

San Martín Scale

Quality of Life Assessment for People with Significant Disabilities

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FUNDACIÓN
OBRA SAN MARTÍN
SANTANDER

INICO – FOSM © 2014





First Edition 2014

Published and Distributed by Fundación Obra San Martín, Valdenoja 48, 39012 Santander (Spain)

Tel. (34) 942 390 900

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www.fosm.es

Design and Layout by Valore Consultores de Marketing, S.L. www.valoreconsultores.com

Printed by Artes Gráficas Campher, S.L.

Legal Deposit: SA-100-2014

ISBN: 978-84-697-0148-5

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<http://inico.usal.es/331/instrumentos-evaluacion/escala-san-martin.aspx>

<http://www.fosm.es/>

Cover Photo: Alberto Macías Martín carrying out an artistic expression activity at the St. Martin’s Work Foundation.

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INTRODUCTION

Despite the progressive development made by care services and programmes to assist people with significant disabilities in recent decades, these individuals historically still pose problems for professionals, organisations and society in general. Confronting these operational difficulties is usually delayed, compared to other population groups with disabilities or even those who have a less visible disability. Reasons for why they have not been made a priority may be that it is seen as difficult to design and implement useful models focused on the person. There is also the large economic cost of care due to the need for a greater proportion of support staff who must dedicate more time and effort to move forward. The lack of specialised training and University research is another sign of the habitual neglect of care of these individuals and a lack of knowledge to create improvements in their lives.

The first international studies which demonstrated the efficiency of systemic interventions into this population were produced in the second half of the last century. These studies, rather than simply highlighting the consequences of delays in the development of the individuals, focus on understanding this development. Driven by committed organisations and professionals, ethics and the defence of human rights were very slowly making headway in this field in a way that was expanding the vision and desire for habilitation rather than rehabilitation. Currently, thanks to the United Nations Convention on the Rights of Persons with Disabilities enacted in 2006, the right to a dignified life the same as any other citizen is recognised.

The UN Convention clearly sets out its intention to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” This statement, which is binding in Spain and in the majority of countries around the world, is committed to achieving the full and effective participation of persons with disabilities in society on the same basis as others. This is precisely the direction of the changes we advocate for persons with significant disabilities, bearing in mind that these groups have to be much more committed to the defence of rights and efficiently organise programs and support services. To do this, highly competent professionals, working as a team and with well-structured organisations with a clear vision of the final objective is required.

The San Martín Scale is a tool which faithfully provides responses to the proposals of the comprehensive approach to quality of life, which has become the main conceptual and evaluation framework to promote improvements in the lives of people with disabilities and therefore in exercising their right to live with dignity. Its development has involved a systematic collaborative effort between professionals from the Obra San Martín Foundation and the University Institute of Community Integration (INICO) at the University of Salamanca. Teamwork, together with a very serious and dedicated approach on the part of the research team, has allowed for a scientific **base/basis**, design and development of the San Martín Quality of Life Assessment Scale. This is the first scale constructed on an international level to assess the quality of life of people with significant disabilities taking into account psychometric characteristics to suitably and sufficiently ensure validity and reliability.

Using the San Martín Scale allows professionals and organisations to look beyond opinions to focus on data that reflects the personal results of the users of its services and programs. The improvement of these personal results is the main objective. The excellent reception received by fieldwork from many professionals and organisations ensures the importance and possible further implementation of the scale. And, to be fair, one must finish sincerely thanking the San Martín Foundation, its Board and all its members, for providing unconditional in manpower and material resources we have relied on for its development.

Miguel Ángel Verdugo Alonso
14th February 2014



AKNOWLEDGEMENTS

ACKNOWLEDGEMENTS

The development of the San Martín Scale was made possible thanks to the collaboration of experts in a Delphi Study and a discussion group. At the same time, the correction of this scale was made possible thanks to the voluntary and generous collaboration of hundreds of professionals from a number of different organisations. To all those mentioned, to all the people with disabilities and their family and friends, we express our sincerest gratitude.

