# STRUCTURE AND VALIDATION OF A CONTEXTUAL QUALITY OF LIFE SCALE FOR PEOPLE WITH INTELLECTUAL DISABILITIES IN SOCIAL SERVICES: AN ORGANIZATION-ORIENTED MEASURE FROM AN EXTERNAL PERSPECTIVE

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***Abstract***

*The aim of this study is to develop and validate a scale on the Quality of Life (QoL) of people with intellectual disabilities as assessed by family members (external perspective). The instrument measures improvement in QoL due to actions by organizations delivering services to individuals with intellectual disabilities (organization-oriented measure). In order to design the items for the scale, focus groups were set up with professionals dedicated to attending to individuals with intellectual disabilities. An initial scale of 20 items was constructed by consensus. A total of 1195 family members answered the questionnaire. In order to assess the structure of the scale, EFA recommended deleting 3 overlapping items. The final scale consisted of 17 items ($\alpha$=95) and was composed of four main dimensions: self-determination (SD), social inclusion (SI), rights (RI) and overall improvement (OI), which explained 74.83% of the variance. Finally, the consistency and validity were assessed. Convergent validity and discriminant validity were satisfactory. Moreover, CFA confirmed the structure of the scale. Main conclusions, limitations and practical implications are discussed.*

***Keywords:*** *Family members. Intellectual disabilities. Quality of Life (QoL). Scale validation.*

## ESTRUTURA E VALIDAÇÃO DE UMA ESCALA DE QUALIDADE DE VIDA DAS PESSOAS COM DEFICIÊNCIA INTELECTUAL EM SERVIÇO SOCIAL: MEDIDA DE ORGANIZAÇÃO ORIENTADA EM PERSPECTIVA EXTERNA

O objetivo deste estudo é desenvolver e validar uma escala sobre a Qualidade de Vida (QV) de pessoas com deficiência intelectual, tal como avaliado por membros da família (perspectiva externa). O instrumento mede a melhoria na qualidade de vida devido a ações de organizações que prestam serviços a pessoas com deficiência intelectual (medida de organização-orientada) . Para projetar os itens para a escala, grupos de discussão foram criados com profissionais dedicados ao atendimento de pessoas com deficiência intelectual. Uma escala inicial de 20 itens foi construída por consenso. Um total de 1.195 membros da família responderam ao questionário. A fim de avaliar a estrutura da grelha , EFA recomendado exclusão 3 sobrepostos itens. A escala final foi composta por 17 itens ( α = 95 ) e foi composto por quatro dimensões principais: a autodeterminação ( SD ) , inclusão social (SI) , os direitos ( RI) e melhoria geral (OI ), que explicou 74,83 % da variância. Finalmente, a consistência e eficácia foram avaliados. Validade convergente e validade discriminante foram satisfatórios. Além disso , CFA confirmou a estrutura da grelha . As principais conclusões , limitações e implicações práticas são discutidos.

**Palavras-chave:** Membros da família. Deficiência intelectual. Qualidade de Vida (QV). Validação da escala.

## 1 INTRODUCTION

Currently, there are more than 4 million people with disabilities living in Spain (Spanish Confederation of Organizations for Persons with Intellectual Disabilities; FEAPS, 2010), and a similar proportion of people with disabilities must live in other countries. People with intellectual disabilities have the right to live their lives with dignity and freedom within modern societies. In other words, they have the right to enjoy their Quality of Life (QoL). However, there are still obstacles to their QoL in societies, which means that it is imperative to make progress toward improving it.

In general terms, present-day societies make efforts to improve the integration and QoL of people with intellectual disabilities. Legal initiatives have been developed around the world (e.g., Individuals with Disabilities Education Improvement Act of 2004, USA; Spanish Dependent's Law, MTAS, 2006). Relevant institutions also emphasize the importance of QoL for individuals with intellectual disabilities (e.g., American Association on Intellectual and Developmental Disabilities & The ARC, 2008; Spanish Confederation of Organizations for Persons with Intellectual Disabilities, FEAPS & Alcalá Declaration, 2013).

