Personal safety***

As shown in Figure 1, the analyses indicate that control of life is conditional on the experience of personal safety. According to the informants, environmental factors (such as adequate medical and social services and support) contribute to the experience of personal safety in everyday life. Previous studies suggest that well-being involves being in good health (Helliwell and Putnam 2004; Goode 1994). In the present study informants relate good health to the absence of aches and pain.

Adequate social support includes formal and informal assistance in everyday life, in housing, at work, with finances and outside the home. One informant said that she was afraid of being alone outside the home when it was dark. She based this fear on the fact that staff and parents told her the dangers of being outside alone at night:

- I: But if you want to go out in the evening, is there someone accompanying you?  
 W05: Yes, the staff.  
 I: Staff working in the group home?  
 W05: Mm.  
 I: Aren't you afraid then?  
 W05: No.

A prerequisite for well-being is feeling secure in the privacy of your own home. A safe and secure home is the kind of home a person wants, a home she or he has chosen and one based on individual preferences. To have private belongings makes an apartment cosy and safe but naturally private safety goes beyond physical shaping. Informants emphasized that personal safety requires that neither the service organization nor staff members nor parents should decide matters concerning when to move and place of living; rather, the person with an intellectual disability should make such decisions:

- M01: I will go and see the staff today.  
 I: I see?  
 M01: I'm going to ask them if it is all right for me to stay on here. I want to live here still.  
 I: I see, do staff decide if you have to move or not?  
 M01: Yes.  
 I: If you can stay on here or not?  
 M01: Yes.  
 I: Where will you move if you are not allowed to stay here?  
 M01: I don't know. If it will be far from here [pause] I can't stay at my job [pause] then my friends will miss me.  
 I: I see. Will you miss your friends?  
 M01: Yes, will miss them I.  
 I: Do you want to live here still?  
 M01: Yes.  
 I: Are you allowed to do that?  
 M01: I don't know. I will talk to the staff.  
 I: When will you know if you can stay here?  
 M01: I don't know.

The man (M01) expresses that absence of influence regarding whether to move involves insecurity and decreased well-being. Influence in everyday chores, irrespective whether one is able to manage without help, and continuity in staff support are other elements contributing to the experience of personal safety in the private home. In addition, personal safety requires self-determination regarding who has the right to attend the private home, including friends and staff members.

To have significant others for support is strongly associated with well-being (Helliwell and Putnam 2004). In the extract below, M04 talks about a family member contributing to personal safety in situations when staff members let him down:

- M04: She [a fellow worker at daily activities] only fights and kicks.  
 I: Can you tell the staff, your staff at work or

- M04: Yes [pause] but they say I slander.  
I: I see.  
M04: Anyway, instead I'm going to call my ma [pause] because ma knows a neighbour well acquainted with Ann [the woman being rude to M04].  
I: Mm.  
M04: So, first, I'm going to call ma. Tomorrow I will call.

However, it may also be the other way around. Staff helped M05 to inform his mother that he had applied for an apartment in a group home in another city:

- M05: Staff in work helped me.  
I: Yes?  
M05: Yes, post, post the welfare officer mailed a letter to my mother. How it is going to be at home. They would say you must not move, you must not move. It's not their business.  
I: Mm.  
M05: Because they, they the welfare officer mailed a letter to my mother, to tell her, I don't dare telling her.  
I: No?  
M05: No. They believe, I'm going to stay on here for the rest of my life. I want to move out. I don't want to live here forever.

### ***Social belonging and self-chosen solitude***

The fourth and fifth themes that emerged from the analyses deal with interaction with other people and may be seen as two sides of the same coin. According to the informants, social belonging and self-chosen solitude are two themes establishing a foundation upon which well-being is experienced and lived. The importance of social capital and social belonging is also documented in previous studies (Helliwell and Putnam 2004). In the current study informants listed a number of experiences that contribute to a sense of social belonging, including mutual state of dependence and fellowship, to be invited at family get-togethers and celebrate eventful days, have a fiancée, living together and community participation. Thus, social belonging is not restricted to 'physical integration' but comprehends interdependence, participation in other people's lives and to be appreciated and welcomed by significant others:

- W07: It is the four of us at the same table [at the work place]  
I: Mm, working together?  
W07: Yes.  
I: Mm. Generally, are you happy when meeting with them?  
W07: Yes, they are happy when catching sight of me.  
I: They are?  
W07: Yees, they miss me often [W07 has been on the sick leave for several months].