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ACOPROS
AFANIAS
AIDEMAR
ALBASUR
AMAPPACE
AMPROS
APACAF
APCA
APNABI
APROSMO
APROSUB Palma
APROSUBA 3
APROSUBA 4
APROSUBA 8
APROSUBA 9
APROSUBA 10
APROSUBA 13
ASINDI
Asociación CEPRI
Asociación de Ayuda a la Parálisis Cerebral "Virgen del Valle" Toledo
Asociación de Discapacitados Intelectuales Vera
Asociación de Discapacitados Psíquicos de Antequera y su Comarca
Asociación de Padres de Parálíticos Cerebrales de Albacete. APACEAL
Asociación Fuensanta para Discapacitados Psíquicos
Asociación Galega San Francisco
Asociación Ibérica para la Normalización e Inclusión Social
Asociación Juan Díaz de Solís
Asociación Pauta
Asociación Riojana pro Personas con Discapacidad Intelectual (ARPS)
Asociación San Xerome Emiliani
Asociación Síndrome de Down de Baleares
Asociación Valenciana de Padres de Personas con Autismo
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ASPANANE
ASPANRI-ASPANRI Down
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ASPRODESA
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Associació Jeroni de Moragas
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ASTOR
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Autismo Burgos
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CDM "Fuente San Luis"
CEE KOYNOS
Centre Assistencial Sant Joan de Deu
Centre Ocupacional "Fundació Mas Alborna"
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Centro Especial Padre Zegrí
Centro Ocupacional Municipal Juan de Garay
Centro Residencial Cabueñes
Centros Juan María (Asociación Esperanza del Valle Miñor)
Consorti Sant Gregori
Coordinadora de Disminuidos Físicos y Psíquicos de Villar y Comarca
Federación Autismo Andalucía
Fundació Arc de Sant Martí
Fundació Montilivi-Grup Fundació Ramón Noguera
Fundació Privada Auria
Fundació Privada MAP
Fundació Privada Onyar la Selva
Fundació Privada Rosella

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Fundació Privada Tallers
Fundació Vimar
Fundació Obra San Martín
Fundación AFANIAS Castilla-La Mancha
Fundación APASCOVI
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Fundación Proyecto AURA
Fundación Purísima Concepción
Fundación Tutelar Sonsoles Soriano
INTEDIS
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Prologu

PROLOGUE

“The future belongs to those who are ready for it”. This quote, by Robert L. Schalock, should make us reflect about *what* we do, *how* we do it and how we *will* do it. In order to face the future, one must accept the changes that take place in the organizations that help and root for people with intellectual disabilities. We commit to their life projects by following a model that is based on offering support and is backed up by current scientific paradigms. These changes also aim to the achievement of organizational skills that are effective, efficient and sustainable.

In this environment of constant change and development, reflection and hard work are put into the adaptation of the organization to fit people’s needs. The “Obra San Martin” Foundation supports innovation, the advancement of scientific knowledge and the development of practices that are backed with evidence. Our responsibility as an organization is even greater given the complex context in which we are nowadays. Thus, in our search for excellence, we have decided to put our economic resources towards research.

Our proposal to Professor Miguel Angel Verdugo stemmed from this search in 2010. From here on, we initiated a process of work and collaboration with the University Institute of Community Integration (INICO) from the University of Salamanca in order to develop the research project that we are now presenting: the San Martin Scale, a Quality of Life Assessment for People with Significant Disabilities. This collaboration has been very fruitful in that it creates bonds and establishes solid networks in which professionals and organizations can exchange experiences and share scientific information with the public. I want to thank all members of INICO for believing in, and rooting for the improvement of the lives of people with disabilities and for promoting the training, exchange, innovation and dynamism in the organizations.

As an organization, we need to recognize what it is that we do; we need to prove that our model of support for people with intellectual disabilities maintains quality standards that are in accordance with the level of quality that people and citizens demand. The constant aim of the organization and its professionals towards scientific principals constitutes a guarantee in comparison to other assistance, paternalistic, charity, etc. models in which the person is forgotten. It is our ethical responsibility to be critical with our daily work to see if it meets the current demands and needs of each person; improve our workers’ skills and include strategies of change that could facilitate a permanent improvement of the provided support and quality of life of people.