Organizations that provide services to people with intellectual disabilities also contribute to developing their QoL (FEAPS, 2010). There are different types of organizations (e.g., day care centres, occupational centres) where professionals and paraprofessionals deliver services designed to foster the QoL of individuals with intellectual disabilities (MARTÍNEZ-TUR; PEIRÓ; MOLINER; POTOCNIK, 2010). These organizations become a fundamental source of QoL for people with intellectual disabilities.

Given the importance attributed to the QoL of individuals with intellectual disabilities, scholars have developed instruments to assess this specific construct or some of its facets (e.g., FIELD; HOFFMAN, 2007; SCHALOCK; VERDUGO, 2002, WEHMEYER, 2000). All of these measures, however, focus on QoL in general. The present study, in contrast, develops and validates an organization-oriented instrument. This contextual approach evaluates the degree to which QoL improves due to the actions and activities of organizations (e.g., day care centres, occupational centres) delivering services to individuals with intellectual disabilities. In these organizations, the quality of the service delivered by the professionals is related to the QoL of users (MARTÍNEZ-TUR et al., 2010). This type of measure allows a specific evaluation of effects of organizational actions on QoL, offering opportunities to re-orient organizations' activities in order to improve the QoL of individuals with intellectual disabilities.

At the same time, previous instruments have focused on measuring QoL from the professional's perspective (e.g., SCHALOCK; VERDUGO, 2002). However, there are other key stakeholders who are actively involved in the process of enhancing the QoL of people with intellectual disabilities and can provide rich information. For example, the family members play an external but involved role within organizations oriented toward providing services to people with intellectual disabilities.

The aim of this study is to develop a specific scale for measuring the QoL of people with intellectual disabilities who receive a service from a professional organization specialized in providing services to people with intellectual disabilities. In developing and validating a QoL scale for persons with intellectual disabilities, we extend previous efforts. Our measure provides an organization-oriented evaluation, as the scale considers the actions taken by the organization to develop the QoL of people with intellectual disabilities. The measure is designed to assess the QoL of people with intellectual disabilities as perceived by their family members. Using family members as the main evaluators to assess the QoL of the persons with intellectual disabilities increases the objectivity of the information because it comes from an external subject. Using a sample of family members of persons with intellectual disabilities allows us to develop and validate a QoL scale for this collective that can complement previous scales. This effort enriches the information related to the QoL of this collective, in order to better evaluate the effectiveness of service quality practices in enhancing QoL, and guide future strategies for their improvement.

## 2 THEORETICAL BACKGROUND

### 2.1 Quality of Life

The World Health Organization (WHO, 1994) defines QoL as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns" (WHOQOL, 1997, p. 1). QoL exists when each person perceives that he/she lives with dignity, feels that his/her dreams are respected, can express his/her interests and opinions, and is an active agent in his/her own destiny (TAMARIT, 2002).

The study of QoL becomes complex because of at least two main characteristics of the construct: the *multi-dimensionality of the concept definition* and its *dynamic nature*. The first issue concerns the concept of 'life' itself. Life involves different domains, such as physical health, social relationships, work, family, etc. Thus, QoL is a multi-domain concept composed of different facets, and a person can rate each facet of life at a different level of quality. Accordingly, a high variability in the quality of the different domains of life impacts the complexity of measuring the construct. The second issue is that QoL is a changeable concept with no limit to its fulfilment (SCHALOCK, 1996). In other words, QoL changes over time depending on personal development, and it never reaches a maximum degree of plenitude. Each person has a hierarchized system of beliefs about what QoL is, depending on his/her beliefs and expectations of achieving his/her vital goals. At the same time, maintaining a specific level of quality of life over time can become a complicated phenomenon (KIERNAN; MARRONE, 1997). Hence, QoL is complex because it has a dynamic nature.

In addition, the literature presents three different approaches to QoL, as it can be conceptualized as an objective or subjective or mixed construct (FELCE; PERRY, 1995). Quality of life as objective conditions is a composite of more or less objective and measurable features, such as physical and psychological health, personal circumstances (e.g. wealth), social relationships, functional activities, and other general economic and societal features (e.g. LANDESMAN, 1986). QoL as satisfaction with life conditions reflects the subjective nature of the concept (e. g. EMERSON, 1985). The third approach to QoL combines the previous approaches, integrating the objective and subjective perspectives (e.g. BROWN, BAYER; MACFARLANE, 1989; BORTHWICK-DUFFY, 1992; CUMMINS, 1992). Hence, an individual's objective life conditions and personal satisfaction with these life conditions should be taken into account in order to understand QoL.

