

Manuscript ID: CJID-2012-0005.R2

Running header: *Family quality of life*

Approximate word count: 5,851 words

Keywords: *family quality of life, family needs, intellectual disability, family quality of life scale*

ORIGINAL ARTICLE

Spanish Family Quality of Life Scales: Under and over 18 years old

**CLIMENT GINÉ GINÉ¹, ROSA VILASECA², MARTA GRÀCIA²,
JOAQUÍN MORA³, JOSÉ RAMÓN ORCASITAS⁴, CECILIA SIMÓN⁵,
ANA MARÍA TORRECILLAS⁶, FRANCESC S. BELTRAN², MARIONA
DALMAU MONTALÀ¹, MARIA TERESA PRO¹, ANNA BALCELLS-
BALCELLS¹, JOANA MARIA MAS MESTRE¹, ANA LUISA ADAM-
ALCOCER¹ & DAVID SIMÓ-PINATELLA¹**

¹*Ramon Llull University, Barcelona, Spain,* ²*University of Barcelona, Spain,* ³*University of Seville, Seville, Spain,* ⁴*University of the Basque Country, San Sebastián, Spain,* ⁵*The Autonomous University of Madrid, Spain,* and ⁶*University of Las Palmas de Gran Canaria, Spain*

Correspondence: Climent Giné Giné, Ramon Llull University, c/ Cister, 34, 08022 Barcelona, Spain. E-mail: ClimentGG@blanquerna.url.edu

Abstract

Background Researchers, professionals, and families have shown increasing concern with the family quality of life (FQoL) of people with intellectual disability (ID) and their families. The goals of this research are (a) to explore how Spanish families understand FQoL by developing 2 different measurement tools for families with a member with ID under and over 18 years old, and (b) to provide 2 diagnostic instruments that will be useful for designing action plans.

Method The study comprised 4 stages: (a) focus groups, (b) expert assessment, (c) pilot study, and (d) normalisation and standardisation. The data were collected in 5 regions in Spain, and 1,205 families with a member with ID took part in the normalisation and standardisation of the scales.

Results Both FQoL scales were consistent and have valid psychometric characteristics.

Conclusions The scales have a diagnostic purpose for use in designing action plans aimed at producing significant changes in families' lives.

Keywords: *family quality of life, family needs, intellectual disability, family quality of life scale*

Introduction

In recent decades, researchers, professionals and families themselves have shown growing concern with the quality of life (QoL) of persons with intellectual disability (ID) and their families. Although research on the QoL of persons with ID has a long history and has generated a large corpus of results with consequences for both theory and practical applications for improving the lives of these people (e.g., Brown, 1997; Cummins, 1996; Cummins, 1997a; Keith & Schalock, 2000; Schalock, 1996; Schalock, 1997; Schalock et al., 2002; Schalock, Gardner, & Bradley, 2007; Schalock & Verdugo, 2002), the same has not happened with regard to family quality of life (FQoL).

In comparison with research on the QoL of persons with ID, research on FQoL is still limited (Summers et al., 2005) and recent. Nevertheless, there is widespread agreement on the importance of this new construct both for improving families' abilities to cope with a child with ID and for assessing the possible impact of the services and supports these families receive, which represent a significant investment in terms of financial and professional resources. To address these issues, various research teams have put considerable effort into conceptualising, measuring, and improving the quality of the families' lives (Aznar & Castañón, 2005; Brown et al., 2006; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Hu, Summers, Turnbull, & Zuna, 2011; Isaacs et al., 2007). This work has led to the development of three scales for measuring FQoL, including different domains: (a) the Beach Center Family Quality of Life Scale (Beach Center FQOL Scale; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006); (b) the Family Quality of Life Survey (FQOLS-2006; Brown et al., 2006; Isaacs et al., 2007); and (c) the Latin American Family Quality of Life Scale (Latin American FQoL Scale; Aznar & Castañón, 2005).

The research presented here is in line with these initiatives and seeks to provide Spanish professionals and families with instruments based on what they understand by FQoL, their values and beliefs, and is sensitive to Spain's social, economic, and cultural reality. As pointed out by Gallimore, Weisner, Kaufman, and Bernheimer (1989), families build and organise their daily routines according to their beliefs, values, objectives, and the circumstances in which they live.