When discussing their social life, informants did not distinguish between informal and formally based relationships. From the interview protocols, both types of relationship seem to be important and contribute to well-being. In addition, domestic animals seem to add to a feeling of togetherness, sometimes in compensation for an absence of social networks and of social relationships.

Furthermore, informants addressed the issue of physical impairment, as a barrier to fulfil dreams of a partner or to spontaneously visit a partner:

M02: If a woman knows I need a lot of practical help, she might not want to be with me [M02 has a severe physical impairment].

W01 reported that the mobility service had to be ordered in advance, so spontaneous meetings with her fiancée were not possible. In addition to social interaction with significant others, a salient feature of well-being is an opportunity to be alone, i.e. self-chosen solitude. If solitude is to be experienced in a positive manner, accessibility, technical aids and support and people being available if needed are necessary conditions. For example, to have an afternoon nap, to watch TV, to read books, to have a cup of coffee, to go fishing, to go for a walk and other recreational activities, may require accessibility, assistive technology or support. In particular, informants who had experienced living in a residential institution emphasized that self-chosen solitude contributed to well-being.

### **General discussion**

The study is an attempt to examine the phenomenon of QoL at the individual level and from the perspective of people with intellectual disabilities. It is useful to gain insight into how people with intellectual disabilities speak about the good life as conscious actors in their own life with preferences and goals that they strive to attain. In addition, the approach is a change in focus from a traditional group-perspective viewing people with intellectual disabilities as a group with homogenous needs to an individual perspective. Thus, the study challenges the traditional historical view emphasizing intellectual disability as the most important identity. A qualitative research approach lends itself to strong internal validity because it obtains information of social life unfiltered through concepts, operational definitions and scales (Taylor and Bogdan 1984). Nevertheless, some methodological issues need to be addressed.

The attempt to describe the structure of the phenomenon of QoL from the perspective of people with intellectual disabilities is certainly difficult. A number of problems in self-reports from people with intellectual disabilities have been identified and reported in the literature (Matikka and Vesala 1997; Finlay and Lyons 2001, 2002; Perry and Felce 2002). Nevertheless, it is argued that whenever possible, information should be provided directly from the persons themselves (Holburn et al. 2007), particularly regarding subjective issues such as definitions of QoL (Goode and Hogg 1994) and experiences of QoL (Cummins 2002; Perry and Felce 2002). In the present study the aim was to obtain a personal account of lived experiences, values and feelings, i.e. subjective issues.

Both of the present authors have long, professional experience in providing service and support to people with intellectual disabilities; social work and education (Umb-Carlsson) and occupational therapy (Lindstedt). In addition, the principal author has much experience in interviewing people with intellectual disabilities. One advantage of this experience was that it allowed good communication with the informants. On the other hand, such experience may pose a risk for preconception. Because pre-understanding should be eliminated in EPP analysis, and in order to secure credibility, the protocols were also analyzed by the second author who had little experience in interviewing persons with intellectual disabilities. Divergent interpretations were discussed until consensus was reached.

The general essence of QoL from the perspective of people with intellectual disabilities is to experience well-being. The connection between QoL and well-being is commonly acknowledged and well documented in the literature (Goode 1994; Albrecht and Devlieger 1999). In the current study informants' experiences of well-being and QoL are complex and encompass a figure that includes five themes (Figure 1). The analyses indicate a hierarchical structure of the themes. However, further studies are needed to validate the figure, i.e. to verify or falsify the themes and the relations or non-relations between them.