Finally, another critical issue in the conceptualization of QoL is the contextualization of the measure. As mentioned above, QoL implies objective and subjective elements, but intra-personal features acquired through the socialization process should also be taken into consideration. These features consist of personal values, aspirations and expectations (FELCE; PERRY, 1995). However, the specific context does not only include personal issues, and the context where people are involved should also be used to understand QoL.

In sum, QoL is a multi-domain dynamic concept composed of objective and subjective issues that depends on personal values and the context and is socially constructed. Therefore, it is important to develop contextualized measures that take the context of QoL into account, specifically in the field of people with intellectual disabilities, where context plays an important role in the enhancement of QoL.

## 2.2 The Operative Model of QoL

The concept of QoL in people with intellectual disabilities became an important research topic in the 1980s (VERDUGO; ARIAS; GÓMEZ; SCHALOCK, 2010). However, only in the 21st century did the International Society for the scientific study of Intellectual Disabilities (IASSID) establish the main principles for the concept, measurement and application of the QoL of people with intellectual disabilities (VERDUGO, 2004).

The IASSID describes five main principles that should be taken into consideration in measuring QoL (p. 40): a) the same factors and relationships are important for people with and without intellectual disabilities; b) it is experienced when a person's needs are met and when one has the opportunity to pursue life enrichment in major life settings; c) it has both subjective and objective components, but it is primarily the perception of the individual that reflects the QoL he/she experiences; d) it is based on individual needs, choices, and control; and e) it is a multidimensional construct influenced by personal and environmental factors, such as intimate relationships, family life, friendships, work, neighbourhood, city or town of residence, housing, education, health, standard of living, and the state of one's nation (VERDUGO, 2004).

As a result of this effort, different conceptual frames have arisen (CUMMINS, 2004; FELCE; PERRY, 2005; GARDNER; CARRAN, 2005; SCHALOCK; VERDUGO 2002). One of the most highly valued models is the Operative Model of QoL by Schalock and Verdugo (2002). This model takes QoL as a multi-domain concept composed of the same dimensions for everyone. The model postulates that levels of QoL are influenced by contextual, interactional and personal factors (VERDUGO; SCHALOCK; KEITH; STANCLIFFE, 2005).

Accordingly, in the Operative Model of QoL, its authors synthesized the measurement of QoL into eight dimensions based on domains (SCHALOCK, 1996b): 1) Emotional well-being, which comprises contentment, self-concept, and lack of stress; 2) Interpersonal relations, which comprise interactions, relationships, and supports; 3) Material well-being, which comprises financial status, employment, and housing; 4) Personal development, which comprises Education, personal competence, and performance; 5) Physical well-being, which comprises health and health care, activities of daily living, and leisure; 6) Self-determination, which comprises autonomy/personal control, goals and personal values, and choices; 7) Social inclusion, which comprises community integrations and participation, community roles, and social supports; 8) Human (respect, dignity, equality) and legal rights (SCHALOCK; VERDUGO, 2002, p. 382).

This theoretical model, and the QoL dimensions it defines, provides a rich potential framework to develop a QoL measure. However, as we argued previously, the specific context should be taken into consideration. Personal and social values generated through complex socialization processes are relevant to assessing the hierarchized system of beliefs about what QoL is within a specific context. Previous research conducted first trials to develop contextualized measures, such as the measurement of social abilities of people with autism (RATTO; TURNER-BROWN; RUPP, 2011). However, in the area of persons with intellectual disabilities, there is still a need to develop contextualized measures that take into account the specific organizational context where people with intellectual disabilities carry out their everyday lives, in order to add complementary information to previous QoL general assessments. Along these lines, organizations that provide services to people with intellectual disabilities are important contexts for studying the development of QoL. The actions of these organizations in delivering services to this collective can impact the enhancement of QoL. Hence, it is relevant to understand how these contexts are able to improve QoL. A contextualized measure of QoL must be designed in order to provide a complete understanding of the QoL that a person experiences as a result of the interaction between personal, interactional and contextual factors.