The QoL concept has subjective and objective components (Perry & Felce, 2002; Schalock et al., 2002; Schalock & Verdugo, 2002) that vary depending on the personal and collective situation of people in different countries. It is therefore no wonder that different scales measuring individual QoL have been produced for different countries: Australia (Cummins, 1997b); USA (Schalock & Keith, 1993); and more recently the Netherlands and Belgium (van Loon, van Hove, Schalock, & Claes, 2008), and Spain (Verdugo, Arias, Gómez, & Schalock, 2008; Verdugo, Arias, Gómez, & Schalock, 2009).

A QoL scale ought to be able to capture as faithfully as possible the situation of families at the macro-, meso-, and microsystem levels in the country where it is used. Spain has a number of particularities in different fields that justify the need for a special scale. For example, the rights of people with ID and their families are recognised by law, but are often ignored in practice; administrative procedures for accessing services can be a trying barrier for families; labour law does not favour reconciliation between work and parental attention to children with ID; around 80% of adults with ID live with their relatives despite the cost involved for parents; and there is a lack of respite care services (Giné et al., 2011). In the field of education, the transition from school to adult life is not well supported. From the social and economic point of view, the government has recently cut down on some aids to people with disability; unemployment now exceeds 20% of the population (Instituto Nacional de Estadística, 2012).

That is why, in spite of their great value, adapting one of the existing QoL scales does not seem the best way of measuring FQoL in Spain. Consequently, it is justified to explore what Spanish families understand by FQoL through grounded theory and identify the most important areas that would serve as the basis for drawing up the first version of the scale for the pilot study, as will be explained. Another feature of this study is that it presents two scales: one for families of children under 18 years old and another for families with children over 18 years old. Although it is true that many items are relevant throughout the whole life span, it is also true that the needs of persons with ID change substantially over time and, in consequence, so do the needs of the families and the impact on their perception of QoL. The wish to enhance the sensitivity to such changes in people's lives and their possible impact on FQoL, often associated with the services received, made it advisable to have two partially different instruments. Cummins (1997b) opted for two instruments to measure individual QoL, one for children and another for adults. The Supports Intensity Scale (Thompson et al., 2004) also has two instruments to measure support needs, one for adults and another that is currently being developed for children.

In addition, it was considered necessary to have instruments that would not only measure FQoL, but would also be useful diagnostic and intervention tools (Zuna, Summers, Turnbull, Hu, & Xu, 2010).

In this study, we set out to explore how Spanish families understand QoL by developing two different measurement tools in keeping with Spain's social and cultural context: one for families with children up to the age of 18 years, the other for families with adults over 18. The second objective of the study was to produce an instrument suited to the characteristics and needs of the population at which it is aimed, and one that would serve as a useful diagnostic tool for designing intervention plans capable of bringing about significant improvements in families' QoL.

Method

This section presents the procedure employed in developing the scales and the characteristics of the participants in the pilot study and fieldwork.

Procedure

The study involved a qualitative inquiry in order to conceptualise and organise the different areas of FQoL, and a quantitative process that included trialling an initial pilot version of the two scales and the final version. The study therefore had five stages.

From conceptualisation of FQoL to the development of the Family Quality of Life – Spain (CdVF-E). Seventeen focus groups, each comprising between eight and 10 members of families with persons with ID, were held to identify and define the areas of how FQoL is conceived of by Spanish families.

Four researchers taking on different roles (one coordinator, one co-coordinator and two observers) participated in each of the focus groups, of which audio and video recordings were made. The 17 sessions held in the different regions were then transcribed and the transcriptions analysed using ATLAS.ti (Version 5.1) (Muhr, 2006) discourse-analysis software. The procedure employed for analysing the focus group data was as follows: (a) each researcher identified the most significant text segments or quotations, assigned them a code, and defined different categories; (b) the two researchers who had analysed the same transcriptions shared their analyses, compared their codes and categories, and established an initial version of codes, categories, and definitions; (c) two discussion meetings in which all the researchers from each team took part were then held to agree on a single proposal regarding codes, areas, (Emotional Wellbeing, Family Interaction, Health, Financial Wellbeing, Parents' Organisation and Skills, Family Accommodation, and Social Inclusion and Participation), and definitions.

