

# INICO-FEAPS Scale

Comprehensive Quality  
of Life Assessment of  
people with Intellectual or  
Developmental Disabilities

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# Introduction

After more than two decades of research, the concept known as 'quality of life' has become the key point of conceptual reference and evaluation in the field of intellectual and developmental disabilities. This research has allowed, on a scientific basis, the identification of the main quality of life categories, which have shown to have a universal character, as well as the operationalization of these via fundamental indicators which are sensitive to culture and thus allow for the evaluation of personal outcomes.

Improving the quality of life, when focusing on users individually, is the main and primary strategic objective of the organizations and professional practices, and must also follow public policy. The quality of life model, which was proposed by Schalock and Verdugo (2002/2003, 2012) uses multidimensional personal outcomes with various objectives, among them are: (a) to identify the true needs and preferences of the users; (b) to provide a guide for strategic planning of the organizations and intervention programs; and (c) as an indispensable instrument to evaluate results/outcomes and efficiency.

Research aimed at improving welfare of individuals must face major changes so that results and innovations are put into practice and thus are permitted to be generalized, in such a way that we may be able to overcome the traditional separation between research and professional practice.

To this end, in recent years, one of the strategies that we have put into action in the University Institute on Community Integration (INICO) is focused on developing mixed groups of researchers between the



university and social organisations who support those individuals with disabilities, the objective being that from the start, thanks to the participation of both sectors, work is carried out to maximum methodological rigor and with a practical criterion of utility and service for the users.

The University Institute on Community Integration (INICO) of the University of Salamanca and of the Spanish Confederation of Organisations in Favour of Individuals with Intellectual or Developmental **Disabilities** (FEAPS) have worked in an altruistic manner in order to develop and validate an integral evaluation type Scale of quality of life; during this process, we have relied on the invaluable support from various entities across Spain and from professionals with many years of experience. These were subsequently joined by the AMAS Group, whose financial contributions have allowed for the publication of the instrument which we now present: The INICO-FEAPS Scale.

The INICO-FEAPS Scale that we will present in the following pages of this manual is an instrument whose origin is found in the Integral Scale (Verdugo, Gómez, Arias and Schalock, 2009), in such a way that its initial purpose is maintained (i.e., integral evaluation of quality of life of individuals with intellectual or developmental disabilities but with sufficient ability of expression and comprehension enabling them to carry out the interview), however considerably improving its content, psychometric properties and usefulness. Therefore, the instrument will consist of two subscales: a self-report and a report of other persons (e.g. professionals or family member), from which an individualized profile of quality of life of the individual or a profile of the aggregated results of the organisation can be obtained.

The use of the INICO-FEAPS Scale will allow the development of many initiatives for implementing the quality of life model in Spain and in other countries, in such a way that both professionals and organisations may focus on the data which reflects individual results of the users, services and programs. These individual results will become the key point of reference in regards to the planning and evaluation of efficiency. Via the implementation of this Scale, alongside other instruments and proceedings, an adequate form of feedback regarding advantages and limitations may be obtained, and this will allow for future improvements in terms of the evaluation and use of the Scale.

Miguel Ángel Verdugo Alonso

The present publication includes a CD with the following: Esto entiendo que hay que adaptarlo, no es un CD a lo que se accede en inglés.

- PDF of this publication.
- A Scale questionnaire in a PDF A4 printable format.
- File maker application specifically designed for the automatic execution of quality of life profile reports and the treatment of those specific profiles as informants of an organisation, program or service. (Only in Spanish)
- Text file with INSTRUCTIONS for using the application. As well as this, these documents and applications can be downloaded free of charge from the INICO web page.

This material has been added with the purpose of being useful to all those professionals, services or entities who wish to work with quality of life profiles.

Both the INICO-FEAPS Scale and the application manual are available free of charge at the following INICO web page: <http://inico.usal.es>

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The development of the INICO-FEAPS Scale has been made possible thanks to the collaboration of the group of experts from the Delphi study, which is listed below. Furthermore, the field work has been supported by the voluntary and generous collaboration of professionals and users from various organisations, to whom we express our sincerest gratitude.

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AMI3	ASOCIACIÓN PARA	COOPERATIVA
AMPROS	LA PROMOCIÓN	VALENCIANA KOYNOS
ANIDI	DEL MINUSVÁLIDO	COORDINADORA DE
APAM	“ALBASUR”	DISMINUIDOS FÍSICOS Y
APCOM	ASOCIACIÓN PROVINCIAL	PSÍQUICOS DE VILLAR Y
APROSUB	APANAS	COMARCA
APROSUBA 3	ASOCIACIÓN SAN JOSÉ	FADEMG GALICIA
APROSUBA 8	ASODEMA	FUNDACIÓN AFANIAS CLM
APROSUBA 9	ASPADEX	FUNDACIÓN APROCOR
ARPS	ASPANANE	FUNDACIÓN EU SON
ASFAVAL	ASPIANAS BURGOS	FUNDACIÓN FUENTE
ASINDI	ASPAS	AGRIA - CCEE ASPADES
ASOCIACIÓN PRO	ASPREM ASPRODEMA	LA LAGUNA
DISMINUIDOS	ASPROMIN	FUNDACIÓN GIL
PSÍQUICOS M <sup>a</sup>	ASPRONA ALBACETE	FUNDACIÓN MADRE
AUXILIADORA	ASPRONAGA	DE LA ESPERANZA DE
ASOCIACIÓN A FAVOR	ASPRONTE	TALavera DE LA REINA
DE PERSONAS CON	ASPROSUB “VIRGEN DE LA	FUNDACIÓN PERSONAS
DISCAPACIDAD	VEGA”	FUNDACIÓN PRIVADA EL
INTELLECTUAL DEL	ASSIDO MURCIA	VILAR
BIERZO	ASSOCIACIÓN D’OCUPACIÓN	FUNDACIÓN PRODE
ASOCIACIÓN ABULENSE	I ESPLAI DE CATALUNYA	FUNDACIÓN SIMÓN RUIZ
DE SÍNDROME DE	ASTOR	FUNDACIÓN TUTELAR
DOWN	ASTRAPACE	CANARIA SONSOLES
ASOCIACIÓN APACE	ATUREMENT	SORIANO BUGNION
“VIRGEN DEL VALLE”	CASA FAMILIAR DR.	GRUPO AMÁS
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DISCAPACITADOS	FRANCISCANOS DE	INTEDIS
INTELLECTUALES DE VERA	CRUZ BLANCA	
ASOCIACIÓN DE PADRES Y	CENTRO DE EDUCACIÓN	
AMIGOS DE PERSONAS	ESPECIAL JUAN MARÍA	
CON DISCAPACIDAD	CENTRO ESPECIAL PADRE	
INTELLECTUAL DE	ZEGRÍ	
CUENCA	CENTRO OCUPACIONAL	
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ASOCIACIÓN HORIZONTE	PEDRO GÁMEZ AFAMP	

Participating organisations:

# I. GENERAL DESCRIPTION

## 1. Data sheet

Name	INICO-FEAPS Scale
Subscales	Self-report and Report of other persons
Authors	Miguel Ángel Verdugo, Laura E. Gómez, Benito Arias, Mónica Santamaría, Daniel Clavero and Javier Tamarit.
Meaning	Multidimensional evaluation of quality of life and study of the relationship between the report of other persons (e.g. professionals, family members, legal tutors, close friends) and those carried out by individual with an intellectual or developmental disability, based on the Schalock and Verdugo (2002,2003) eight category model.
Scope	Individuals with intellectual or developmental disabilities
Age range	Adults from the age of 18 years old (or 16, if and when they have left school and carry out some sort of professional, work or occupational activity).
Reporter	Report of other persons: Professionals, family members, legal guardian, close friends or someone close who knows the individual with intellectual or developmental disability well (for a period of at least three months).  Self-report: Carried out by the individual with an intellectual or developmental disability (or by two people who have known said individual for a period of no less than six months).
Validation	University Institution of Community Integration (INICO), University of Salamanca, Spain.

Administration	Individual or in a group. Both Scales are self-sufficient. It is possible to run one application at a time; however it is recommended they are done in a joint manner.
Duration	Report of other persons takes approximately 15 minutes; self-report is 45 minutes.
Objective	Identify the quality of life profiles in order to carry out individual support plans, study the relationship or discrepancies among them and supply a feasible method for the supervision of their progress and for the results of the plans.
Scale	Standard marking of (M = 10; DT = 3) in the quality of life categories, percentile and indexes of quality of life (M = 100; DT = 15).

## 2. Theoretical foundation

The INICO-FEAPS Scale of quality of life is an instrument with sufficient evidence of validity and reliability that allows professionals working in the provision of services, to people with an intellectual or developmental disability to conduct evidence based practices via assessed individual results relating to quality of life. It is therefore an instrument that seeks to answer the remarkable evolution that the concept of quality of life has experienced in the past three decades. It has advanced in terms of its application, from a being a general and philosophical term and a social construct, to an area of applied research and basic principle in the provision of services. Thus the use of this concept has become paramount within social services, health and education. It serves to underline the importance of the individuals own views and experiences, and therefore justifies the programs and activities based on measurable progress in terms of the personal achievement of service users: in other words, when the principles of quality of life becomes the basis of intervention and support, they become a key component in education and in professional training. The implementation of the concept serves to improve the welfare of said individuals within their social context.

The research carried out over the past decade has served to develop the theoretic model, to identify categories and its central/core indicators,

and to guide the implementation of planning centred on the individual, in terms of the evaluation of results and the improvement of quality (Schalock, 2004; Schalock and Verdugo, 2002/2003). Research efforts, evaluation and implementation over the last decade have been directed to provide a strong conceptual and empirical basis for assessing and applying the construct. Therefore, today we can confirm that there are three types of uses of the concept of quality of life: (a) as a framework for the provision of services (e.g. Tamarit, 2005); (b) as a basis for evidence based practices (e.g. Brown, Schalock and Brown, 2009); and (c) as a vehicle to develop strategies to improve quality (e.g. Schalock and Verdugo, 2007).

Thanks to the work carried out by the ‘Special Interest Research Group on Quality of Life’ from the ‘International Association for the Scientific Study of Intellectual Disabilities’ (IASSID), we can confirm that today, there is an **international consensus regarding essential aspects** of the construct. This consensus is specific to the main basic concepts of quality of life (Schalock and Verdugo, 2008), which is shown in Table 1.

Table 1. International consensus regarding the essential aspects of quality of life

1. Quality of life is composed of the same indicators and relationships that are of the same importance to all individuals.
2. Quality of life is experienced when a person’s needs are met and when an individual has the opportunity to improve in all major life aspects.
3. Quality of life has subjective and objective components, however the concept of quality of life is completely down to the individuals own perception of the quality of life he/she experiences.
4. Quality of life is based on the needs, choices and control exerted by the individual.
5. Quality of life is a multidimensional construct, which is influenced by personal and environmental factors, for example, intimate relationships, family life, friendship, work, sense of community, city or place of residence, the home, education, health, living standard and the state of the country in which you reside.