### 2.3 Contextual measure of QoL

As mentioned above, enhancing the QoL of people with intellectual disabilities becomes a very important aim in present-day societies. Specifically, social, educational and health services oriented toward providing services to people with intellectual disabilities establish this issue as a specific organizational goal to pursue in developing a progressive enhancement of QoL in the future (SCHALOCK; VERDUGO, 2004, 2007). Therefore, the assessment of QoL becomes a key tool to improve quality and innovation for future development in this type of social services.

One main reason for the need to assess QoL is that it makes it possible to highlight the importance of personal opinions and experiences. At the organizational level, it facilitates the planning of programs and activities for the progressive personal development of QoL (SCHALOCK; VERDUGO, 2007). In this vein, it is necessary to develop a contextualized measure that would be shared by all the stakeholders involved in making progress toward QoL. Organizations that provide services to people with intellectual disabilities usually have three main stakeholders involved in the daily processes: people with intellectual disabilities, professionals, and family members. Family members are involved in decision-making processes and communication systems. Therefore, their participation is fundamental to understanding the reality in organizations and the values that give them meaning (MARTÍNEZ-TUR et al., 2010).

Developing a contextualized measure of QoL that assesses family members' perceptions allows service organizations to have an external indicator of their service quality, which in turn relates to the users' QoL (MARTÍNEZ-TUR et al., 2010). This external vision of the quality provided to persons with intellectual disabilities can help to design future strategies for improving all those factors that are directly or indirectly related to their quality of life.

Thus, a contextualized measure assessing the QoL of people with intellectual disabilities from the family members' perspective is needed in order to continuously enhance the services in this field. This study aims to structure and validate a contextualized measure of QoL for people with intellectual disabilities that can provide assessments by external stakeholders, that is, family members of the people with intellectual disabilities. In the following sections, we describe the process and methodological strategy.

## 3 METHOD

### 3.1 Sample and Procedure

A total of 100 healthcare organizations providing services to persons with intellectual disabilities participated in the study. All the participating service organizations were affiliated with the Confederation of Organizations for Persons with Intellectual Disabilities (FEAPS, Spain).

FEAPS has the mission of contributing to developing a QoL project for anyone with intellectual disabilities and promoting the insertion of this collective in society through ethical commitment, support and providing opportunities as citizens with full rights in a fair society (FEAPS, 2010). Therefore, these service organizations are a fundamental source of QoL for people with intellectual disabilities, due to the quality of the service they deliver.

Family members from three differentiated types of centres participated in this study: occupational centres (57.9%), day centres (19.3%), and residences (22.8%). Participants were randomly sampled to answer the questionnaire voluntarily and anonymously. To participate in the study, family members had to have frequent contact with the centre. The questionnaire administration process took 10 min (on average) for each family member.

The final sample was composed of 1195 parents and other caregivers. Of them, 62% were women. On average, the family members were 58.53 years old (ranging from 23 to 94; SD = 11.96). The participants' relationships with the person with intellectual disabilities were: 28.4 % fathers, 46.9% mothers, 12.3% legal guardians, and 10% other family relationships.

### 3.2 Measures and Statistical Strategy

*Quality of Life perceived by family members*. As one of the contributions of the present study is to provide a contextual measure of QoL, this scale was designed with the collaboration of a group of experts pertaining to FEAPS. The dimensions of QoL specified in Schalock and Verdugo's *Operative Model of QoL* (2002) were also considered as a starting point in designing the structure of the scale.

A panel of experts composed of professional members of FEAPS and the research team cooperated in developing the scale. During the group discussion process, different versions of items were analysed, with a special emphasis on the wording of the QoL items. The group of experts agreed on the wording of 20 items to represent the domain found in each of the four dimensions of QoL. Three of the eight dimensions of the *Operative Model of QoL* (SCHALOCK; VERDUGO, 2002) were used as the basis for this scale. The rest of the dimensions of the *Operative Model of QoL* (Emotional well-being, Interpersonal relations, Material well-being, Personal development, Physical well-being) can overlap current measures of well-being, and they are also more difficult to associate with the service provided by the organizations. Thus, they are not related to the aim of this study, which is to develop an Organization-Oriented Measure from an External Perspective. The items chosen measured QoL resulting from actions and activities of organizations delivering services to individuals with intellectual disabilities**.** Items were distributed as follows: 1) Self-determination (SD; 5 items). An example of an item is: *This centre provides training for developing the self-determination of people with intellectual disabilities, improving their QoL*; 2) Social inclusion (SI; 6 items). An example of an item is: *The actions of this centre have improved the inclusion of persons with intellectual disabilities in different sectors, such as education, utilities, etc.;* 3) Rights (RI; 4 items). An example of an item is: *This centre has agreements with other organizations to defend the rights of people with intellectual disabilities;* 4) Overall improvement (OI; 5 items). An example of an item is: *The QoL for my family member with intellectual disabilities has improved thanks to this centre*. All the items followed a Likert scale design, with scores ranging from 1 (strongly disagree) to 7 (strongly agree), and higher scores indicating better QoL (see Annex 1 for a complete description of the QoL).