Development of the primary survey items. On the basis of the domains and the quotations transcribed from the focus groups, the different teams produced items for each of the areas, which were subsequently revised in accordance with the criterion that the items (statements) should refer to the key aspects of FQoL.

At this stage, each of the FQoL areas had between 10 and 15 items consisting of statements, and the families were asked to rate each item in terms of both importance and satisfaction. This process concluded with two proposed FQoL scales, one for over-18-year-olds and one for under-18-year-olds, each with 105 items. Both scales had a 5-point Likert format and were self-administered.

Experts' assessment and revision. Experts from different fields (research, professional, and public administration) reviewed the scales. The under-18-year-old scale was reviewed by 21 experts and the over-18-year-old scale by 22 experts. The experts were requested to give their view on (a) the instructions given to the families on how to respond to the scale statements; (b) the clarity, suitability, and importance of the items; (c) the type of response (in terms of importance and satisfaction); and (d) the length of the instrument. All the experts' comments were discussed by the research teams until a consensus was reached. The final wording of the items on each scale was drawn up, taking into account the experts' comments, and a total of 101 items remained on each scale.

Pilot test and revision. As a result of the experts' contributions and reflection by the researcher group, as will be explained, the characteristics of the two scales used for the pilot study were as follows: (a) each scale contained statements from the seven areas identified through the focus groups, (b) the items were not grouped by domains within the instrument, (c) each item required a response on a 5-point Likert scale, (d) these statements were to be answered in terms of importance and frequency, (e) items could be scored as *not applicable*, and (f) the two scales were self-administered.

Participants were recruited from associations of parents of children with ID in the Spanish regions of Andalusia, the Basque Country, the Canary Islands, Catalonia, and Madrid. The lead researcher in each region contacted the coordinators of the associations by telephone and described the details of the study and what was required for participation. Whenever an association decided to participate, its coordinator contacted the families about the study. Families who agreed to participate were given a research package which included an informed consent form (in accordance with the ethical guidelines of the Spanish Psychological Society), an information sheet, a form on which to record the family's relevant demographic details, a copy of the pilot FQoL scale and an envelope in which to enclose, seal, and return the scale and demographic details form to the association once they had been filled in. Families were asked to complete the scale from the viewpoint of the family as a whole, irrespective of whether the mother or the father filled it in. The associations undertook to post the envelopes with the scales and forms on to the respective research groups. The families were aware that they could raise any queries they might have with the lead researcher at any time during the process.

An analysis of the item-total correlation matrix was used to identify low-discrimination items ($r < .15$) and these were eliminated from the final version of the scale.

Field test. Stratified sampling was used to select families with persons with ID from associations of parents of persons with ID in the five regions of Spain mentioned earlier. The procedure employed for sending out and collecting the scales was the same as in the pilot study. The selection criteria for participation in the sample were the degree of disability (mild, moderate, and severe) and age (under/over 18 years old) of the person with ID, and the family's place of residence (urban/rural area).

Altogether, 1,679 scales for families with a child with ID under 18 years old and 1,487 scales for families with a child with ID over 18 years old were sent out. A total of 607

(36.15%) under-18 scales and 598 (40.21%) over-18 scales were returned, although four of the latter had to be discarded as they were incomplete.

A total of 116 families participated in the pilot study. Of these, 61 families took part in the trial of the scale for families with children under 18 years old, and 55 in the trial of the scale for families with children over 18 years old.

A total of 1,205 people, all different from those in the pilot study, took part in the field test. Of these, 598 completed the over-18 scale and 607 the under-18 scale. The demographic characteristics of the participants in the field test process are shown in Table 1.

<Please insert Table 1 about here>

Results

This section describes the final characteristics of the two scales that were produced and their psychometric properties.