In this sense, Schalock and Verdugo (Gómez, Verdugo and Arias, 2010; Schalock and Verdugo, 2002/2003; 2007; 2012; Schalock, Keith, Verdugo and Gómez, 2010; Verdugo, 2006) conceptualized and defined

quality of life as a desired state of personal welfare that: (a) is multidimensional; (b) has universal properties and properties linked to culture; (c) has objective and subjective components; and (d) is influenced by personal characteristics and environmental factors. As for its measurement, the authors have argued that the way in which people have these valued vital experiences must be made reference to and are reflected in the dimensions that contribute to a full and interconnected life. They bear in mind the context of the physical, social and cultural environments, which are all of importance to people, and include unique vital and common human experiences. The model put forward by Schalock and Verdugo, which will be detailed in the following pages, serves as the basis for the development of the instrument of evaluation that we present here, it is one of the models with the highest evidence of validity on an international scale (Aznar and Castañón, 2005; Chou et al., 2007; Chou and Schalock, 2009; Gómez, Verdugo, Arias and Arias, 2010; Jenaro et al., 2005; Schalock et al., 2005; Wang, Schalock, Verdugo and Jenaro, 2010).

Perhaps these are the reasons that have made this model the most cited in the field of intellectual disabilities and which are currently allowing its application to spread to other groups, such as those of people with visual disabilities (Caballo, Crespo, Jenaro, Verdugo and Martínez, 2005; Verdugo, Prieto, Caballo, and Peláez, 2005), the elderly (e.g. Alcedo, Aguado, Arias, González and Rozada, 2008; Aguado, Alcedo, Rueda, González and Real, 2008; Bowling and Gabriel, 2004; Gómez et al., 2008), individuals with addictions (Arias, Gómez, Verdugo and Navas, 2010; De Maeyer, Vanderplasschen and Broekaert, 2009), individuals with spinal cord injury (Aguado and Alcedo, 2005; Aguado, González, Alcedo and Arias, 2003), individuals with multiple and profound disabilities (Verdugo, Gómez, Arias, Santamaría, Navallas, Fernández and Hierro, esto sigue en prensa, in print) and users of social services in general (Gómez, 2010; Gómez, Arias, Verdugo and Navas, 2012; Verdugo, Arias, Gómez and Schalock, 2008a, 2008b, 2009, 2010).

The model of quality of life is put into operation through categories, measurements and individual results. The basic **categories** of quality of life are understood to be “a number of factors that that makeup personal well-being” (Schalock and Verdugo, 2003, p.34). The categories of quality proposed in the model are: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion and rights.



In turn, the categories are put into operation by core indicators, defined as "perceptions, behaviours or specific conditions of the quality of life categories that reflect the welfare of a person" (Schallock and Verdugo, 2003, p. 34). These comply with at least, five useful functions (Schallock, Gardner and Bradley, 2007/2009): (a) they allow the categories to be measured; (b) they facilitate accountability via measurement of individual results; (c) allow you to track and improve programs and promote changes in individual areas, within organisations, the community and systems; (d) demonstrate intergroup stability and sensitivity towards individual perceptions. The need to develop specific indicators is continually being raised for each category sensitive to the concrete culture in which the assessment will be carried out. Thus, it is common to find in each investigation various proposals for indicators, although in truth, such differences tend to be very mild.

The evaluation of the individual situation or of the individuals own aspirations in these indicators are reflected in the individual results, which are defined as "defined aspirations and personal values" (Schallock, Gardner and Bradley, 2007, p.20). These can be: (a) analysed in an individual area; (b) aggregated at the level of suppliers and systems (e.g. Gómez, Verdugo, Arias, Navas and Schallock, in print<sub>?</sub>); or (c) complemented by other indicators in the systems area (e.g. health and safety indicators, personal renovation, the belonging to community organisations). When these personal results are obtained via the evaluation of central indicators of quality of life based on a conceptual model and via a transculturally validated method, they can be used with multiple objectives and counts as evidence of validity and reliability. They are thus defined as personal outcomes based on the relationship of quality of life, which are based on evidence (van Loon et al., 2013).

Next, in Table 2, we present the **operational definition** of the categories of quality of life that we have used in this work and of which are the results of a profound revision of scientific literature and other evaluative instruments of quality of life, from the discussions and previous experience of the investigative team and the opinion of various experts in the field, via their participation in the Delphi study,

which we will describe in greater detail in the following section of this manual.

CATEGORIES	INDICATORS
SELF-DETERMINATION (SD)	Autonomy; goals, opinions and personal preferences; decisions and choices
RIGHTS (RI)	Exercising of rights; knowledge of rights; intimacy; privacy; confidentiality
EMOTIONAL WELLBEING (EW)	Satisfaction with life; concept of self; Absence of stress or negative feelings
SOCIAL INCLUSION (SI)	Integration; participation; support
PERSONAL DEVELOPMENT (PD)	Training and education; competency at work; problem solving; daily living skills; technical aids
INTERPERSONAL RELATIONSHIPS (IR)	Family relationships; social relationships; Sexual-emotional relationships
MATERIAL WELLBEING (MW)	Income; living conditions; work conditions; access to information; possessions; services
PHYSICAL WELLBEING (PW)	Rest; hygiene; physical activities; leisure; medication, health care

Table 2. Operational definition of the INICO-FEAPS Scale

Sé que es un lío, pero igual poner aquí algo más general que la ley Española le da más alcance a esta traducción... The following Law 39/2006 of the 14<sup>th</sup> of December on the Promotion of Personal Autonomy and Care for people in situations of dependency, as well as recognition of the right to the necessary attention, also recognized the need to overcome certain criteria of quality in services. It is noteworthy that this Act makes provision to that effect, although it should be kept in mind that the fulfilment of the law shall result in an effective quality assurance of services. A clear model should exist establishing the following proceedings and the awaited results

as produce from the mentioned proceedings. On the other hand, also worth mentioning is the resolution of 2<sup>nd</sup> December 2008, regarding criteria for accreditation, which ensured the quality of the care centres and services in the System for Autonomy and Care Unit of the Ministry of Social Policy, Families and Care for Dependency and Disability. Its importance lies in the stipulation to establish requirements and quality standards for the accreditation of centres, which requires, among other information: (a) a Quality Management Plan; and (b) evaluation of the results in terms of improving the quality of life of users. Also, the focus on rights enacted in the **Convention on the Rights of Persons with Disabilities** (United Nations, 2006) promulgates principles in accordance with the model of quality of life, turning it into a vehicle to implement and monitor (Verdugo, Navas, Gómez and Schalock, 2012).

Current emphasis on intervention and improving personal outcomes which are related to quality of life implies the need for **useful tools for assessment**, in order to determine the real situation of each person and to establish the appropriate action which must be carried out (Hogg and Raynes, 1987) in order to develop plans focused on said individual (Claes, van Hove, Vandeveldel, van Loon and Schalock, 2010). In this sense, the concept may be used for several purposes, which include: (a) an objective evaluation of the individuals needs and their subjective levels of satisfaction; (b) the evaluation of the program results, strategies and activities aimed towards the improvement of quality of life conducted by social and human services; (c) the collection of relevant information, which seeks to guide and direct the provision of services; and (d) the planning and formulation of policies aimed at improving the quality of life of those individuals, with or without a disability, and the quality of those organisations which provide social services to distinct groups in risk of exclusion and in need of support.

If an review was to be carried out of existing instruments which assess the quality of life of people with intellectual disabilities, it would be uncovered that the development of such instruments is consistent with the evolution of the concept. Thus, they can be classified **according to the quality of life perspective** with which they were designed; that is, gathering the person with disability's perspective or perception, reflecting on the evaluation or observation of a third party who knows them well (i.e. close friend, a professional,

family member, legal tutor, etc.), or via using an integrated perspective which combines all of these (Cummins, 2005; Gómez, Verdugo and Arias, 2010; Schalock y Felce, 2004; Schalock, Gardner y Bradley, 2007/2009; Schalock and Verdugo, 2007). Our aim is to create distance from previous positions in which objective and subjective instruments were distinguished between, based on the respondent, given the inaccuracies and confusions that such a distinction used to carry. The fact that the questionnaire is answered by a third person does not make the assessment objective; and it still reflects a perception or evaluation, that are always subjective. The distinction between the following self-report (when the individual with a disability completes the questionnaire) and report of other persons (when a third party provides their own perception of the life of the individual who is being assessed) is emphasized in this work. Thus, if personal outcomes are to be evaluated and **person-centred programs** are to be developed, self-reports answered by the individual whose quality of life was assessed must be used. on the other hand, when the aim is conducting the evaluation of said programs, the improvement of the quality of services or to evaluate organisation based changes in a sensitive manner, it is recommended to use reports of other persons based on the direct observation of experiences and personal circumstances.

The existing **relationship** between quality of life assessed from both perspectives has aroused great interest among researchers from the birth of the concept. There are several authors who agree that there is a limited, or even nonexistent, relationship (Claes et al., 2012; Cummins, 2000, 2005; Janssen, Schuengel and Stolk, 2005; Keith and Schalock, 2000; Perry and Felce, 2005; Verdugo, Gómez, Arias and Schalock, 2009). These are the discrepancies which motivate us to continue researching in this field, as they must not be seen or understood as an undesirable outcome. On the contrary, such discrepancies constitute a potential source of information which increases the possibility of developing programs for the provision of care and services adjusted to the real needs of people (Janssen et al., 2005). In this sense, Olsen and Schober (1993) provide an interesting conceptualization of perspectives of concordance and discordance in regards to quality of life, and also reflect on the psychological processes (such as cognitive

dissonance and learned helplessness) which underlie and explain this inconsistency.

There are hundreds of instruments for assessing quality of life in the field of intellectual and developmental disabilities. However, if we focus on those that have been developed from the model of quality of life in eight categories, and reflect the dual perspective detailed earlier (i.e. self-report and report of other persons) and which are adapted to the Spanish context, the range is reduced to a single instrument: the INTEGRAL Scale (Verdugo, Gómez, Arias and Schalock, 2009; Verdugo, Gómez, Schalock and Arias, 2010). This scale emerged as an original and innovative tool in the international arena by being the only one to date to have developed from this model and for retaining both perspectives. It also has sufficient evidence of validity and reliability, making it an instrument both widely used and useful in organisations for people with disabilities in our country. The relevance of the instrument for assessing the quality of life of people with disabilities is reflected both in the national and international context. As a proof of this, processes of adaptation and validation have already begun to be implemented (aquí se puede poner que se han hecho, supongo) in other countries like the Netherlands (Verdugo, Arias, Gómez and van Loon, 2007), Belgium, Portugal, Ireland, Colombia, Argentina and Brazil (Gómez, Verdugo, Arias, López, Moreno and Córdoba, 2010). Furthermore, based on this scale, another instrument has been developed and validated in the Netherlands with similar characteristics: 'Personal Outcomes Scale' (POS, 'outcomes Scale' (van Loon, van Hove, Schalock and Claes, 2008).

However, although the Integral Scale was the most up to date and most recently complete instrument for people with intellectual or developmental disabilities, its extensive application in Spanish organisations and feedback provided by their applicators revealed some limitations that needed to be overcome. Amongst these, it was highlighted that the scale: (a) did not allow for a quantitative assessment (although it did qualitatively) of the model's eight categories; (b) the two versions (the self-report and report of other persons) were not parallel (i.e. they did not contain exactly the same items); and (c) the so called ceiling effect was frequently produced (i.e. the majority of people achieved very high scores, indicating that the

collected content from the scale had already begun being worked with and reached by the majority of organisations).