Once the panel of experts had designed the items of the scale and the questionnaire had been filled in by the participants, several steps were taken to test the characteristics of the scale: similarity between items, item-factor distribution, reliability, and construct, convergent and discriminant validity.

First, descriptive analyses were performed to examine the similarity between the items. In other words, similar patterns in the answers to the items were explored. Second, an exploratory factor analysis (EFA) was performed to test the item-factor distribution and the dimensionality of the measure. EFA allows exploring the distribution of items between different factors and the degree of saturation in each of the factors. The structure of the construct was also tested by Confirmatory Factor Analysis (CFA). In fact, Confirmatory factor analysis (CFA) tests construct validity, which makes it possible to establish whether the markers of a construct measure what they are supposed to measure (BABIN; BOLES; ROBIN, 2000). In this vein, the four proposed dimensions of QoL (Self-determination, Social inclusion, Rights, and Overall improvement) are expected to show an adequate fit. In order to test this factorial structure more accurately, we compared the proposed four-factor model with a one-factor model (with all items loading in a single QoL factor). Third, the internal consistency or reliability of the scale (Cronbach's alpha) was calculated. Finally, convergent and discriminant validity were tested. While convergent validity explores the item-factor loadings and construct reliability estimates of the scale, discriminant validity assesses the correlations between the QoL factors and the scale compared to the correlation between the QoL factors and competing scales (LI; WAND; SHENG, 2002).

## 5 RESULTS

### 5.1 Discrimination among items, dimensionality of the measure and reliability

To analyse similarity between items, descriptive analyses of the items were performed. Table 1 shows means and variances of items. The scale items had approximately equal variances and means, as is required in order to maintain consistency in the answers within dimensions (LI et al., 2002).

**Table 1** - Means and variances of the pre-scale of Quality of Life

| Item | Subscale | Mean | Variance |
|---|---|---|---|
| ***1*** | Self-determination | 5.82 | 1.42 |
| ***2*** | Self-determination | 5.86 | 1.38 |
| ***3*** | Self-determination | 5.68 | 1.68 |
| ***4*** | Self-determination | 5.73 | 1.64 |
| ***5*** | Self-determination | 5.73 | 1.65 |
| ***6**** | Social inclusion | 6.05 | 1.18 |
| ***7**** | Social inclusion | 6.04 | 1.15 |
| ***8*** | Social inclusion | 5.71 | 1.49 |
| ***9*** | Social inclusion | 5.93 | 1.27 |

| | | | |
|---|---|---|---|
| ***10*** | Social inclusion | 5.72 | 1.50 |
| ***11*** | Social inclusion | 5.82 | 1.43 |
| ***12*** | Rights | 6.06 | 1.26 |
| ***13*** | Rights | 6.04 | 1.30 |
| ***14*** | Rights | 5.83 | 1.52 |
| ***15*** | Rights | 6.085 | 1.26 |
| ***16**** | Overall improvement | 5.90 | 1.67 |
| ***17*** | Overall improvement | 5.95 | 1.46 |
| ***18*** | Overall improvement | 6.23 | 1.00 |
| ***19*** | Overall improvement | 6.24 | 0.99 |
| ***20*** | Overall improvement | 6.18 | 0.95 |