Final characteristics of the two scales

The characteristics of the final versions of the two scales were as follows: (a) the items of both scales are representative of the seven FQoL areas identified (Emotional Wellbeing, Family Interaction, Health, Financial Wellbeing, Parents' Organisation and Skills, Family Accommodation, and Social Inclusion and Participation); (b) the items relating to the different areas were arranged in random order; (c) each of the areas had between six and 12 items consisting of statements; (d) respondents indicated their extent of agreement with each statement on a 5-point Likert scale; (e) there was a *not applicable* option; (f) there were 61 items in the under-18-year-old scale and 67 in the over-18-year-old scale; and (g) the two scales were self-administered.

Appendix 1 shows a small sample of the items in the final version of each scale.

Psychometric characteristics of the scales

From the returned responses, an item correlation matrix was made for both the over-18 and under-18 scales. Items with a correlation value of $r < .15$ were discarded, leaving the under-18 scale with 61 items and the over-18 scale with 67 items. The reliability according to the Cronbach's alpha coefficient for both scales was .96.

An intercorrelation matrix showed that the seven domains helped to measure FQoL effectively and efficiently (Table 2 shows the mean and standard deviation score by domain for each scale).

<Please insert Table 2 about here>

However, a factor analysis showed that a main factor accounted for 30% of variance in the over-18 scale and 28% of the variance in the under-18 scale. Both scales measured a single factor (overall FQoL) and, as Samuel, Rillotta, and Brown (2012) stated, the domains could be combined in order to describe FQoL as a whole. The previously identified FQoL areas should therefore be interpreted as trends and used only as a guide for more clinical work.

Discussion

The first goal of this study was to produce two scales that would enable measurement of FQoL of Spanish families with children with ID throughout their life span. In this regard, it can be said that two valid and reliable scales for measuring the FQoL of families with children and adults with ID were constructed.

The areas identified in relation to Spanish families are generally consistent with the two most important FQoL scales (Samuel et al., 2012). This supports the existence of common areas affecting FQoL, such as health, economic and material welfare, and family interactions. Some of the areas identified with regard to Spanish families, such as emotional wellbeing and parenting, coincide most clearly with the dimensions of the Beach Center

FQOL Scale (Hoffman et al., 2006). However, the family accommodation area, which reflects aspects to do with acceptance of, and adaptation to, their child's disability by the different family members, includes, among other things, some aspects that in the FQOLS-2006 (Brown et al., 2006; Isaacs et al., 2007) are included in Careers and Preparing for Careers, and also other matters related to Influence of Values. The participation and social inclusion area in the Spanish scale (CdVF-E) refers to the social relations of the family and the person with ID, and includes aspects that are covered by the Leisure and Recreation and Community Interaction dimensions in the FQOLS-2006 (Brown et al., 2006; Isaacs et al., 2007). In summary, the content of the areas of the CdVF-E coincide to a large extent with the Beach Center FQOL Scale (Hoffman et al., 2006) and FQOLS-2006 (Brown et al., 2006; Isaacs et al., 2007), although some aspects are occasionally included in different dimensions.

Unlike the Beach Center FQOL Scale (Hoffman et al., 2006) and the FQOLS-2006 (Brown et al., 2006; Isaacs et al., 2007), the scale presented here (CdVF-E) does not include any dimension regarding the support received by the families or the persons with disability. The reason for this is that the scale seeks to measure the effects of the various types of support on FQoL rather than whether or not families receive such support. Supports should be regarded more as an input than as an output. Certainly, the construct of supports is mediated by multiple inputs (i.e., finance, community, services), but we felt it appropriate not to include in the scales the supports that come directly from services as there are other tools specifically designed to capture the support needs of people with ID and their families.

Following the recommendations by Cummins (2002) and the Beach Center researchers (Hoffman et al., 2006), the CdVF-E does not use "importance" as a family response variable. Cummins said, "However, I am forming the view that importance may not be a useful construct to measure" (Cummins, 2002, p. 3), and that "importance" becomes a "weak and ambiguous concept" (Cummins, 2002, p. 3). For their part, Samuel et al. (2012)

recall that the scores families give to “importance” are usually high on most items and so it is not useful for measuring FQoL.