In order to overcome these limitations the development of the scale presented here arose: the INICO-FEAPS Scale, with a larger number of items, organized around the eight categories of the quality of life model with fully parallel forms, and with content that seeks to cover a wide range of difficulty (i.e. collecting aspects which should be worked with in the organisations and that today are not reachable by everyone). The originality and main contribution of this instrument lies mainly in the facts that the INICO-FEAPS Scale: (a) is based on the latest advances carried out based on the theoretic model of quality of life of Schalock and Verdugo (2002/2003); (b) allows for the of the relationship between the report of other persons and the self-report of quality of life; and (c) highlights the similarities and differences between the perceived quality of life of people with disabilities and the perception of professionals working with the individuals or relative who knows them well. Also, the INICO-FEAPS Scale is presented as a valid and reliable instrument for planning person-centred interventions and supports, as well as providing valuable information from which to guide processes of change and improvement.

### 3. Development process of the scale

The INICO-FEAPS Scale is an instrument developed to assess the quality of life of those adults with intellectual disabilities from the perspective of the individual with the developmental or intellectual disability themselves (self-report), as well as from the perspective of an outside observer who knows them well. The developmental process of the scale has placed special emphasis on creating an instrument that allows the assessment of the eight categories of the model put forth by Schalock and Verdugo (2002/2003), with adequate evidence of validity and reliability. Thus, the first step has been to conduct a thorough review of the scientific literature which then allowed for the selection and proposal of items and core indicators of quality of life for assessing each of the eight categories contemplated in the model.

Following this, a rigorous Delphi study was developed, which is composed of four rounds, in which 12 experts participated in defining the concept of quality of life. They also participated in regards to evaluation and application of the construct in the services aimed at those individuals with intellectual or developmental disabilities, and they all with extensive experience in the mentioned field.

- Round 1:** The task consisted of assessing, on a scale from 1 to 4 the suitability, importance and sensitivity from the pool of items (N = 80). The majority of items were conserved (n= 67) to show an average  $\geq 3$  and standard deviation  $<1$ . Experts were also encouraged to propose new items and indicators not included in the set to assess the different categories. In this sense, the judges proposed a high number of items (n = 388).
- Round 2:** The 388 items proposed by the experts were revised by the research team. Once the redundant items were eliminated, the pool was reduced to 231. Following this, the experts had to decide whether the following were to be included into the INICO-FEAPS Scale or not: 38 of the items were added to the set once all the experts were in accordance regarding their relevance. Also, a forum based discussion was carried out regarding the 13 items designated as invalid from the first round. After the anonymous discussion, the majority of the items (N = 8) were finally considered to be valid after them having been reformulated.
- Round 3:** Subsequently, the adequacy, importance and sensitivity of the 46 items selected in the second round were assessed (38 items selected from those proposed by the judges over 8 accepted following discussion). The task consisted of once again assessing the suitability, importance and sensitivity of the items on a scale of 1 to 4. Only 8 items were not valid, according to the same criterion of inclusion from the first round.
- Round 4:** The research team selected the 86 items which obtained the highest scores in terms of suitability, importance and sensitivity, from the items deemed valid so that there were between 8 and 10 statements to assess each quality of life domain. They also ensured the assessment of all of those

indicators which had been deemed relevant. These 86 items, plus 2 items which the research team had added to the social inclusion domain, as the previous number was insufficient, had conformed to the pilot scale (N = 88). The task of the judges consisted this time on assessing the suitability of the format instructions, the vocabulary, the socio-demographic data and the answer options. The participation of the judges brought once again several suggestions that contributed to significantly improving the format of the scale.

Subsequently, a sample scale was applied to 1627 people with intellectual or developmental disabilities who had been receiving some type of service in one of the 66 entities belonging to FEAPS (Spanish confederation of Organisations for Persons with Intellectual Disability and Development) across Spain. Apart from intellectual disabilities, participants occasionally showed some other disabilities associated with health problems (13.8%), physical disabilities (13.5%), Down syndrome (11.4%), mental health (6.5%), visual impairment (6%), language problems (3.8%), hearing disabilities (2.5%), learning disabilities (2%), brain damage (1.8%), autism spectrum disorders (0.9%) and developmental delays (0.6 %). The percentage of women slightly exceeded the number of men (56.1% vs. 43.9%). Regarding the level of dependence, 20.1% were evaluated in level I moderate dependence, 21.7% were evaluated in level II of severe dependence and 7.2% were evaluated in level III high dependency (for more than half of the sample, 50.5% this assessment was not available).

Once the fieldwork had been done, a preliminary analysis of the internal consistency of the items was conducted (using Cronbach's alpha) and a calculation based on the discrimination parameter ( $\alpha$ ) by the Samejima Graduate response model was also conducted. Results of such analyses led to the elimination of 16 items that showed low values in some of the two statistics cited (ie. less than .20 Cronbach alpha of .40 and below the discrimination parameter). Therefore, the scale was set by 72 items, nine in each of the eight dimensions.

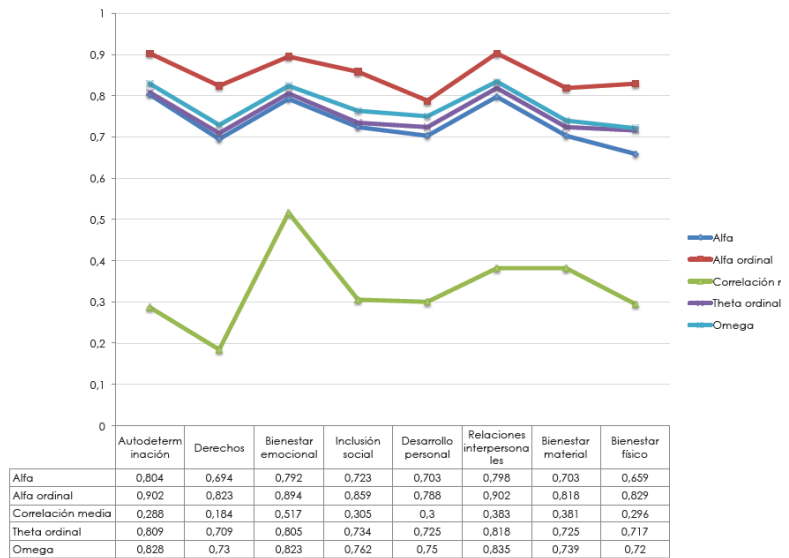


## 4. Psychometric Properties

### 4.1. Internal Consistency

The analysis of internal consistency of the statements was performed using Cronbach's alpha, in such a way that in the "Report of other persons"  $\alpha = 0.937$  was obtained and in the "Self-report", a slightly lower, but equally suitable, coefficient of  $\alpha = 0.893$  was obtained. Results of the subscales are shown in Figures 1 and 2.

Figure 1. Internal Consistency of the "Report of other persons"



\Alfa – Alpha

\Alfa ordinal – Ordinal alpha

\Correlación media – Moderate correlation

\Theta ordinal – Ordinal theta

\Omega – oOmega

Self Determination	Rights	Emotional Wellbeing	Social Inclusion	Personal Development	Interpersonal Relationships	Material Wellbeing	Physical Wellbeing
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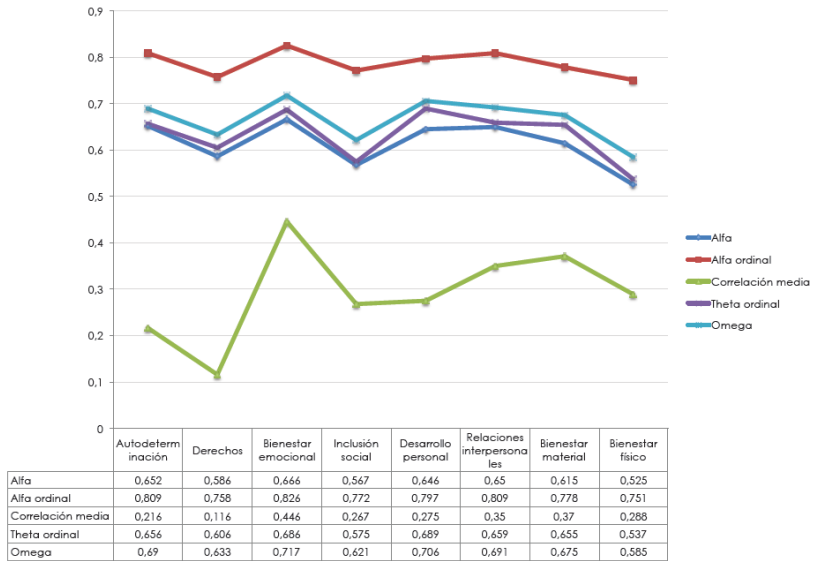
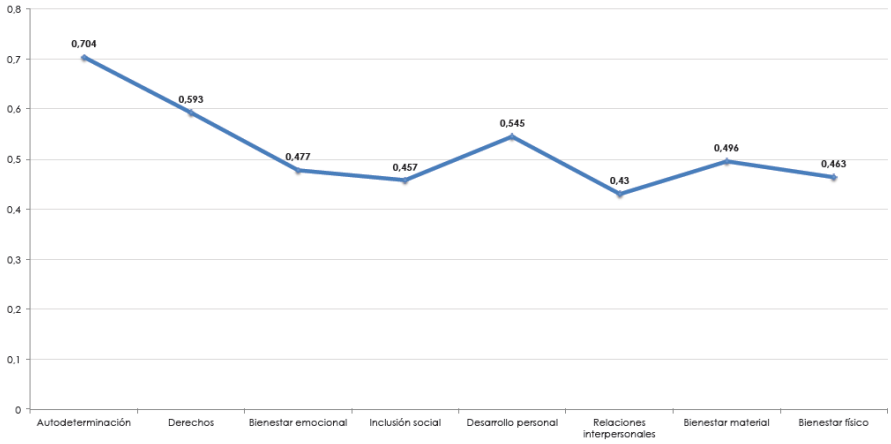


Figure 2. Internal Consistency of the “Self-report”

## 4.2. Inter-evaluator Reliability

With the aim of determining the inter-evaluator reliability of the “Report of other persons”, external evaluators (observers who knew the person well) were sought out. 87 people were assessed in this way. The inter-evaluator reliability was analyzed using the Pearson correlation coefficient calculation in each one of the categories. General results are presented in Figure 3, while Figure 4 provides a more detailed analysis. From these it can be concluded that there is evidence of suitable reliability.



Self Determination	Rights	Emotional Wellbeing	Social Inclusion	Professional Development	Interpersonal Relationships	Material Wellbeing	Physical Wellbeing
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Figure 3. Inter-evaluator reliability of the “Report of other persons” (Pearson Correlation)

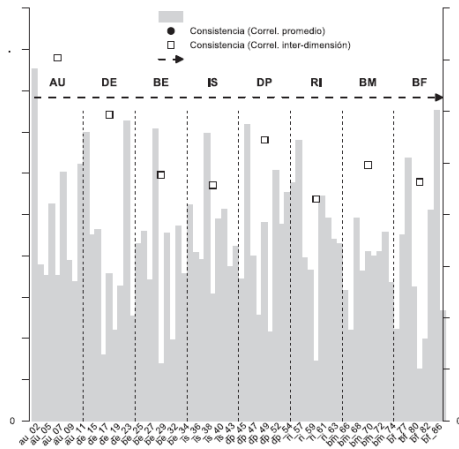


Figure 4. Inter-evaluator reliability of the “Report of other persons” (Average coefficient correlation between categories and overall)

Consistencia (correl. promedio) = consistency (expected correl.)