It is of great satisfaction for the Obra San Martin Foundation that this research project has ended with the creation of the San Martin Scale, an evaluation tool that fulfils reliability and validity criteria. Because of this, we wish that, with the wide and free of charge expansion of this Scale, many people with significant disabilities benefit from this tool and that the outcome of its use is the improvement of the quality of life. This is only the beginning, people with disabilities must build their own path and we must assist them with

their decisions.

José María Carceller Malo

President of the Board of Trustees of the Obra San Martín Foundation

*general
description*

1. General Description

1.1. FACT SHEET

Name	San Martín Scale
Authors	Miguel Ángel Verdugo, Laura E. Gómez, Benito Arias, Mónica Santamaría, Ester Navallas, Sonia Fernández and Irene Hierro.
Meaning	Multidimensional assessment of the quality of life, based on Schalock and Verdugo's eight dimensional model (2002/2003) and carried out by other people (e.g., professionals, family members, legal guardians, close friends).
Scope of action	People with significant disabilities (i.e., people with intellectual disabilities that require thorough and general support, with other possible associated conditions).
Age of action	Adults, from 18 and on (16 if and only if they don't partake in the educational system)
Informants	Professionals from social services who have known the person for at least three months. Family members and close friends who know the person well.
Validation	University Institute of Community integration (INICO). University of Salamanca, Spain.
Administration	Individual.
Duration	Approximately 30 minutes.
Purpose	Identify the outline of the quality of life of the person, with evidence of validity and reliability in order to put it into a practice based on evidence and the design of personal support plans.
Scale	Standard score (M=10; DT= 3) in the dimensions of the quality of life, percentiles and Quality of Life Index (M=100; DT= 15).

1.2. THEORETICAL FOUNDATION

Without a doubt, the importance and utility of the concept of quality of life has achieved nowadays, not only as a notion of awareness, but also as a social construct that guides **the** practice and interventions. The concept has become so relevant in the social, medical and educational services that it is currently considered a key aspect in the development of plans that are centred around the person and the improvement of personal results) e.g., Claes, van Hove, Vandeveld, van Loon and Schalock, 2012; Gomez, Arias, Verdugo and Navas, 2012; van Loon et al., 2013), in the strategies of the improvement of the quality of life of the organizations which provide services (e.g., McCabe, Firth y O'Connor, 2009; Schalock, 2013, Shogren et al., 2009). So much that, after the coming into force of the UN Convention of the Rights of Persons with Disabilities (United Nations, 2006) the construct has become the link between the reflected social rights and the lives of the people; it has also become a tool that improves human rights such as equality, empowerment and self-determination (Verdugo, Navas, Gómez & Schalock, 2012).

Nevertheless, the implementation of these principles hasn't been carried out at the same pace by all the people with disabilities. Changes are occurring thanks to the effort of the important representatives of the organizations and because of their constant demands for the necessity of being able to rely on tools of evaluation with sufficient evidence of validity and reliability that can allow them to assess the efficacy of their interventions in the scientific community. Up until now, these changes have been limited to people

with intellectual disabilities and people with developmental disabilities who have a higher degree of functionality. In other words, people who have the sufficient ability to comprehend and express themselves, who can answer the questions in the self-report in a reliable manner (i.e., people with severe, profound, or, in the best cases, moderate disabilities??).

In our **framework** there are in fact valuable tools that allow **for** the evaluation of the quality of life of adults and elderly people of the group: the INTEGRAL Scale (Gómez, Arias, Verdugo & Navas, 2012); Verdugo, Gómez & Arias, 2007; Verdugo, Gómez, Arias & Schalock, 2009), the INICO-FEAPS Scale (Verdugo, Gómez, Arias, Santamaría, Clavero & Tamarit, 2013a, 2013b), the GENCAT Scale (Gómez, Arias, Verdugo & Navas, 2012; Verdugo, Arias, Gómez & Schalock, 2008a, 2008b, 2009, 2010), the FUMAT Scale (Gómez, Verdugo, Arias & Navas, 2008; Verdugo, Gómez & Arias 2009) and the Scale of quality of life for people with disabilities who are growing older (ECV) (Alcedo, Aguado, Arias, González & Rozada, 2008), among them.