How respondents perceive satisfaction within the domains of FQoL has been an important issue from the earliest systematic assessment of FQoL (Barnes & Olson, 1982&. Certainly, in the more recent scales—the Beach Center FQOL Scale (Hoffman et al., 2006) and the FQOL-2006 (Brown et al., 2006; Isaacs et al., 2007)—levels of satisfaction are considered to be a good measure to describe family perceptions of QoL. Nevertheless, as Rillotta, Kirby, and Shearer (2010) and Zuna et al. (2009) state, one of the results generally found when these scales have been used is that the degree of satisfaction expressed tends to be high and therefore has little discriminating power. Additionally, when attempts were made to supplement the responses of the families with an interview, the results were contradictory (Rillotta, Kirby, & Shearer, 2010; Zuna et al., 2009).

We think that the results we obtained using the CdVF-E scales may help us to find other ways to complement the measurement of FQoL and to develop action plans. We can also supplement the results obtained from the scales with other measures, such as interviews, to explore the satisfaction levels of the families.

The decision to produce two scales (one for children up to 18 years old and the other for adults over 18) has a theoretical basis in the fact that the different scales respond better to families’ changing needs throughout the life span. This decision was also supported by the comments of families in the focus groups that revealed different concerns among younger and older parents, which seemed necessary to capture. Different versions of scales are common practice in the field of individual QoL assessment. For example, Cummins (1997b) developed one scale for adults and another for children, whereas Schalock and Keith’s (1993) Quality of Life Questionnaire is aimed at schoolchildren. In addition, both the Latin American FQoL Scale (Aznar & Castañón, 2005) and the Beach Center FQOL Scale

(Hoffman et al., 2006) are fundamentally designed for young families (Samuel et al., 2012). Consequently, two scales have been constructed that are sensitive to the needs of Spanish families with young and adult children.

Lastly, our scales, in addition to measuring FQoL, also have a diagnostic purpose for use in designing action plans aimed at producing significant changes in families' lives. This facilitates the work of professionals by enabling them to link the measurement of FQoL with the goal of fostering real improvements in the lives of all family members, including the person with disability (Zuna et al., 2010).

In summary, both scales—the under-18 and over-18 CdVF-E—represent a step forward in investigating the QoL of families with persons with ID in relation to both research and, especially, professional practice. The scales appear to be useful instruments for working with families throughout the life span and for drawing up action plans that will help to improve the QoL of the families and persons with ID.

Conclusions

As was proposed at the outset, Spanish professionals and families now have two scales available to them—one for children and young people up to 18 years old and another for persons over 18 years old—constructed on the basis of what families in Spain understand by family QoL, which are sensitive to their political, social, and cultural reality, and are standardised and validated. Although a large number of items are common to both instruments, having two scales makes it possible to better capture situations that change in the course of families' life cycles and potentially have an impact on their QoL.

According to Samuel et al. (2012), interest in the QoL and FQoL field has recently shifted from measurement to application; that is, translating concepts into practice in order to produce observable improvement in the life of persons and families (Brown, Schalock, & Brown, 2009; Verdugo & Schalock, 2009; Zuna et al., 2009). Professionals in Spain now

have available to them instruments validated in that country enabling them to move from measurement to action. The scales provide them with tools to identify families' strengths and weaknesses and QoL trends that may be useful in setting goals, planning, and implementing family-centred intervention plans. This is the objective that gives meaning to all our work: helping, through our research, to promote changes in the lives of families in terms of a better QoL. That is why we have given both scales to FEAPS (Spanish Confederation of Organisations in Favour of Persons with Intellectual Disability) and have developed a user's manual together with it so the scales can be used as intervention tools once professionals have received the appropriate training, which we are currently engaged in providing.

The CdVF-E can be used in two ways: the scales can be self-administered like other scales, such as the Beach Center FQOL Scale (Hoffman et al., 2006) , and they can also be used for clinical purposes by means of an interview. The CdVF-E scales are a modest contribution to cross-cultural studies on FQoL and to the construction of FQoL theory, as called for by Zuna et al. (2009, 2010).