Consistencia (correl. Inter-dimensión) = consistency (inter-dimensional correl.)

AW = SD, DE = RI, BE = EW, IS = SI, DP = PD, RI = IR, BM = MW, BF = PW

### 4.3. Evidence of validity based on the internal structure of the scale

With the objective of providing evidence of validity based on the internal structure of the scale, a confirmatory factor analysis (CFA) was carried out. Due to the high number of statements, the CFA was carried out in parcels *packets* made up using the following method: (a) each parcel *packet* is made up of 4 statements; and (b) the statements are assigned to parcels *packets* based on their asymmetric value function (i.e. the most and least asymmetric make up parcel *packet* 1; the next most and least asymmetric make up parcel *packet* 2 etc.). As can be observed in Figures 5 and 6, in all cases linearity criteria are met, namely/specifically: (a) the ratio between the first and second *eigenvalue* is greater than 4; (b) the proportion of variance explained by the first factor is greater than 40%; and (c) the difference between the percentage variance explained by the first and the second factor is greater than 40.

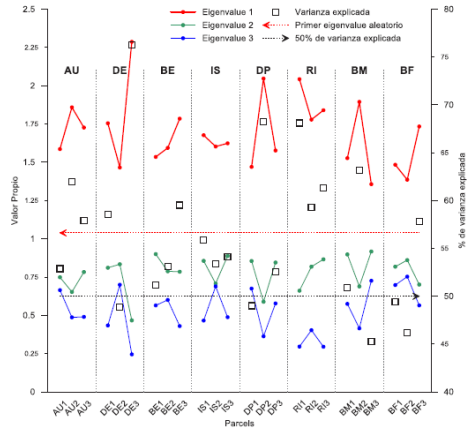


Figure 5. Single-dimensional parcels packets of the “Report of other persons”

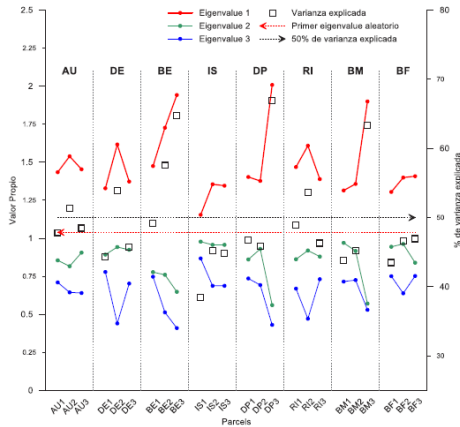


Figure 6. Single-dimensional parcels packets of the “Self-report”

Varianza explicada – Explained variance

Primer eigenvalue aleatorio – First random eigenvalue

50% de varianza explicada – 50% of explained variance

AW = SD, DE = RI, BE = EW, IS = SI, DP = PD, RI = IR, BM = MW, BF = PW

Valor Propio – Intrinsic Value

Parcels – Packets ¿¿?? Parcels no es en inglés???

% de varianza explicada - % of explained variance

The CFA was calculated using LISREL v9.1. The estimation method used on the covariance and asymptotic variance-covariance matrices was DWLS. The model submitted to the test was that of Schallock and Verdugo (2003/2003), in which the quality of life is understood to fall into comprise eight interlinked domains (Figure 7): Self Determination (SD), Rights (RI), Emotional Wellbeing (EW), Social Inclusion (SI), Professional Development (PD), Interpersonal Relationships (IR), Material Wellbeing (MW) and Physical Wellbeing (PW). As shown in Table 3, results of the CFA show that the eight dimension model is a good fit to the data.

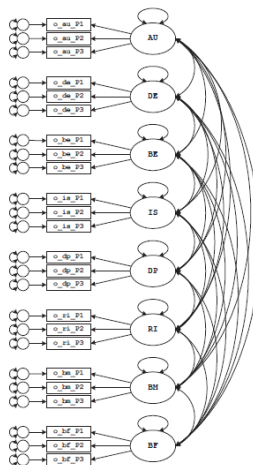


Figure 7. Model of the eight categories being tested

AW = SD, DE = RI, BE = EW, IS = SI, DP = PD, RI = IR, BM = MW, BF = PW

	“Report of other persons”	“Self-report”
S-B $\chi^2$	1809.91	1640.99
GL	224	224
P	.000	.000
RMSEA	.066	.056
(90%)	.063 ; .069	.053 ; .059
CFI	.94	.96
TFL	.93	.96
SRMR	.021	.052

Table 3. Model Adjustment

## 5. The INICO-FEAPS Scale

Both the subscales “Report of other persons” and “Self-report” contain the same statements (i.e. the statements assess the same content in both versions of the scale). All content refers to one of the eight central quality of life domains, in such a way that each one provides differentiated quantitative scores. Also, each subscale provides a general rating of quality of life. All scores obtained are presented graphically in a Quality of Life Profile which facilitates the interpretation of the results, as well as the analysis of similarities and differences found between the two subscales.

To be more specific, the **“Report of other persons”** contains 72 statements written in third person using Likert type response format of four options: *never, sometimes, often and always*. All statements gather information on observable aspects of the quality of life of the individual with disability. It is filled out by a respondent who knows the individual whose quality of life is being assessed well (for at least three months). In the case of responses being left blank, the respondent may be consulted if necessary in order to obtain precise and complete information. However this should never be consulted to the individual with a disability whose quality of life is being assessed. If necessary, it must be brought up in the appropriate box (“Other

informants”) in the annotation booklet. The time estimated for completion is 15 minutes.

The “**Self-report**” contains the same 72 statements as in the previous version but this time written in first person and in simpler language. The response format is also the same, using the Likert type scale with four options: *never*, *sometimes*, *often* and *always*. This subscale is filled out by the individual with an intellectual disability (preferably via an interviewer, however it could be completed independently, in which case it is advisable to provide the individual with the necessary support to ensure a proper understanding of the statements and the response format of the interviewer). In the case that the individual with the intellectual or developmental disability does now have the necessary level of communicative and expressive ability, this version may be filled out by two people who know the individual well (for at least six months). Estimated completion time is 45 minutes.

## 6. Application material

As well as the current Application Manual, the reading of which is obligatory before proceeding with the assessment, the INICO-FEAPS Scale Questionnaire, which contains the “Report of other persons” and the “Self-report”. This questionnaire is included at the end of the manual and also as an independent document on the INICO website and **in CD format** revisar esto to facilitate printing on A4 paper.



## II. APPLICATION GUIDELINES

### 1. INICO-FEAPS scale

The INICO-FEAPS Scale provides information regarding the parts of life most important for a person from the point of view of others and from the perspective of the person with an intellectual or developmental disability. In this way it is possible to confront both points of view and arrange programmes better suited to the true needs of the person. The assessment should not be carried out in cases where the individual with the disability has recently been through a significant event, which could distort the results of the test (e.g. finding yourself in the pain process, being diagnosed with a health problem, being in the process of surgical intervention or a change of address). This tool consist of two subscales: “Report of other persons” and “Self-report”, both with 72 parallel statements further organised into eight quality of life categories.

Report of other persons	Self-report
<ul style="list-style-type: none"><li>- Reflect the perception of an external observer who knows the person well.</li><li>- Completed by a third party: professional, family member, friend, tutor or other.</li></ul>	<ul style="list-style-type: none"><li>- Reflect the assessment and perception of the person with intellectual or developmental disability.</li><li>- Completed by the person with intellectual or developmental disability.</li></ul>

Both versions are in the same form, answered by different people, including: (a) three sections of gathered data: from the individual being assessed, the main respondent and the other respondents; (b) the 72 statements with a four option response (never, sometimes, often and always), set out in third person in the case of the “Report of other persons” and in first person in the case of the “Self-report”; (c) a section where the person being assessed and/or the respondent may record any other information deemed relevant.

## 2. Application of the Scale

Detailed instructions are included in the INICO-FEAPS scale for completing each of the sections. Before carrying out any evaluation/test, please read these instructions carefully.

### 2.1 Details of the individual being assessed

The section “Details of the individual being assessed”, refers to the details of the individual with the disability whose quality of life is being assessed and therefore, will complete the “Self-report” (i.e. the individual with intellectual or developmental disability, over the age of 16 years, provided that the individual is not within the education system and is carrying out some kind of work activity, professional or occupational).

### 2.2 Details of the observer/respondent

The respondent is the individual who must complete the details section for the individual being assessed, as well as the Report of other persons. An eligible respondent is a social services professional who has known the person for at least three months and would have the opportunity to observe the individual in different contexts and during prolonged periods of time. The respondent could also be a relative, legal guardian, close friend or a member of immediate family who knows the person with an intellectual disability well.

### 2.3 Details of the other respondents

Other respondents are considered to be any individual whom it might be necessary to consult on any aspect of the subscale, “Report of other persons”. Another respondent could be a professional, a relative or someone close, who meets the requirements to be a main respondent (i.e. those included in the previous section), but it must NEVER be the individual who is the subject of the assessment. It is considered normal to consult one or two respondents to complete the Report of other persons.

## 2.4 “Report of other persons” Subscale

The report of other persons does not require any special prior preparation, rather just the careful reading of this application manual. Further to the reading of this manual, it is necessary that the respondent (e.g. the professional, family member or someone close) knows the person with the intellectual disability well (for at least three months) and would have the opportunity to observe the individual in different contexts during prolonged periods of time. Furthermore, the respondent must have the opportunity to consult with another person (never the same person whose quality of life is being assessed) in the case of not knowing the response to one of the statements due to not being able to observe the individual with the disability in a particular area.

The subscale consists of 72 statements written in third person which gather information on important aspects of the life of a person and which are answerable with four options (never, sometimes, often and always). Read the following instructions in order to use the response format correctly.

**‘Never’** if the person never does or if the content of the statement never happens. For example, in response to the statement ‘Sleeps well’, NEVER would be marked if the individual has problems sleeping every day of the week.

**‘Sometimes’** if the person does it occasionally, or the content of the statement does happen very now and again, but not the majority of the time. For example, in response to the statement ‘Sleeps well’, SOMETIMES would be marked in the case that the individual only sleeps well 2 or 3 days a week.

**‘Often’** if the individual does it often, or the content of the statement happens majority of the time. For example, in response to the statement ‘Sleeps well’, OFTEN would be marked if, for example, the individual sleeps well between 4 and 6 days a week.

**‘Always’** if the person always does, or if the content of the statement always happens. For example, in response to the statement ‘Sleeps well’, ALWAYS would be marked if the individual sleeps well every day (even if there might be an exceptional night when the individual has trouble sleeping; for example, if the individual slept badly a few times a year, maybe because of indigestion for example, ALWAYS would still be the answer).

In the case of actions which do not take place every single day, use proportional criteria, taking into consideration bigger units of time (e.g. monthly or annually).

The 72 statements are organized into eight subscales which coincide with the eight quality of life categories. You must make sure to respond to every statement of each subcategory before moving on to the next and do not forget that other respondents can be consulted in case of any doubt, however the individual with the disability being assessed must NEVER be consulted.