Source: Results

Note. * = Deleted items in the final version of the scale

According to the results from the exploratory factorial analyses for the four main dimensions of QoL, Self-determination, Social inclusion, Rights and Overall improvement were identified. However, results recommended deleting three overlapping items on the QoL scale. Specifically, the results of the EFA recommended deleting two items from the social inclusion dimension (item 6 and item 7) and one item (item 16) from the Overall improvement dimension. A final scale of 17 items organized in four main dimensions (self-determination, social inclusion, rights and overall improvement) explained 74.83% of the variance. The final distribution of the items was as follows (see Table 2):

**Table 2** - Exploratory Factor Analysis (EFA) loading estimates

| ● | Self-determination | Social inclusion | Rights | Overall improvement |
|---|---|---|---|---|
| Item 1 | .66 | ● | ● | ● |
| Item 2 | .64 | ● | ● | ● |
| Item 3 | .74 | ● | ● | ● |
| Item 4 | .77 | ● | ● | ● |
| Item 5 | .77 | ● | ● | ● |
| Item 8 | ● | .64 | ● | ● |
| Item 9 | ● | .67 | ● | ● |
| Item 10 | ● | .73 | ● | ● |
| Item 11 | ● | .73 | ● | ● |
| Item 12 | ● | ● | .80 | ● |
| Item 13 | ● | ● | .79 | ● |
| Item 14 | ● | ● | .71 | ● |
| Item 15 | ● | ● | .73 | ● |
| Item 17 | ● | ● | ● | .56 |
| Item 18 | ● | ● | ● | .88 |
| Item 19 | ● | ● | ● | .88 |
| Item 20 | ● | ● | ● | .58 |

Source: Results

Note: Only loadings.50 or above are showed

Confirmatory factorial analysis (CFA) also confirmed the structure of the scale. Table 3 shows both the proposed four-factor model and the alternative one-factor model. The hypothesized model with four dimensions of QoL fit the data better. Paths between sub-dimensions and items were all statistically significant and had loadings from .63 to .95. The one-factor model did not fit the data. Therefore, the factorial structure of four dimensions of QoL (Self-determination, Social inclusion, Overall improvement and Rights) was confirmed.

**Table 3** - Goodness-of-fit indices for the tested models

| *Model* | $\chi^2$ | *df* | *p* | *RMSEA* | *NFI* | *CFI* | *IFI* | *TLI* |
|---|---|---|---|---|---|---|---|---|
| Four-factor model* | *990.779* | *113* | *.000* | *0.08* | *.93* | *.94* | *..94* | *.93* |
| One-factor model | *3,588.410* | *119* | *.000* | *0.16* | *.76* | *.77* | *.77* | *.74* |

Source: Results

*Note:* $\chi^2$ = Chi-square; df = degrees of freedom; IFI = Incremental Fit Index; TLI = Non-Normed Fit Index or Tucker-Lewis Index, CFI = Comparative Fit Index, RMSEA = Root Mean Square Error of Approximation. AIC = the Akaike Information Criterion, $\Delta\chi^2$ = Delta Chi-square; $\Delta$df = delta degrees of freedom.

The Cronbach's alpha coefficients for the four dimensions ranged from .86 to .90, which confirms the internal consistency of the sub-dimensions. The total Cronbach's alpha for the scale was .95, confirming the reliability of the scale.

## 5.2 Scale convergent and discriminant validity

Finally, to test the convergent validity, item-scale correlations were calculated. Item-scale correlations should be roughly equal for all the items on a given scale, and the correlation of each item with its hypothesized scale should be .40 or above (LI et al., 2002). Table 4 shows the item-scale correlations. Correlations ranged from .65 to .80. All the correlations were above .40, which confirms the convergent validity of the scale.

**Table 4** - Correlations between QoL items, QoL full scale and Satisfaction

| • | Item QoL- full scale correlation | Item QoL-satisfaction scale correlation |
|---|---|---|
| Item 1 | .68 | .47 |
| Item 2 | .68 | .52 |
| Item 3 | .68 | .46 |
| Item 4 | .54 | .39 |
| Item 5 | .73 | .49 |
| Item 8 | .70 | .55 |
| Item 9 | .70 | .54 |
| Item 10 | .72 | .58 |
| Item 11 | .74 | .49 |
| Item 12 | .80 | .48 |
| Item 13 | .74 | .41 |
| Item 14 | .76 | .42 |
| Item 15 | .74 | .43 |
| Item 17 | .78 | .44 |
| Item 18 | .74 | .39 |
| Item 19 | .71 | .37 |
| Item 20 | .65 | .36 |

Source: Results

To test discriminant validity, the correlation of each item with its hypothesized scale should be significantly higher than the correlation of the same item with competing scales (LI et al., 2002). Table 4 shows correlation coefficients between item-total scale and item-satisfaction scale, providing evidence for adequate discriminant validity.