Limitations of the study

One limitation concerns the composition of the participant sample. Recruitment of families from parent associations may mean that the participants in this study are not representative of the wider population of families with a member with ID (Hoffman et al., 2006; Summers et al., 2005).

A second limitation relates to the fact that although the people who answered the questionnaire were asked to do so from the family perspective, there is no way of being sure this instruction was always followed.

A final limitation has to do with the scope of the population at which the Spanish FQoL scales are aimed. They were constructed to provide Spanish professionals and families with a person with ID with instruments attuned to their social and cultural characteristics.

Although such contextualisation was one of the objectives, it may also be a limitation in regard to the possible use of these scales in other countries. If they are used elsewhere, care must be taken to ensure that the social, cultural, and economic conditions, and the legislation and access to services are similar.

Author note

This research was supported by a grant from the Spanish Ministry of Education and Science under the National R&D&I Plan 2006–2009 (SEJ 2006-04773). The funding bodies have not imposed any restrictions on free access to or publication of the research data.

Conflict interest: None.

Acknowledgements

The project was carried out in collaboration with Almudena Fernández and Ignacio Martínez, Deusto University; Asunción González del Yerro, Autonomous University of Madrid; Virginia Cagigal, Comillas Pontifical University of Madrid; Gabriel Díaz Jiménez and Celia Fernández Sarmiento, University of Las Palmas de Gran Canaria; and José Florido Sanabria, Ministry of Education, Government of the Canary Islands.

We would like to express our thanks to the families with persons with ID and to the professionals from the different associations who participated in our research.

References

- Aznar, A. S., & Castañón, D. G. (2005). Quality of life from the point of view of Latin American families: A participative research study. *Journal of Intellectual Disability Research*, 49, 784–788. doi:10.1111/j.1365-2788.2005.00752.x
- Barnes, H. L., & Olson, D. H. (1982). Parent-adolescent communication scale. In D. H. Olson et al., *Family inventories: Inventories used in a national survey of families across the family life cycle* (pp. 33-48). St. Paul, MN: Family Social Science, University of Minnesota.
- Brown, I., Brown, R. I., Baum, N. T., Isaacs, B. J., Myerscough, T., Neikrug, S., ... Wang, M. (2006). *Family Quality of Life Survey: Main caregivers of people with intellectual or developmental disabilities*. Toronto, Canada: Surrey Place Centre.
- Brown, R. I. (Ed.). (1997). *Quality of life for people with disabilities: Models, research and practice*. (2nd ed.). Cheltenham, UK: Stanley Thornes.
- Brown, R. I., Schalock, R. L., & Brown, I. (2009). Quality of life: Its application to persons with intellectual disabilities and their families—introduction and overview. *Journal of Policy and Practice in Intellectual Disabilities*, 6, 2–6. doi:10.1111/j.1741-1130.2008.00202.x
- Cummins, R. A. (1996). The domains of life satisfaction: An attempt to order chaos. *Social Indicators Research*, 38, 303–328.
- Cummins, R. A. (1997a). Self-rated quality of life scales for people with an intellectual disability: A review. *Journal of Applied Research in Intellectual Disabilities*, 10, 199–216. doi:10.1111/j.1468-3148.1997.tb00017.x