In contrast, people with severe intellectual disabilities have traditionally been a part of the group which has benefited from the improvements on a smaller scale; in addition, for this group, the implementation of the changes has been more complex, to the point where most of them have not even been able to initiate the process. Equally as worrying is the situation of the people whose intellectual disability is made even more complicated with other associated disabilities (e.g. physical disabilities and/or sensory disabilities,

general developmental disorders, mental health problems, behaviour problems or chronic diseases), because they need general and extensive support. Thus, the San Martín Scale was created in order to progress in the improvement of the quality of life of a group of individuals who, given the difficulty they present in terms of research, have received less attention from the scientific community: the quality of life of this group of people with significant disabilities who have a need of receiving intensive, general or complex support.

Nowadays, in the same way, the necessity of developing a functional model of the quality of life for people with significant disabilities (also called people with multiple and severe disabilities) has become an urgent and important necessity that has been noticed in scientific literature since almost two decades ago (Borthwick-Duffy, 1990; Goode and Hogg, 1994; Oulette-Kuntz and McCreary, 1996). In this sense, there are various models that deal with making the construct of quality of life functional for this group of people with the objective of being able to assess it. In this paper, we will focus on the most widely accepted model with which the organizations that are in favour of people with disabilities are most familiar when it comes to developing their practice in the Spanish context: the model with eight dimensions proposed by Verdugo and Schalock (2002/2003). Another reason why we chose this model is because of the large quantity of empirical evidence there is that shows its validity in recent years (e.g., Azanar and Castañón, 2005, Chou et al., 2007; Chout and Schalock, 2009; Gómez, 2010; Gómez, Verdugo, Arias and Arias, 2010; Jenaro et al., 2005; Schalock et al., 2005; Wang, Schalock, Verdugo and Jenaro, 2010).

According to this model (Gómez, Verdugo, Arias and Arias, 2010; Schalock and

Verdugo 2002/2003; 2007; 2012; Schalock, Keith, Verdugo, Gómez, 2010; Verdugo, 2006), **quality of life** is defined as a desired state of personal well-being which is (a) multidimensional; (b) has universal properties and properties that are tied to culture; (c) has objective and subjective components and (d) it is influenced by individual characteristics and environmental factors. In terms of its measurement, the authors argue that it makes reference to the degree in which people have vital and valuable experiences, it reflects the dimensions that contribute to a full and interconnected life; it takes into account the context of the physical, social and cultural environments that are important to people and it includes common human experiences, as well as unique vital ones.

The quality of life model functions through various dimensions, indicators and personal results. The domains dimensions of quality of life proposed in the model are: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion and social rights. At the same time, the assessment of the personal condition or the aspirations of each individual in these indicators is reflected in the personal results (Schalock, Gardners and Bradley, 2007).

Among the poor effort put into making the concept of quality of life functional for people with significant intellectual disabilities, the research of Petry, Maes and Vlaskamp (2005, 2007, 2009) is worth mentioning. These authors carried out the first research study with participants from Belgium, Holland and Germany in order to determine if the five basic dimensions of the quality of life presented by Felce and Perry (1995, 1996) were applicable and valid for this specific group of people. A result that needs to be mentioned is that the functionality of the basic

dimensions differed in two fundamental aspects when compared to other groups. The first difference pertained to the type of indicators related to hygiene, nutrition, rest, technical aid, communication, basic safety and individual attention (categories that were not included in the original model). Secondly, they put forth the fact that people with multiple and severe disabilities are extremely dependent on third parties when it comes to the satisfaction of their needs. Thus, their quality of life depends greatly on those who support them. Both results allow us to conclude that the dimensions of the quality of life are universal but their functioning through specific indicators varies considerably depending on the diagnostic group that we are treating. This result is consistent with other research about quality of life models (Cummins, 1997; Felce and Perry, 1997; Gardner and Carran, 2005; Hughes and Hwang, 1996; Ouellete-Kuntz and McCreary,

1996; Schalock, Gardner and Bradley, 2007/2009; Schalock and Keith, 1993; Schalock and Verdugo, 2002/2003; Schalock, Verdugo and Gómez, 2011).