Finally, a blank space is provided to include any comments or suggestions. If any information is not known, the name of anyone who may be able to provide this information can be noted, and indicated in the section “Details of other respondents”.

In the case of the individual who fills out the version “Report of other persons” being the interviewer or the support assistant for the individual with an intellectual disability in completing the “Self-report”, it is crucial to make sure to complete the “Report of other persons” before the individual with disabilities completes the “Self-report” as to not distort the responses. Also, in this case it is vitally important that the interviewer or the support assistant does not direct or exert any influence on the responses of the disabled person to avoid bias.

## 2.5 “Self-report” Subscale

The Self-report is completed by the individual with intellectual disability, with a sufficient level of expressive and comprehensive ability in order to understand the questions and the response options. If the individual with the disability were not to have the required level of ability even with the available support, the report may be completed by two people who know the individual well (for at least six months). The individual with disabilities should preferably be over the age of 18, however it could be applied to individuals from the age of 16, provided that they are carrying out some kind of work activity, professional or occupational (as several of the statements refer to this type of activity and are not applicable to individuals in school). As it is of a parallel format, the same sections as the Report of other persons are included.

The subscale consists of 72 statements written in first person and organized into eight subcategory which coincide with the eight domains of quality of life, and which gather information on important aspects of life. The individual must choose between the four response options (*never, sometimes, often and always*) not leaving any question blank. It is important that the individual being assessed knows that there are no right or wrong answers and that the important thing is to find out their opinion in order to improve their life. It is also essential to clarify that all responses are confidential and they will never result in any detrimental consequences. In order to

complete the assessment, the individual must understand the following response format:

‘**Never**’, if what is described in the statement never happens.

‘**Sometimes**’, if what is described in the statement sometimes happens, but not the majority of the time (i.e. infrequently; for example, every other day).

‘**Often**’, if what is described in the statement happens most of the time (i.e. frequently; for example, nearly every day).

‘**Always**’, if what is described in the statement happens all the time (for example, every day).

In the case of actions which do not take place every single day, use proportional criteria, taking bigger units of time into consideration (e.g. monthly or annually).

Despite the Self-report having been developed to be completed independently by individuals with an intellectual or developmental disability, it is recommended to carry out the process through an interviewer or support assistant with the aim of guaranteeing total understanding of the statements and the response format.

Where an interviewer is used, special care must be taken not to influence the response of the individual. Especially in the case that the interviewer and the respondent who completed the “Report of other persons” are the same person, it is important that the latter report is always completed **before the individual with disabilities completes the “Self-report”** so that the responses of the latter do not influence their understanding.

To make carrying out of the Self-report easier, a simple key has been included: a blank rectangle to represent the option **never**, a rectangle with one third colored in to represent the option **sometimes**, a rectangle with two thirds colored to represent **often** and a completely filled in rectangle to represent the option **always**. This is the main difference between this scale and the “Report of other persons”.

In any case, if the individual with the disability has a high function level and expressly states his/her desire to answer the questionnaire independently, the reliability of his/her responses must be ensured. This reliability is the responsibility of the assistant.

Finally, a section is provided for any comments or suggestions that the individual with the disability, the interviewer (if any/applicable) or the assistant deems necessary/wished noted.

### 2.5.1 Instructions for the application of the Self-report

As it has been mentioned previously, it is recommended that the self-report is carried out via an interviewer with the aim of ensuring total comprehension of the statements and the response format (unless, as previously specified, the individual expressly states his/her desire to complete it independently, once the assistant has made sure that the individual perfectly understands the instructions, statements and the response options). Even in the case of the individual filling in the subscale independently, it is recommended to verbally explain the instructions detailed below.

The assessment should be scheduled for a time which would minimally interrupt the daily activities of not only the individuals with disabilities but also the professionals working with them, in a pleasant place and free of distractions. However, it would be advisable to carry out the whole assessment in one session. If this is not possible, the remaining questions may be completed in another session, provided that there is not a long delay. In fact, if more than three days pass by between the first and second session, the assessment should be started again. To avoid this situation, it is recommended that the interviewer and the individual with the disability leave at least an hour to carry out the assessment.

The administration of the assessment by an interviewer requires a certain amount of preparation. It is important that the interviewer is familiar with the statements, the instructions and the response format as well as careful consideration of the recommendations included in this manual. If the interviewer is also carrying out the role of respondent in the Report of other persons, special care must be taken to not influence the responses of the individual with the disability in any way.

The person with the disability should receive the information, in a language appropriate to his/her level of understanding, about the purpose and characteristics of the assessment. It is essential that the person is motivated to answer the questions. It is advisable that the interviewer knows the person well and, given the personal information that is required, can establish a rapport and trust relationship. If there is not a close personal relationship with the interviewer, there is the risk that the information obtained may be uncertain or imprecise. Therefore, it is recommended that before starting the assessment, interviewer and subject chat about general topics (e.g. weather, sports, TV shows, etc.) to help reduce anxiety or nerves that the individual may be feeling (additional recommendations on how to interview people with disabilities can be found in Tassé, Schalock, Thompson and Wehmeyer, 2005).

To start with, the interviewer should read aloud the instructions included in the “Self-report”, putting special emphasis on the fact that there are no right or wrong answers and that their responses will be completely confidential and therefore will

not affect their relationship with any care centre, family member or close friends. Special emphasis should be placed on the importance of their honesty, since the objective is to find out what they think and feel in order to improve their quality of life. All necessary explanations should be provided to motivate the individual, to ensure their honesty and make sure that no doubts remain about the assessment process. As it has been already indicated, before starting to respond to the statements, the interviewer should make sure that the person understands the response format, by using the examples given in the instructions.

The interviewer can clarify or reform each statement as much as required for the individual with an intellectual disability to understand (clarifications such as those included in the previous comments section may also be included). To do this, the statement should always be read in second person followed clearly by all four response alternatives. It would be advisable to introduce a system for each response and always show the iconic key (prepare the cut out cards at the end of the manual: Appendix B). The answer which corresponds to the response given by the individual is then marked. It is very important not to leave any statements unanswered, however this can but can be done if the individual does not understand the content of one of the statements (only in special circumstances).

The interviewer should not put any special emphasis on any of the responses, nor influence in any way. When the individual feels that several or none of the response options are suitable, the interviewer or assistant who helps them to fill out the questionnaire independently should explain that this is normal but that the option which best describes what the individual thinks or believes should be chosen.

Summary of the essential questions which should be considered by the interviewer (Tassé et al., 2005):

1. Carry out the assessment at a time which minimally interrupts the activities of both the interviewer and the individual with a disability.
2. Choose a nice quiet place.
3. Complete the assessment in a single session.
4. Be familiar with the assessment.
5. Convey information in a language suitable for the individual with a disability without influencing their answers and making sure everything which is asked is understood.
6. Know the person well and establish a rapport and a (feeling/environment of) trust.

### 2.5.2 Completion of the Self-report with individuals without the necessary understanding and expressive skills.

If the individual with a disability does not have the sufficient understanding and expressive ability to be able to complete the “Self-report”, it can be completed by two people who know the individual well (for at least six months). This is on the condition that they do not bring with them their own perception of the life of the individual, but rather to try to put themselves in the place of the individual being assessed, reflecting what they think the individual with the disability would respond if they were able. Once the assessment has been completed by both persons, the mean of the scores obtained in each category is calculated, then used for the following scores, ratings and profiles. The validity of this approach is obviously less ideal, therefore these results should be taken with caution.



### III. CORRECTION

#### 1. Correction of the scale

The section focuses on providing detailed keys and descriptions in order to review the “Report of other persons” and the “Self-report”, as well as how to interpret the results of the indicators of quality of life. A practical example that illustrates the correction and interpretation of the results of both subscales is included at the end of this section.

On the website (<http://inico.usal.es>) there is an application specifically designed to facilitate the automated production of individual profiles and treatment of data grouped by organization, programme or service. The reader is urged to consult and practice with this tool, to have a good command of it.

#### 2. Report of other persons

The scores obtained in the Report of other persons serve to complete the score summary of this subscale and to complete the “Other persons” Quality of Life Profile which is included at the end of the INICO-FEAPS Scale.

##### Raw Scores

To obtain the total raw score in each domain, the sum of the responses (1-2-3-4) for each statement is required, as shown in Figure 8.

EMOTIONAL WELLBEING		N	S	O	A
19	He/she shows signs of depression	4	3	2	1
20	He/she doesn't want to do anything	4	3	2	1
21	He/she shows signs of anxiety	4	3	2	1
22	He/she has behavioural problems	4	3	2	1
23	He/she is self-confident	1	2	3	4
24	He/she is satisfied with what he/she may be able to do in the future	1	2	3	4

25	He/she is proud of him/herself	1	2	3	4
26	He/she shows a desire to change his/her way of life	4	3	2	1
27	He/she enjoys the things he/she does	1	2	3	4
Total Raw Score					28

Figure 8. Calculation of the raw score of a category (from the “Report of other persons”)

The total raw score is calculated in the same way for each of the eight quality of life categories. These total raw scores are used later on to complete the “Summary of Report of Other Persons Scores/Scoring”.

### Standard and percentile scores for each category

In Annex A, the table with the scale is included (Table A) which is needed to transform the raw scores into standard scores and to obtain the corresponding percentiles. To do this, the standard score and percentile which correspond to the total raw score for each of the domains need to be found. The results are recorded in the corresponding columns of the “Summary of the Report of Other Persons Scores” as shown in Figure 9.

### Quality of Life Rating and Quality of Life Rating Percentile

To obtain the Quality of Life Rating from the Report of Other Persons first the sum of the standard scores for each of the eight domains has to be entered into “Total Standard Score (sum)”. This value becomes the Quality of Life Rating (or Composite Standard Score) using Table C, included in Annex A. The row “Total Standard Score (sum)” should be found in this table and in the two columns on the left, the Quality of Life Rating and its corresponding percentile can be found. Following the example (Figure 9), a sum of the scores from the eight domains of “69” would become “91” in the Quality of Life Rating for the subscale Report of other persons. The Quality of Life Rating percentile in this case would be “27”.

REPORT OF OTHER PERSONS			
1. Enter the total raw scores for each domain			
2. Enter the standard scores and percentiles			
3. Enter the Quality of Life Rating and its corresponding percentile			
QUALITY OF LIFE DOMAINS	Total Raw Scores	Standard Scores	Percentiles
SELF DETERMINATION	23	9	37
RIGHTS	27	8	25
EMOTIONAL WELL BEING	28	10	50
SOCIAL INCLUSION	29	10	50
PERSONAL DEVELOPMENT	26	9	37
INTERPERSONAL RELATIONSHIPS	24	9	37
MATERIAL WELL BEING	28	8	25
PHYSICAL WELL BEING	25	6	9

Total Standard Score (sum)	69	
Quality of Life Rating (Composite Standard Score)	91	
Quality of Life Percentile		27

Figure 9. Calculation of the “Report of other persons” Quality of Life Rating

### Quality of Life Profile

The Quality of Life Profile for the “Report of other persons” is found on the last page of the questionnaire. It provides a graphical representation of standard scores obtained for the eight quality of life categories, the Quality of Life Rating and the corresponding percentiles. To create the profile, the standard scores obtained should be circled then a line drawn between them (Figure 10).