- Cummins, R. A. (1997b). *The Comprehensive Quality of Life Scale – Adult (ComQOL-A5*; 5th ed.). Melbourne, Australia: School of Psychology, Deakin University.
- Cummins, R. A. (2002). *Vale ComQol : caveats to using the comprehensive quality of life scale. Welcome : the Personal Wellbeing Index*. Retrieved from <http://www.deakin.edu.au/research/acqol/instruments>
- Gallimore, R., Weisner, T. S., Kaufman, S. Z., & Bernheimer, L. P. (1989). The social construction of ecocultural niches: Family accommodation of developmentally delayed children. *American Journal on Mental Retardation*, 94, 216–230.
- Giné, C., Balcells, A., Simó-Pinatella, D., Font, J., Pró, M. T., Mas, J. M., & Carbó, M. (2011). Necesidades de apoyo de las familias de personas con discapacidad intelectual en Catalunya [Support needs of families of people with intellectual disabilities in Catalunya]. *Siglo Cero*, 42(4), 31–49.
- Hoffman, L., Marquis J., Poston, D., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of the Beach Center Family Quality of Life Scale. *Journal of Marriage and Family*, 68, 1069–1083. doi:10.1111/j.1741-3737.2006.00314.x
- Hu, X., Summers, J. A., Turnbull, A., & Zuna, N. (2011). The quantitative measurement of family quality of life: A review of available instruments. *Journal of Intellectual Disability Research*, 55, 1098–1114. doi:10.1111/j.1365-2788.2011.01463.x
- Instituto Nacional de Estadística. (2012). Economically active population survey. Retrieved from http://www.ine.es/en/prensa/epa_prensa_en.htm
- Keith, K. D., & Schalock, R. L. (Eds.). (2000). *Cross-cultural perspectives on quality of life*. Washington, DC: American Association on Mental Retardation.
- Muhr, T. (2006). ATLAS.ti (Version 5.1) [Computer software]. Berlin: Scientific Software.

- Perry, J., & Felce, D. (2002). Subjective and objective quality of life assessment: Responsiveness, response bias, and resident:proxy concordance. *Mental Retardation*, 40, 445–456. doi:10.1352/0047-6765(2002)040<0445:SAOQOL>2.0.CO;2
- Rillotta, F., Kirby, N., & Shearer, J. (2010). A comparison of two family quality of life measures: An Australian study. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities: From theory to practice* (pp. 305–348). Dordrecht, the Netherlands: Springer. doi:10.1007/978-90-481-9650-0_17
- Samuel, P. S., Rillotta, F., & Brown, I. (2012). The development of family quality of life concepts and measures. *Journal of Intellectual Disability Research*, 56, 1–16. doi:10.1111/j.1365-2788.2011.01486.x
- Schalock, R. L. (Ed.). (1996). *Quality of life: Vol. I. Conceptualisation and measurement*. Washington, DC: American Association on Mental Retardation.
- Schalock, R. L. (Ed.). (1997). *Quality of life: Vol. II. Application to persons with disabilities*. Washington, DC: American Association on Mental Retardation.
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., ... Parmenter, T. (2002). Conceptualisation, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation*, 40, 457–470. doi:10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.CO;2
- Schalock, R. L., Gardner, J. F., & Bradley, V. J. (2007). *Quality of life for people with intellectual and other developmental disabilities: Applications across individuals, organizations, communities, and systems*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Schalock, R. L., & Keith, K. D. (1993). *Quality of Life Questionnaire manual*. Worthington,

OH: IDS Publishing Corporation.

Schalock, R. L., & Verdugo, M. A. (2002). *Handbook on quality of life for human service practitioners*. Washington, DC: American Association on Mental Retardation.

Summers, J. A., Poston, D. J., Turnbull, A. P., Marquis, J., Hoffman, L., Mannan, H., & Wang, M. (2005). Conceptualizing and measuring family quality of life. *Journal of Intellectual Disability Research*, 49, 777–783. doi:10.1111/j.1365-2788.2005.00751.x

Thompson, J. R., Bryant, B. R., Campbell, E. M., Craig, E. M., Hughes, C., Rotholz, D. A., ... Wehmeyer, M. (2004). *Supports Intensity Scale: Users manual*. Washington, DC: American Association on Mental Retardation.

van Loon, J., van Hove, G., Schalock, R. L., & Claes, C. (2008). *Personal Outcomes Scale*. Middleburg, NL/Gent, the Netherlands: Arduin Steichlich/Department of Special Education, University of Gent.

Verdugo, M. A., Arias, B., Gómez, L. E., & Schalock, R. L. (2008). *GENCAT Scale. Formulary of the Gencat Scale. Application manual of the Gencat Scale*. Barcelona, Spain: Department of Social Action and Citizenship, Generalitat of Catalonia.