Figure 1 has much in common with previous theories and conceptualizations of well-being and QoL in relation to the general population. The Finnish sociologist Erik Allardt (1993) distinguishes between level of living and QoL in his discussion of welfare components. Level of living is described by the term *Having* and includes physiological needs and resources, such as health, employment and housing, which in the current model correspond to living conditions. Allardt describes QoL in terms of *Loving* and *Being*. In the current model *Loving* corresponds closely to the theme *Social belonging*. *Being* includes the opportunity of personal development, to influence one's own life course and to be respected and treated as an equal. In the present model *Social adult status* and *Control of life* correspond to the category *Being*.

Furthermore, there are similarities between the current QoL model and the way in which the SIRG-QoL group conceptualizes the phenomenon (Cummins 2005). QoL is influenced by environmental factors, has both objective and subjective components and is highly responsive to the social relationships the individual enters in different settings. However, the findings suggest that people with intellectual disabilities may address some components somewhat differently compared with people without intellectual disabilities, which is particularly evident regarding *Social adult status* and *Control of life*.

*Social adult status* is considered self-evident for adults in the general population, but not so for people with intellectual disabilities. Informants spoke about social adult status as something desirable and necessary for the experience of QoL. However, typically staff members and parents were authorized to define what is meant by an adult life and what is suitable. Referring to the argumentation by Jingree and Finlay (2008) regarding the concept 'bounded employment', the phenomena may be named '*bounded adulthood*'. Others deciding the norms for adult life may be interpreted as '*adult-less*' adulthood. The concept was coined by the authors to illustrate that the individual is regarded as 'a child in an adult body' and who is deprived of adult status and responsibility. Previous research indicates that there is a tendency to view people with intellectual disabilities as eternal children (Barron 2002; Riddell, Baron, and Wilson 2001; Wehmeyer and Metzler 1995). In some instances, adults without intellectual disabilities may laugh if treated as children by their aged parent and it is unspoken that it is a sign of consideration and not to be taken literally. However, this is typically not the case of parents and staff members treating people with intellectual disabilities as children, which may have complex underlying causes. The view of people with intellectual disabilities as adult-less adults illustrates the marginalization and the tenuous nature of citizenship for people with intellectual disabilities (Riddell, Baron, and Wilson 2001). In the present study informants expressed that QoL includes receiving help and support when needed but also giving help and support to others. This finding challenges the stereotype of people with intellectual disabilities as passive receivers of support from others. Informants resist the adult-less status and expressed that QoL involves being included in the adult

community and performing different social roles, including being a citizen, worker, friend, sibling and co-habitué. It is necessary to draw attention to this issue to staff and professional training, in service delivery systems and in the research community.

The relation between self-determination and QoL has been demonstrated in a number of studies (Lachapelle et al. 2005; Zhang, Wehmeyer, and Chen 2005). It has been suggested that empowerment of people with intellectual disabilities often appears to come into conflict with routines, practices and policies of service (Jingree, Finlay, and Antaki 2006; Rapley and Antaki 1996). It may be argued that people with intellectual disabilities are allowed to exert influence and self-determination as long as their choices fall within what staff and parents consider being in the best interest of the person in question, i.e. 'bounded empowerment' (Jingree and Finlay 2008). *Bounded empowerment* not only provides staff members and parents a position of control over the life situation of people with intellectual disabilities but also enables them to ensure personal safety and support when these are needed. In the present study the opinions of the informants were found to differ as to whether bounded empowerment decreases or increases well-being and QoL. Thus, a necessary task for future research is to problematize the matter of bounded empowerment.

Although in the past few years scientific interest in QoL has shifted from theoretical issues to ways of measurement, much remains to learn about this complex and multifaceted concept. The current model enhances our understanding of QoL by including the perspective of persons with intellectual disabilities. The present results indicate that the phenomenon of QoL is made up of five hierarchically formed themes. To explain the interrelatedness and balance between these building components further studies are needed. In addition, research on other vulnerable groups would be useful in order to determine whether the model is supported and whether the same essence and themes emerge.

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