In Table 1 the operational definition of quality of life that has been used in this project is presented. It stems from a thorough revision of scientific literature and other instruments of assessment of the quality of life, also, of the discussion and previous experience and arguments of the research team and of the assessment of numerous experts of the field by participating in the Delphi study and a discussion group, both of which are described more thoroughly in the next section of this manual.

Table 1. Operational Definition of the Quality of Life according to the San Martín Scale

DIMENSIONS	INDICATORS
SELF-DETERMINATION (SD)	Autonomy; goals, opinions and personal preferences; decisions and choices
RIGHTS (RI)	Knowledge of rights; intimacy; privacy; confidentiality; respect
EMOTIONAL WELLBEING (EW)	Satisfaction with life; concept of self; absence of stress, negative feelings or behaviour problems; basic safety; emotional communication
SOCIAL INCLUSION (SI)	Integration; participation; support
PERSONAL DEVELOPMENT (PD)	Self-improvement; learning; skills; and motivational abilities
INTERPERSONAL RELATIONSHIPS (IR)	Family relationships; social relationships; communication

MATERIAL WELLBEING (MW)	Income; pensions; household conditions; work conditions; technical aid
PHYSICAL WELLBEING (PW)	Nutrition; exercise; hygiene; mobility; medication; medical service; sexuality

One of the consequences of the problems mentioned in respect to functionality of the concept of the quality of life is the difficulty of finding assessment tools that are adequate for people with significant disabilities; that is, people who present not only severe or profound significant disabilities, but also significant motor malfunctions, chronic diseases, mental health problems, behaviour problems and sensory disabilities. It is more difficult to find tools of assessment which are adequate and have sufficient evidence of validity and reliability that backs them up. In fact, a systematic revision of the topic at hand (Townsend-White, Pham and Vassos, 2012) shows that many of the already existent tools assess at least one of the eight categories of the quality of life model, but only six of them, all of which are in English, can be considered adequate given their psychometric properties although none are considered adequate for people with behavioural problems.

Following this, even though it is true that there have been great improvements in terms of the evaluation of the quality of life of people with significant disabilities in the last decade, most of these can only be qualified merely as “psychometrically promising” (e.g., Petry, Kuppens, Vos and Maes, 2010; Petry, Van den Noortgate and Maes, 2009; Ross and Oliver, 2003) or they haven’t even been assessed (e.g., Lyons, 2005; Vos, De Cock, Petry, Van den Noortgate and Maes, 2010). Among the most

notable efforts, it is important to mention the studies carried out by Petry et al. (2005, 2007, 2009), although the scale developed by these authors is not adjusted to the Spanish context, it assesses five categories or dimensions of the quality of life (those proposed by Felce and Perry) and to this day, it only counts with preliminary studies on their psychometric properties in a small sample.

In conclusion, the San Martin Scale is the first quality of life assessment tool based in a Spanish context and based on the eight dimensional model of Verdugo and Schalock, with sufficient evidence that proves its validity and reliability (Verdugo, Gómez, Arias, Navas and Schalock, 2014; Verdugo et al., 2013). It allows professionals who work in providing services for people with significant disabilities to carry out practices based on evidence through the assessment of individual results related to quality of life. It also allows them to plan interventions and provide support that are focused on the individual; provide information that is relevant and from which they can straighten and improve the quality of the services; test out programs and develop organizational change. With this tool, the urgent and important necessity of having an operative model of the quality of life for people with significant disabilities, which has slightly been touched upon in the past but mentioned in scientific literature for more than two decades, has finally been achieved (Borthwick-Duffy, 1990; Goode and Hogg, 1994; Oulette-Kuntz and

McCreary, 1996).

1.3. DEVELOPMENT PROCESS OF THE SCALE

The San Martín Scale was created to assess the quality of life of adult persons with significant disabilities who require extensive and general support (i.e., people with multiple or profound disabilities) from the perspective of an external observer who knows the individual well. In the development process of the San Martín Scale, a special emphasis has been placed on building a tool that allows the assessment of the eight categories of the model proposed by Schalock and Verdugo (2002/2003) with adequate evidence of validity and reliability.