Verdugo, M. A., Arias, B., Gómez, L. E., & Schalock, R. L. (2009). *The integral scale*. Madrid, Spain: CEPE.

Verdugo M. A., & Schalock R. L. (2009). Quality of life: From concept to future applications in the field of intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 6, 62–64. doi:10.1111/j.1741-1130.2008.00201.x

Zuna, N., Summers, J. A., Turnbull, A. P., Hu, X., & Xu, S. (2010). Theorizing about family quality of life. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities: From theory to practice* (pp. 241–278). Dordrecht, the Netherlands: Springer. doi:10.1007/978-90-481-9650-0_15

Zuna, N. I., Turnbull, A., & Summers, J. A. (2009). Family quality of life: Moving from measurement to application. *Journal of Policy and Practice in Intellectual Disabilities*, 6, 25–31. doi:10.1111/j.1741-1130.2008.00199.x

Table 1.

Demographic characteristics of the families who took part in the normalisation and standardisation stage

Variables by individuals	Families with a member with ID			
	Under 18 (N = 607)		Over 18 (N = 598)	
	n	%	n	%
Place of residence				
Urban	332	54.69	321	53.68
Semi-urban	181	29.82	189	31.61
Rural	61	10.05	60	10.03
Not available	33	5.44	28	4.68
Age of the person with disability				
0 to 9	253	41.68	-	-
10 to 18	315	51.89	-	-
19 to 39	-	-	431	72.07
40 to 70	-	-	134	22.41
Not available	39	6.43	33	5.52
Disability percentage				
33 to 64%	259	42.67	110	18.39
65 to 74%	141	23.23	222	37.13
> 75%	137	22.57	249	41.64
Other (being processed or assessment not requested)	36	5.93	-	-
Not available	34	5.60	17	2.84

Table 2.
Mean and SD score by domain for each scale (CdVF-E over and under 18)

Domain	Families with a member with ID					
	Over 18			Under 18		
	Items	<i>M</i>	<i>SD</i>	Items	<i>M</i>	<i>SD</i>
Emotional Wellbeing	10	0.84	0.11	8	0.81	0.12
Family Interaction	13	0.85	0.12	13	0.82	0.11
Health	6	0.77	0.13	7	0.76	0.13
Financial Wellbeing	10	0.79	0.16	11	0.69	0.18
Parents' Organisation and Skills	12	0.76	0.13	8	0.77	0.12
Family Accommodation	9	0.83	0.12	7	0.76	0.11
Social Inclusion and Participation	7	0.77	0.88	7	0.79	0.14
Total	67	0.80	0.10	61	0.77	0.10

Note. Items = number of items; *M* = mean; *SD* = standard deviation. The values of the table are proportions.

Appendix. Example of how the items are presented in the CdVF-E

	Never	Rarely	Sometimes	Often	Always	NOT APPLICABLE
<hr/>						
Under 18 years old						
My family is hopeful and has projects for the future.	1	2	3	4	5	0
All the members of my family, including brothers and sisters and close relatives, try to create a pleasant family environment.	1	2	3	4	5	0
The family member with ID has healthy eating habits.	1	2	3	4	5	0
My family has enough financial stability to face the future without any major concerns.	1	2	3	4	5	0
My family engages in activities for all its members to enjoy together (outings, theme parks, days at the beach, etc.).	1	2	3	4	5	0
My family understands the disability of the member with ID.	1	2	3	4	5	0
The family member with ID gets on well with his/her schoolmates.	1	2	3	4	5	0

Over 18 years old

In general, all the members of my family have good emotional stability.	1	2	3	4	5	0
All the members of my family manage to stay calm and treat each other with respect, even when things are tense.	1	2	3	4	5	0
My family has sufficient energy to cope with the situations arising out of the disability of one of its members.	1	2	3	4	5	0
My family can pay for basic necessities (food, clothing, etc.).	1	2	3	4	5	0
My family talks to the member with ID about matters to do with the healthy exercise of sexuality.	1	2	3	4	5	0
My family look for existing resources and supports to improve our quality of life.	1	2	3	4	5	0
The family member with ID has a group of friends.	1	2	3	4	5	0