## 6 DISCUSSION

Currently, the concept of QoL is considered a complex multi-domain concept. The aim of this study was to develop a complementary measure of the QoL of persons with intellectual disabilities, considering the contextualization of the measure and an external assessment for service organizations. Our QoL measure has taken into consideration the complexity of the concept of QoL. This study based the development of the scale on the Operative Model of QoL (SCHALOCK & VERDUGO, 2002), which considers the full complexity of QoL (VERDUGO et al, 2005).

This effort focused on two directions. We designed a contextualized measure of QoL that considers the improvement in QoL due to the actions and activities of organizations delivering services to persons with intellectual disabilities. Contextual factors should be taken into consideration in order to understand the full concept of QoL (FELCE & PERRY, 1995). For this reason, this study designed a contextualized measure that collects the complexity of the concept of QoL as a multi-domain concept. Specifically, this contextualized measure of QoL has diagnostic value for organizations providing services to people with mental disabilities because it gives them specific information about QoL as an outcome of previous activities. Hence, it allows them to design specific actions and activities to enhance QoL.

In addition, this QoL measure was designed considering an external perspective. This scale has the peculiarity of taking family members as the main evaluators to assess the QoL of people with intellectual disabilities resulting from organizations' activities. This perspective increases the objectivity of the information because an external subject provides it. Family members are stakeholders in improving the QoL of this collective, and they provide an external vision of the quality of service provided by service organizations. Thus, their perceptions of QoL provide valuable information.

The scale was designed through cooperation from researchers and professionals who are actively working in the field of providing service to people with mental disabilities. Four main dimensions arose from different focus group sessions: (1) *Self-determination,* understood as the active promotion of self-determination of people with intellectual disabilities*;* (2) *Social inclusion,* understood as the inclusion in society of people and social capital in the environment; (1) *Rights,* understood as the defence and promotion of the rights of people with intellectual disabilities and their families; and (4) *Overall improvement,* understood as the overall improvement in the QoL of people with intellectual disabilities.

Different analyses confirmed the reliability and validity of the scale. Descriptive analyses showed the consistency between the items (approximately equal variances and means), and EFA identified the four dimensions of QoL (Self-determination, Social inclusion, Rights, and Overall improvement). The final 17-item scale explained 74.83% of the variance and showed high levels of internal consistency of the dimensions and the general scale. The CFA also confirmed that the measure showed a good differentiation of the four expected dimensions, better than the one-factor scale. Finally, satisfactory indicators of convergent and discriminant validity were obtained. Therefore, this study confirms that the contextualized QoL scale reached the necessary methodological levels of rigor, validity and reliability to be a useful measure of QoL.

### 6.1 Limitations and future studies

This study has some limitations that represent opportunities for future studies. First, the instrument assumes that family members are relevant informants for measuring QoL in service organizations, but other stakeholders are also critical (e.g., professionals, persons with intellectual disabilities, managers, etc.). Future studies should compare the QoL perceived by different stakeholders in order to analyse any differences or gaps. Future work could take into consideration the perception of all the stakeholders involved in the process of enhancing QoL.

The cross-sectional nature of the data creates the need to collect longitudinal data to confirm the validity of the QoL scale over time. Future studies are encouraged to develop repeated measures and test whether the reliability and validity of the scale are stable over time.

Finally, the scale assumes that QoL is the same construct for every kind of person in the world. By focusing on a specific context in Spain that provides services to people with intellectual disabilities, we were unable to generalize the results. Therefore, cross-cultural studies should be developed, as well as studies using samples with other kind of disabilities. However, we were able to provide a contextualized measure for QoL. Without focusing on a specific context, our study would lack this strength.

### 6.2 Practical implications

Assuming that these findings are confirmed by future research, they have substantial practical implications. The development of one contextualized scale that assesses the QoL of people with intellectual disabilities who join particular service organizations, as perceived by family members, has three main implications.