For this, the first step was a thorough revision of scientific literature, which allowed for the selection and proposal of the main indicators of quality of life in order to assess each one of the eight dimensions proposed in the model. Following this, a Delphi study of four rounds was carried out in which 12 experts participated in the concept of the quality of life in people with significant disabilities, as well as in the assessment and application of the construct in services directed at people with intellectual disabilities; all of them had ample experience in the field.

Round 1: The task consisted of evaluating on a scale from 1 to 4, the suitability, importance, sensitivity, observation and difficulty of a pool of 120 items. Most of the items ($n=91$) were conserved in order to show an average ≥ 3 and a standard deviation < 1 . In addition, experts were encouraged to propose a maximum of five items and indicators for each one of the eight categories. In this sense, the judges proposed a large number of items ($n = 452$; 49-61 items per category) and 7 new indicators.

Round 2: The 452 items proposed by the

experts were revised by the research team. After eliminating repetitions, the pool was reduced to 127 items (11-19 items per category). On this occasion, the judges debated whether or not to include it in the scale. When the 12 experts agreed on the importance of this item, it was included so that 21 items were added to the pool.

Round 3: The task centred on arguing about the suitability, importance, sensitivity, observation and difficulty of the non-valid items ($n = 29$) in the first round. Thanks to the discussion between the judges and the agreements these made, most of the items were reformulated so that the content of these could be more precise and clear ($n = 18$) and 4 were appointed to a new category which was different to the one they were first in. No agreements were made in terms of the reformulation and clarification of the 7 items.

Round 4: The task consisted in evaluating the suitability, importance, sensitivity, observation and difficulty of 50 items: the 21 new ones selected in the second round and 29 items which were discussed in the third round. After selecting those with an average ≥ 3 and standard deviation < 1 ($n = 27$), it came to be a pool of 118 items.

Following this, the pool of 118 items was assessed by a discussion group consisting of nine professionals who have ample experience in providing support to people with significant intellectual disabilities of the Obra San Martín Foundation (Santander, Cantabria, Spain). The result of the analysis of the gathered information gave way to numerous reformulations and specifications in order to clarify and set examples of the content of the items, also to avoid possible ambiguities. In addition, two new items were proposed in order to test a new indicator (i.e.,

conditions of the centre in the category of material well-being). From this, the pilot test of the San Martin Scale was achieved and it consisted of 120 items.

The Scale was applied to a sample of 1770 people with significant disabilities who received some type of service in 99 entities throughout Spain. Thus, 18 people on average were evaluated in each organization. The criteria necessary to be a part of the sample was the following:

- The informants (i.e., assessors of the quality of life of people with disabilities) could be professionals, family members or close people who knew the person well, for at least three months and who had the opportunity to observe the person in different contexts and during extended periods of time.
- The people who were being evaluated had to: (a) have an intellectual disability and present the need for extensive and general support (e.g., people with severe and profound intellectual disabilities, people with problems relating to the development of serious health issues and related disabilities); (b) they had to be users of some social service (e.g., care centre, day centre, leisure centre, occupational centre); and (c) they had to be 16 or older (only if they do not partake in the educational system)

The age of the participants ranged from 16 and 77 years old ($M = 37.78$; $SD = 12.32$). The number of men was slightly higher than the number of women (56% vs. 44%). The analysis of

the standard results of Pearson of the proportions between men and women in terms of age led to the conclusion that the predicted equiprobability was true with the exception of a slight underrepresentation of women under 28 in the sample ($X = 14.658$; $p = .002$). All of them required extensive support (45%) or generalized support (55%) and most of them had a high level of “great dependency” (62%). Besides from intellectual disabilities, 92% presented other related conditions such as epilepsy (27,8%), limitations in lower limbs (27,4%), behavioural problems (26%), Down Syndrome (17,2%), autism (17,2%), cerebral palsy (19,9%), mental health problems (16,4%) limitations in upper limbs (15, 3%), visual disability (14,9%), hearing disability (6,4%) or serious health problems (4,7%). Also, 34,3% presented only one related condition, 28,5% presented two, 16% presented three, 6% presented four, while the rest had between six or seven related conditions.