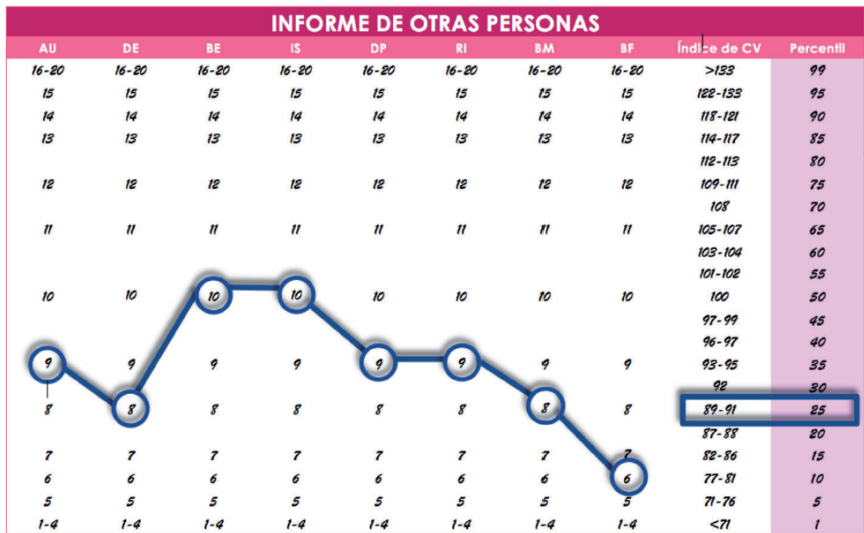


Figure 10. “Report of other persons” Quality of Life Profile

#### REPORT OF OTHER PERSONS

AW = SD, DE = RI, BE = EW, IS = SI, DP = PD, RI = IR, BM = MW, BF = PW

Índice de CV – QL index

Percentile - percentile

### 3. Self-report

The process for scoring and correcting the “Self-report” is similar to that presented in the previous section. The scores obtained are used to complete the score summary for this subscale and to complete the “Self-report” Quality of Life Profile included at the end of the INICO-FEAPS Scale.

#### Raw Self-report Scores

To obtain the total raw score in each category, the addition of the responses (1-2-3-4) for each statement is required (Figure 11). Once the total raw scores for each of the eight categories have been calculated, these are transferred to the “Self-report Score Summary”, found at the end of the scale.

<b>SOCIAL INCLUSION</b>		<b>N</b>	<b>S</b>	<b>O</b>	<b>A</b>
28	I join in conversations with other people on topics that interest me	1	2	3	4
29	I often go to places in my community (e.g., restaurants, shops, parks) without any problem	1	2	3	4
30	I have friends who do not have a disability	1	2	3	4
31	I feel excluded from my work group, leisure group or group of friends	4	3	2	1
32	I find it difficult to engage in activities with people who do not have a disability	4	3	2	1
33	I get the support necessary to do well in my job/tasks	1	2	3	4
34	There are only a few people able to help me when I need it	4	3	2	1
35	People tell me when I do things well	1	2	3	4
36	The people around me have a negative image of me	4	3	2	1
Total Raw Score		26			

Figure 11. Calculation of the raw score of a category (from the “Self-report”)

### Standard and percentile scores for each category in the Self-report

In Annex A, the table with the scale is included (Table B) which is needed to transform the raw scores into standard scores and to obtain the percentiles. The standard score and the percentiles which correspond to the total raw score for each of the categories should be found in Table B. The results are recorded in the corresponding columns of the “Summary of the Self-report Scores” table, as shown in Figure 12.

### Quality of Life Rating and Quality of Life Rating Percentile in the Self-report

To obtain the Quality of Life Rating for the Self-report first the sum of the standard scores for each of the eight domains has to be entered into “Total Standard Score (sum)”. This value becomes the Quality of Life Rating (or Composite Standard Score) using Table C, included in Annex A. The row “Total Standard Score (sum)” should be found in this table, and in the two columns on the left, the Quality of Life Rating and its corresponding percentile can be found. Following the example (Figure 12), a sum of the scores from the eight categories of “60” would become “82” in the Quality of Life Rating for the subscale Report of other persons. The Quality of Life Rating percentile in this case would be “11”.

SELF REPORT			
1. Enter the total raw scores for each domain (yellow boxes)			
2. Enter the standard scores and percentiles			
3. Enter the Quality of Life Rating and its corresponding percentile			
QUALITY OF LIFE DOMAINS	Total Raw Scores	Standard Scores	Percentiles
SELF DETERMINATION	20	7	19
RIGHTS	22	6	9
EMOTIONAL WELL BEING	29	10	50
SOCIAL INCLUSION	26	8	25
PERSONAL DEVELOPMENT	25	8	25
INTERPERSONAL RELATIONSHIPS	24	8	25
MATERIAL WELL BEING	22	4	2
PHYSICAL WELL BEING	29	9	37

Total Standard Score (sum)	60	
Quality of Life Rating (Composite Standard Score)	82	
Quality of Life Percentile		11

Figure 12. Calculation of the Standard Scores and Percentiles for the “Self-report”

### Self-report Quality of Life Profile

The Quality of Life Profile for the “Self-report” is found on the last page of the questionnaire/assessment. It provides a graphical representation of standard scores obtained for the eight quality of life categories, the Quality of Life Rating and the corresponding percentiles. To create the profile, the standard scores obtained should be circled then a line drawn between them (Figure 13).

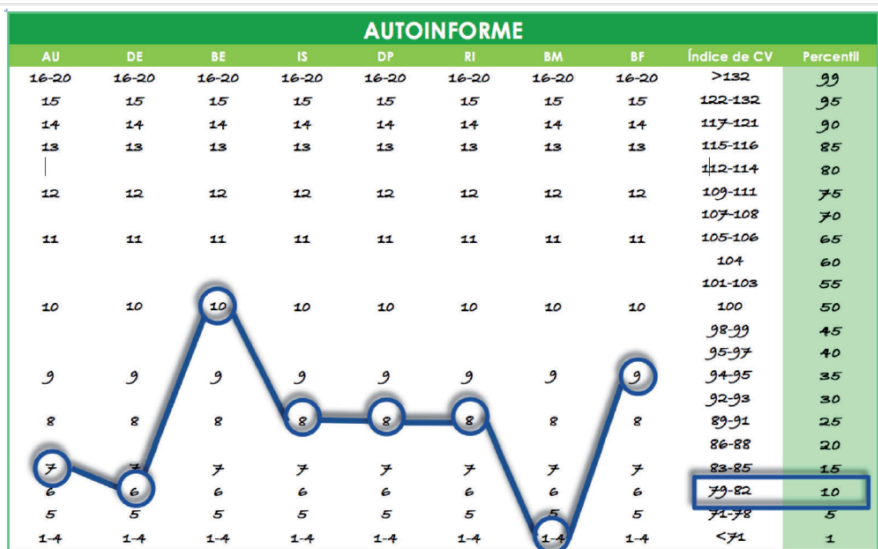


Figure 13. “Self-report” Quality of Life Profile

SELF-REPORT

AW = SD, DE = RI, BE = EW, IS = SI, DP = PD, RI = IR, BM = MW, BF = PW

Índice de CV – QL index

Percentile - percentile

## 4. Example

In the following pages, a complete assessment carried out by a fictitious person is provided with the aim of serving as an example to possible assessors/interviewers. All data contained in the assessment are invented, so any resemblance to reality is purely coincidental.

To assess the quality of life of María Torres (a 30 year old woman with an intellectual disability), Fernando López (social worker) required the help of another respondent from the care centre and a family member to complete the Report of other persons. María completed the Self-report with support from the interviewer Fernando.



Person Assessed		Day	Month	Year
	Date Assessment Administered	08	04	2013
	Date of Birth	12	11	1983

Person Assessed

Identification Code: MTJ8300

First Name and Surname(s): María Torres Jiménez

Address: Avenida de los Álamos

Town/City: Madrid State/Province/Region: Madrid

Post/Zip Code: 28032 Telephone: 91XXXXXX

Main Respondent

First Name and Surname(s): Fernando López García

Position: Social Worker

Agency / Affiliation: FEAPS Madrid

Address: Avda. Ciudad de Barcelona,  
108

E-mail: xxxxxx@feapsmadrid.org Telephone: 915018335

OTHER RESPONDENTS

Name of other Respondents	Relationship to the Individual being Assessed
Mercedes Montilla	Mother
Ramón Hermida	Psychologist

<b>SELF DETERMINATION</b>		<b>N</b>	<b>S</b>	<b>O</b>	<b>A</b>
1	He/she uses public transport (bus, train, taxi etc.) by him/herself (unsupervised)	1	2	3	4
2	He/she decides who comes into his/her personal spaces	1	2	3	4
3	He/she participates in the decisions that are taken in his/her home	1	2	3	4
4	He/she chooses his/her own clothes to buy	1	2	3	4
5	Someone else decides what clothes he/she will wear each day	4	3	2	1
6	Someone else chooses what activities he/she does in his/her free time	4	3	2	1
7	He/she weighs up all the possible consequences before taking a decision	1	2	3	4
8	He/she lacks personal goals, hobbies and interests	4	3	2	1
9	He/she expresses his/her preferences, verbally or by gesturing, when he/she is allowed to choose	1	2	3	4
Total Raw Score		23			

<b>RIGHTS</b>		<b>N</b>	<b>S</b>	<b>O</b>	<b>A</b>
10	He/she is allowed to take part in designing his/her individual plan	1	2	3	4
11	He/she disrespects other people's rights and property	4	3	2	1
12	People around him/her respect his/her privacy (e.g. they knock on the door before coming in)	1	2	3	4
13	He/she has a place where he/she can be alone if he/she wants	1	2	3	4
14	People take his/her things without asking	4	3	2	1

15	The service provider adequately protects the confidentiality of his/her data (the information cannot be accessed by unauthorised persons, private information is not disclosed, etc.)	1	2	3	4
16	He/she is given information about the activities contained in his/her individual plan	1	2	3	4
17	His/her rights have been explained to him/her	1	2	3	4
18	He/she finds it difficult to know when his/her behaviour may lead to legal problems	4	3	2	1
Total Raw Score		27			

<b>EMOTIONAL WELLBEING</b>		<b>N</b>	<b>S</b>	<b>O</b>	<b>A</b>
19	He/she shows signs of depression	4	3	2	1
20	He/she doesn't want to do anything	4	3	2	1
21	He/she shows signs of anxiety	4	3	2	1
22	He/she has behavioural problems	4	3	2	1
23	He/she is self-confident	1	2	3	4
24	He/she is satisfied with what he/she may be able to do in the future	1	2	3	4
25	He/she is proud of him/herself	1	2	3	4
26	He/she shows a desire to change his/her way of life	4	3	2	1
27	He/she enjoys the things he/she does	1	2	3	4
Total Raw Score		28			

<b>SOCIAL INCLUSION</b>		<b>N</b>	<b>A</b>	<b>F</b>	<b>S</b>
28	He/she joins in conversations with other people on topics of shared interest	1	2	3	4