From the contextualized measurement of QoL, this scale provides a specific organization-oriented measure that makes it possible to specifically describe the main indicators of QoL in people with intellectual disabilities. For this reason, it may be easier for managers to develop appropriate strategies to improve QoL, emphasizing the most relevant areas.

Likewise, organizations should not assume that relevant information only comes from insiders in organizations. This scale adds information from a new informant who can provide rich information about the current levels of QoL in people with intellectual disabilities. FEAPS identifies family members as a key collective in providing excellent service. Thus, taking into consideration this collective’s perceptions highlights their importance for the confederation and strengthens cooperation between professionals and family members in working toward a common goal.

Along these lines, collecting information from other different stakeholders was recommended by Parasuraman, Zeithaml and Berry (1985). They recommend collecting information from different stakeholders from one organization in order to identify the existing gaps between stakeholders’ perceptions, such as gaps between managers’ perceptions and family members’ perceptions about their levels of QoL. In this way, these perceptions of family members can help to detect differences between stakeholders. These differences may identify errors or mistakes in the service process. Therefore, collecting information from family members can help to develop improvement strategies for the future. Accordingly, one of the most effective techniques for organizational change and improvement, the survey-feedback technique, recommends collecting objective information, in this case from family members who are able to identify weaknesses and strengths, in order to generate innovative strategies for improvement in organizations. In this way, this scale is an interesting tool that can help FEAPS to enhance the QoL of their users, as they expressed in their strategic guidelines.

### 6.3 Final Thoughts

This study has developed a contextualized organization-oriented measure of the QoL of persons with intellectual disabilities who are users of different organizations that provide service to these users. Thus, it focuses on the QoL of persons with intellectual disabilities, which can be improved by the actions and activities of organizations, employees, and manages. In addition, our specific scale has the peculiarity of taking family members as the main evaluators to assess the quality of life of the persons with intellectual disabilities, which increases the objectivity of the information because an external subject provides it. At the same time, this scale complements previous scales, and it enriches the information related to the centre's previous QoL.

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**ANNEX 1**

Self-determination

1. This centre has boosted my collaboration in promoting the independence of my relative with intellectual disabilities.
2. This centre provides training in the self-determination of my relative with disabilities, improving his/her quality of life.
3. Because of this centre, I have noticed an increase in the possibilities for self-management and independence of the person with intellectual disabilities for whom I am responsible.
4. This centre has increased my sensitivity to the need to achieve the self-determination of my relative with intellectual disabilities.
5. This centre encourages the person with intellectual disabilities I am responsible for to participate in making decisions about him/herself.

Social inclusion

6. Social awareness actions that this centre has developed for people with intellectual disabilities and their families have improved the quality of life of my relative with intellectual disabilities.
7. The improvement in the adaptation of the social environment to the needs of people with disabilities and their families carried out by the centre has improved the quality of life of my relative with intellectual disabilities.
8. The actions of this centre have increased the inclusion of my relative with intellectual disabilities in various areas (e.g. education, public services, etc.).
9. The social value of my relative with intellectual disabilities has improved, improving his/her quality of life, thanks to the actions developed by this centre.
10. Society’s attitudes towards my relative with intellectual disabilities are more positive, thanks to the actions developed by this centre.
11. The social integration of my relative with disabilities has improved, thanks to the actions developed by this centre.

Rights

12. This centre provides clear information about the rights of people with intellectual disabilities.
13. The centre is interested in the rights of families of people with intellectual disabilities.
14. Using this centre allows me to have greater influence on the rights of my relative with intellectual disabilities.
15. This centre has established agreements with other organizations to defend the rights of people with intellectual disabilities.

Overall quality of life

16. This centre has asked us about the quality of service offered to my relative with intellectual disabilities.
17. The Family Support services developed at this centre for people with intellectual disabilities have improved the quality of life of my relative with intellectual disabilities.
18. The quality of life of my relative with intellectual disabilities has been improved because of this centre.
19. I think the quality of life of my relative with intellectual disabilities has been improved through this centre.
20. The centre develops planned actions that improve the quality of life of the person with intellectual disabilities for whom I am responsible.

Note: items 6, 7 and 16, were deleted in the final version of the scale.