29	He/she goes to places in his/her community (e.g. bars, shops, swimming pools etc.) without any problem	1	2	3	4
30	He/she has friends who do not have a disability	1	2	3	4
31	He/she is excluded from his/her work group, leisure group or group of friends	4	3	2	1
32	He/she finds it difficult to engage in activities with people who do not have a disability	4	3	2	1
33	He/she gets the support he/she needs to do well in his/her job/tasks	1	2	3	4
34	Only a few people are prepared to help him/her when he/she needs it	4	3	2	1
35	His/her merits, skills, abilities and contributions are recognised	1	2	3	4
36	The people around him/her have a negative image of him/her	4	3	2	1
Total Raw Score		29			

PERSONAL DEVELOPMENT		N	S	O	A
37	He/she has opportunities to learn about things that interest him/her	1	2	3	4
38	He/she has an individual plan tailored to his/her preferences	1	2	3	4
39	He/she is given training activities to encourage his/her autonomy	1	2	3	4
40	He/she lacks opportunities to learn new things	4	3	2	1
41	He/she carries out his/her work/tasks competently and responsibly	1	2	3	4
42	He/she has difficulty solving problems	4	3	2	1
43	He/she manages his/her own money	1	2	3	4

44	He/she dresses appropriately for the occasion	1	2	3	4
45	He/she lacks the technical support that he/she needs	4	3	2	1
Total Raw Score		26			

INTERPERSONAL RELATIONSHIPS		N	S	O	A
46	He/she has difficulty finding or keeping a girlfriend/boyfriend	4	3	2	1
47	He/she has difficulty maintaining intimate relationships	4	3	2	1
48	He/she has few friends to go out and have fun with	4	3	2	1
49	He/she has friends who listen to him/her when he/she has a problem	1	2	3	4
50	He/she shows emotions/feelings in an appropriate way Distinto en la escala en inglés)	1	2	3	4
51	He/she has good relationships with work colleagues/colleagues at care centre	1	2	3	4
52	He/she has good relationships with people of different ages	1	2	3	4
53	Most people enjoy his/her company	1	2	3	4
54	He/she calls, writes to or visits people he/she likes	1	2	3	4
Total Raw Score		24			

MATERIAL WELLBEING		N	S	O	A
55	He/she does not have the money to buy the things he/she needs	4	3	2	1
56	He/she saves up to be able to buy special things (e.g. a present, special clothes etc.)	1	2	3	4
57	The place where he/she lives is uncomfortable or dangerous	4	3	2	1

58	The place where he/she works (or carries out some type of activity, for example occupational) is uncomfortable or dangerous	4	3	2	1
59	He/she has access to the information that interests him/her (newspaper, television, internet, magazines etc.)	1	2	3	4
60	He/she has access to new technologies (e.g. mobile phone, internet)	1	2	3	4
61	He/she has access to the things needed to pursue his/her hobbies	1	2	3	4
62	He/she lacks what is needed to live with dignity (well en el original)	4	3	2	1
63	He/she has access to the services and support that he/she needs	1	2	3	4
Total Raw Score		28			

PHYSICAL WELLBEING		N	S	O	A
64	He/she gets enough rest	1	2	3	4
65	He/she wears dirty clothes	4	3	2	1
66	He/she has poor hygiene habits	4	3	2	1
67	He/she does sports or engages in leisure activities	1	2	3	4
68	He/she takes his/her medication as directed	1	2	3	4
69	He/she tells others when he/she is not feeling well	1	2	3	4
70	He/she receives proper healthcare services	1	2	3	4
71	He/she gets routine medical check-ups (e.g. dentist, optometrist etc.)	1	2	3	4
72	He/she watches his/her weight	1	2	3	4
Total Raw Score		25			

# SELF-REPORT

<b>SELF DETERMINATION</b>		<b>N</b>	<b>S</b>	<b>O</b>	<b>A</b>
1	I use public transport (bus, train, taxi etc.) by myself (unsupervised)	1	2	3	4
2	I decide who comes into my personal spaces (e.g. my bedroom, my bathroom etc.)	1	2	3	4
3	I participate in the decisions that are taken in my home	1	2	3	4
4	I choose my own clothes to buy	1	2	3	4
5	Someone else decides what clothes I will wear each day	4	3	2	1
6	Someone else chooses what activities I do in my free time	4	3	2	1
7	I weigh up all the possible consequences before taking a decision	1	2	3	4
8	I make plans to do activities that interest me	1	2	3	4
9	I state my preferences when I am allowed to choose	1	2	3	4
Total Raw Score		23			
<b>RIGHTS</b>		<b>N</b>	<b>S</b>	<b>O</b>	<b>A</b>
10	I am allowed to take part in designing my individual plan	1	2	3	4
11	I respect other people's property and rights	1	2	3	4
12	The people around me respect my privacy (e.g. they knock on the door before coming in)	1	2	3	4
13	I have a place where I can be alone if I want to	1	2	3	4
14	People take my things without asking	4	3	2	1

15	People at the agency tell others the things I say to them (my private comments)	4	3	2	1
16	I am given information about the activities contained in my individual plan	1	2	3	4
17	My rights have been explained to me	1	2	3	4
18	I find it difficult to know when my behaviour may lead to legal problems	4	3	2	1
Total Raw Score		22			

<b>EMOTIONAL WELLBEING</b>		<b>N</b>	<b>S</b>	<b>O</b>	<b>A</b>
19	I feel like crying	4	3	2	1
20	I don't feel like doing anything	4	3	2	1
21	I'm too worried or nervous	4	3	2	1
22	I have behavioural problems	4	3	2	1
23	I am self-confident	1	2	3	4
24	I feel good when I think about what I can do in the future	1	2	3	4
25	I am proud of myself	1	2	3	4
26	I would like to change my way of life	4	3	2	1
27	I enjoy the things I do	1	2	3	4
Total Raw Score		29			

<b>SOCIAL INCLUSION</b>		<b>N</b>	<b>A</b>	<b>F</b>	<b>S</b>
28	I join in conversations with other people on interesting topics	1	2	3	4
29	I go to places in my community (e.g. bars, shops, swimming pools etc.) without any problem	1	2	3	4
30	I have friends who do not have a disability	1	2	3	4



31	I feel excluded from my work group, leisure group or group of friends	4	3	2	1
32	I find it difficult to carry out activities with people who do not have a disability	4	3	2	1
33	I get the supports I need to do well in my job (tasks or activities)	1	2	3	4
34	There are only a few people able to help me when I need it	4	3	2	1
35	People tell me when I do things well	1	2	3	4
36	The people around me have a negative image of me	4	3	2	1
Total Raw Score		26			

PERSONAL DEVELOPMENT		N	S	O	A
37	Others teach me things that interest me	1	2	3	4
38	I have an individual plan tailored to my preferences	1	2	3	4
39	I am learning things that make me more independent	1	2	3	4
40	I have opportunities to learn new things	1	2	3	4
41	I carry out my work (tasks or activities) competently and responsibly	1	2	3	4
42	I am unable to solve problems	4	3	2	1
43	I manage my own money	1	2	3	4
44	I dress appropriately for the occasion	1	2	3	4
45	I have the technical support (e.g. adapted keyboard, adopted mouse, pictograms etc.) that I need	1	2	3	4
Total Raw Score		25			

INTERPERSONAL RELATIONSHIPS		N	S	O	A
-----------------------------	--	---	---	---	---

46	I have difficulty finding or keeping a girlfriend/boyfriend	4	3	2	1
47	I have difficulty maintaining sexual and emotional relationships	4	3	2	1
48	I have few friends to go out and have fun with	4	3	2	1
49	I have friends who listen to me when I have a problem	1	2	3	4
50	I express my emotions and feelings to my friends	1	2	3	4
51	I get on well with work colleagues (or at the agency I attend)	1	2	3	4
52	I have good relationships with people of different ages	1	2	3	4
53	Most people dislike being with me	4	3	2	1
54	I call, write or visit people I like	1	2	3	4
Total Raw Score		24			

MATERIAL WELLBEING		N	S	O	A
55	I have money to buy the things I need	1	2	3	4
56	I save up to be able to buy special things (e.g. a present, special clothes etc.)	1	2	3	4
57	The place where I live is uncomfortable or dangerous	4	3	2	1
58	The place where I work (or carry out some type of activity or task) is uncomfortable or dangerous	4	3	2	1
59	I have access to the information that interests me (newspaper, television, internet, magazines etc.)	1	2	3	4
60	It is impossible for me to access new technologies (e.g. mobile phone, internet)	4	3	2	1

61	I have the things I need to pursue my hobbies	1	2	3	4
62	I have what is needed to live with dignity	1	2	3	4
63	I have the services and support I need	1	2	3	4
Total Raw Score		22			

PHYSICAL WELLBEING		N	S	O	A
64	I get enough rest	1	2	3	4
65	I wear dirty clothes	4	3	2	1
66	I have poor hygiene habits	4	3	2	1
67	I do sports or engage in leisure activities	1	2	3	4
68	I take my medication as directed	1	2	3	4
69	I tell other people when I am not feeling well	1	2	3	4
70	I am happy with the healthcare services I receive	1	2	3	4
71	I attend routine medical check-ups (e.g. dentist, optometrist etc.)	1	2	3	4
72	I watch my weight	1	2	3	4
Total Raw Score		29			

# SCORE SUMMARY

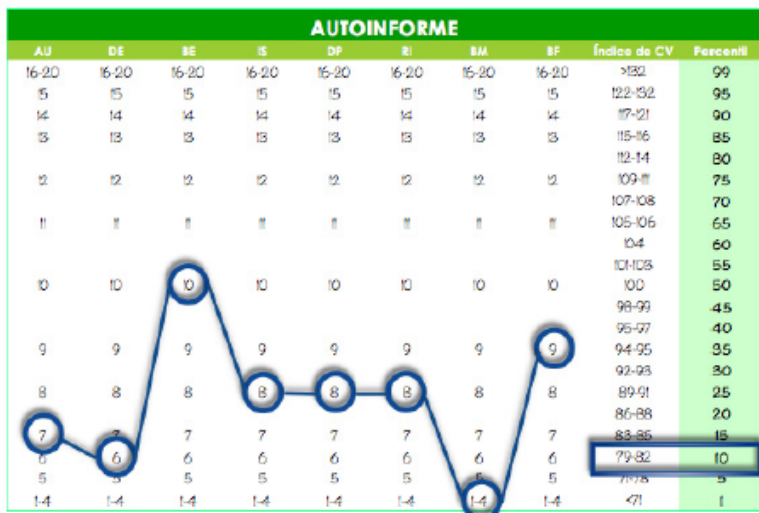
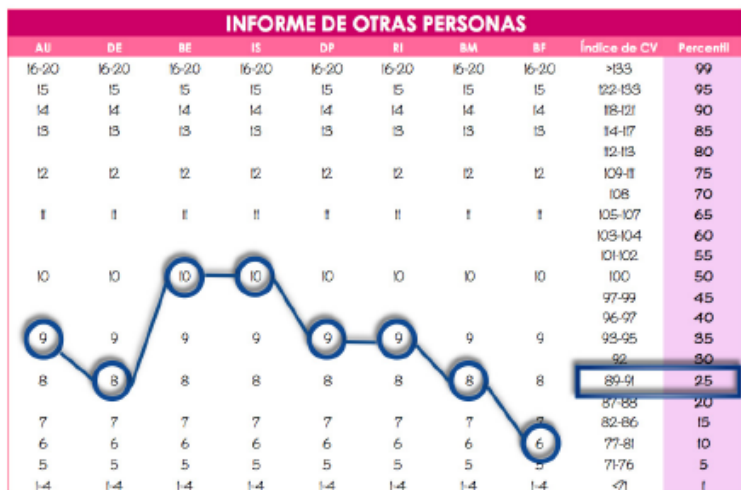
REPORT OF OTHER PERSONS			
<ol style="list-style-type: none"> <li>1. Enter the total raw scores for each dimension</li> <li>2. Enter the standard scores and percentiles</li> <li>3. Enter the Quality of Life Rating and its corresponding percentile</li> </ol>			
QUALITY OF LIFE DOMAINS	Total Raw Scores	Standard Scores	Percentiles
SELF DETERMINATION	23	9	37
RIGHTS	27	8	25
EMOTIONAL WELL BEING	28	10	50
SOCIAL INCLUSION	29	10	50
PERSONAL DEVELOPMENT	26	9	37
INTERPERSONAL RELATIONSHIPS	24	9	37
MATERIAL WELL BEING	28	8	25
PHYSICAL WELL BEING	25	6	9
Total Standard Score (sum)		69	
Quality of Life Rating (Composite Standard Score)		91	
Quality of Life Percentile			27

SELF REPORT			
<ol style="list-style-type: none"> <li>1. Enter the total raw scores for each domain (yellow boxes)</li> <li>2. Enter the standard scores and percentiles</li> <li>3. Enter the Quality of Life Rating and its corresponding percentile</li> </ol>			
QUALITY OF LIFE DOMAINS	Total Raw Scores	Standard Scores	Percentiles
SELF DETERMINATION	20	7	19

RIGHTS		22	6	9
EMOTIONAL WELL BEING	29	10	50	
SOCIAL INCLUSION	26	8	25	
PERSONAL DEVELOPMENT	25	8	25	
INTERPERSONAL RELATIONSHIPS	24	8	25	
MATERIAL WELL BEING	22	4	2	
PHYSICAL WELL BEING	29	9	37	
Total Standard Score (sum)		60		
Quality of Life Rating (Composite Standard Score)		82		
Quality of Life Percentile			11	

# QUALITY OF LIFE PROFILES

Circle the standard score for each domain and the Quality of Life Rating as well as the Percentile. Then connect the circles for each category with a line to form the profile.



## 5. Scores Interpretation

The correction of the test is simple; however, the interpretation of the results requires a more thorough analysis in order to get the most out of them. Guidelines on how to interpret the scores obtained from the two subscales are listed next.

### 5.1 Interpreting the Subscales

#### **Standard Scores**

In transforming the raw scores to standard scores, it must be kept in mind that the scores have a distribution with a mean of 10 and standard deviation of 3. High standard scores denote a higher quality of life.

#### **Quality of Life Index**

The Quality of Life Index for the “Report of other persons” and the “Self-report”, also known as the “Composite Standard Score”, presents a distribution with a mean of 100 and standard deviation of 15. Interviewers should be familiar with the distributions so that the interpretation of results is straight forward. To obtain the Quality of Life Index, first the standard scores for each of the eight categories must be added and the result recorded in the Total Standard Score (sum) box of the booklet. This value becomes the Quality of Life Index (or standard composite score) using the table included in Appendix A. In this table, the total standard score will be found. The Quality of Life Index and percentile is in the same row.

#### **Percentiles**

The percentiles indicate the proportion of people who have a higher or lower score. The higher the percentile obtained, the higher the quality of life. As mentioned previously, the percentile is found in Table C of Annex A.

#### **Quality of Life Profile**

The Quality of Life Profile is found on the last page of the booklet and provides a graphical representation of the standard scores for the individual for each of the quality of life domains and its corresponding percentile. To create the profile, the standard scores for each category should be circled and then joined together by a line. The profile allows you, in a simple and immediate way, to see which of the categories have the highest and lowest scores, which could be aided by support plans to improve quality of life.

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# ANNEX A

Table A. “Report of other persons” Scale

Puntuación Estándar	Puntuaciones Directas								Percentil
	AU	DE	BE	IS	DP	RI	BM	BF	
20									>99
19									>99
18									>99
17	35-36								99
16	34			36	35-36	36			98
15	32-33	36	35-36	35	34	34-35	36	36	95
14	30-31	34-35	34	34	33	32-33	35	35	91
13	28-29	33	32-33	32-33	31-32	30-31	34	33-34	84
12	27	32	31	31	30	28-29	32-33	32	75
11	26	30-31	29-30	30	29	27	31	31	63
10	25	29	28	29	27-28	25-26	30	30	50
9	23-24	28	26-27	27-28	26	23-24	29	28-29	37
8	21-22	26-27	25	26	25	21-22	27-28	27	25
7	19-20	25	23-24	25	23-24	19-20	26	26	16
6	16-17	24	22	23-24	22	18	25	25	9
5	14-15	22-23	20-21	22	21	16-17	24	24	5
4	13	21	19	21	19-20	14-15	22-23	22-23	2
3	11-12	20	17-18	19-20	18	12-13	21	21	1
2	9-10	18-19	16	18	17	10-11	20	20	<1
1	<10	<18	<16	<18	<17	<10	<20	<20	<1

Table B. “Self-report” Scale

Puntuación Estándar	Puntuaciones Directas								Percentil
	AU	DE	BE	IS	DP	RI	BM	BF	
20									>99
19									>99
18									>99
17									99
16	35-36					36			98
15	33-34	35-36	36	35-36	36	35		36	95
14	32	34	34-35	34	34-35	33-34	35-36	35	91
13	30-31	32-33	33	33	33	31-32	34	34	84
12	28-29	31	31-32	31-32	31-32	30	33	33	75
11	26-26	29-30	30	30	30	28-29	31-32	32	63
10	25	28	28-29	28-29	28-29	26-27	30	30-31	50
9	23-24	26-27	27	27	27	25	29	29	37
8	21-22	25	26	26	25-26	23-24	27-28	28	25
7	19-20	23-24	24-25	24-25	24	21-22	26	27	16
6	18	22	23	23	22-23	20	25	26	9
5	16-17	20-21	21-22	21-22	21	18-19	23-24	24-25	5
4	14-15	19	20	20	19-20	16-17	22	23	2
3	12-13	17-18	19	19	18	14-15	20-21	22	1
2	11	16	17-18	17-18	16-17	13	19	21	<1
1	<11	<16	<17	<17	<16	<13	<19	<21	<1

Puntuación Estándar – Standard Score

Puntuaciones Directas – Raw Scores

Percentil - Percentile

AW = SD, DE = RI, BE = EW, IS = SI, DP = PD, RI = IR, BM = MW, BF = PW

Table C. Quality of Life Index and Quality of Life Index Percentile

INFORME OTRAS PERSONAS		Puntuación Estándar Total	AUTOINFORME	
Índice de Calidad de Vida	Percentil		Índice de Calidad de Vida	Percentil
142	>99	130	145	>99
141	>99	129	144	>99
140	>99	128	144	>99
139	>99	127	143	>99
138	99	126	142	>99
138	99	125	141	>99
137	99	124	140	>99
136	99	123	139	>99
135	99	122	138	99
134	99	121	137	99
133	99	120	136	99
133	98	119	135	99
132	98	118	134	99
131	98	117	134	99
130	98	116	133	99
129	97	115	132	98
128	97	114	131	98
128	97	113	130	98
127	96	112	129	97
126	96	111	128	97
125	95	110	127	97
124	95	109	126	96
123	94	108	125	95
123	93	107	124	95
122	93	106	124	94
121	92	105	123	93
120	91	104	122	93
119	90	103	121	92
118	89	102	120	91
118	88	101	119	90
117	87	100	118	89
116	85	99	117	87
115	84	98	116	86
114	83	97	115	85
113	81	96	115	83
113	80	95	114	82
112	78	94	113	80
111	76	93	112	78
110	75	92	111	77
109	73	91	110	75
108	71	90	109	73
108	69	89	108	71
107	67	88	107	69
106	65	87	106	66
105	63	86	105	64
104	61	85	105	62
103	59	84	104	60
103	57	83	103	57
102	54	82	102	55
101	52	81	101	52
100	50	80	100	50
99	48	79	99	48
98	46	78	98	45
97	43	77	97	43
97	41	76	96	40
96	39	75	95	38
95	37	74	95	36



Table C. Quality of Life Index and Quality of Life Index Percentile (continued)

INFORME OTRAS PERSONAS		Puntuación Estándar Total	AUTOINFORME	
Índice de Calidad de Vida	Percentil		Índice de Calidad de Vida	Percentil
94	35	73	94	34
93	33	72	93	31
92	31	71	92	29
92	29	70	91	27
91	27	69	90	25
90	25	68	89	23
89	24	67	88	22
88	22	66	87	20
87	20	65	86	18
87	19	64	85	17
86	17	63	85	15
85	16	62	84	14
84	15	61	83	13
83	13	60	82	11
82	12	59	81	10
82	11	58	80	9
81	10	57	79	8
80	9	56	78	7
79	8	55	77	7
78	7	54	76	6
77	7	53	76	5
77	6	52	75	5
76	5	51	74	4
75	5	50	73	3
74	4	49	72	3
73	4	48	71	3
72	3	47	70	2
72	3	46	69	2
71	3	45	68	2
70	2	44	67	1
69	2	43	66	1
68	2	42	66	1
67	2	41	65	1
67	1	40	64	1
66	1	39	63	1
65	1	38	62	1
64	1	37	61	<1
63	1	36	60	<1
62	1	35	59	<1
62	1	34	58	<1
61	<1	33	57	<1
60	<1	32	56	<1
59	<1	31	56	<1
58	<1	30	55	<1
57	<1	29	54	<1
57	<1	28	53	<1
56	<1	27	52	<1
55	<1	26	51	<1
54	<1	25	50	<1
53	<1	24	49	<1
52	<1	23	48	<1
52	<1	22	47	<1

Informe otras personas – Report of other persons

Autoinforme – Self-report

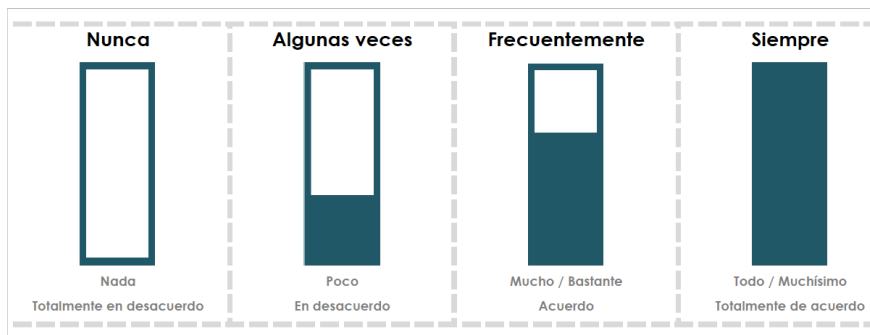
Índice de calidad de vida – Quality of life index

Percentil – percentile

Puntuación estándar total – Total standard score

## ANNEX B

Cut –out cards with icons representing the response options:



1. Never: Nothing; totally disagree
2. Sometimes: Little; disagree
3. Frequently: Lots/a good deal; agree
4. Always: A lot; in totally agree