Once the fieldwork had been completed, an analysis of the indexes of corrected homogeneity (using Cronbach's alpha) in order to eliminate those with a value of less than 20. Such analysis led to the elimination of five items: items 20 and 22 of emotional well-being (“He is nervous or restless”; “Has behavioural problems”), item 56 of material well-being (“The household is suited for people with reduced mobility and users of wheel chairs”), and items 63 (“Encounters violent, abusive, negligent environments”) and 73 (“Other people take and touch his things without permission”) which belong to the category of rights. Among the rest, 12 with the highest **IHc** for each category were selected.

Thus, the Scale was made up of 95 items (12 in all categories, except the social inclusion category which consisted of 11). Such analysis

gave place to the final scale which consisted of a total of 95 items, whose psychometric

properties are described in the following sections.

1.4. PSYCHOMETRIC PROPERTIES

1.4.1 Internal Consistency

Reliability was measured in terms of internal consistency through a version of ordinal data of Cronbach's Alpha. As we know, reliability associated with internal consistency depends on the degree of homogeneity of the items of a test.

Thus, a value of 0.97 was obtained for the whole scale, while the coefficients of the subscales varied between 0.82 (physical well-being) and 0.93 (personal development). Taking this into account, we can affirm that internal consistency is adequate in the subscales. (Figure 1)

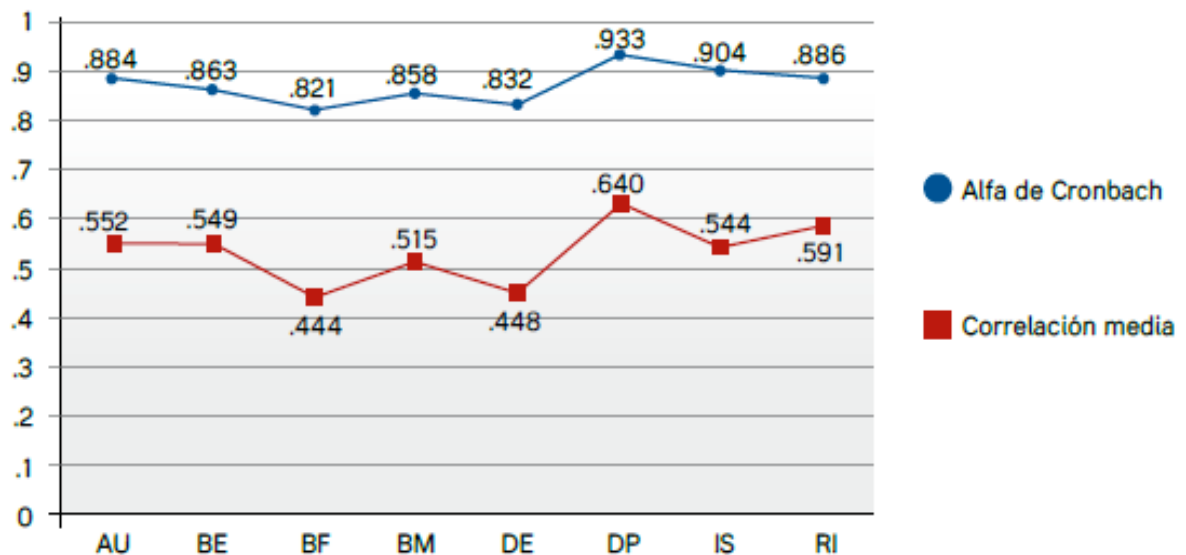


Figure 1. Internal Consistency

1.4.2. Evidence of validity based on the internal structure of the scale

With the aim of providing evidence of validity based on the internal structure of the scale, we carried out a confirmatory factorial analysis (CFA). Given the high number of items in each dimension, this was carried out over *parcels* formed by four items each. The items were assigned to the parcels depending on the function of the symmetry value. Thus, the least asymmetrical and the most asymmetrical were a part of the first one; the next least asymmetrical and most asymmetrical were a part of the second one and so on. One of the prerequisites of the parcels is that they are unidimensional, which was tested by using an exploratory factorial analysis and a parallel analysis.

The CFA was carried out with LISREL v. 9.1. Given the nature of the data, a method of estimation was used DWLS with the covariance matrix and covariance asymptotic matrix. With it, the eight categorical model proposed by Verdugo and Schallock was tested, resulting in adjustment indexes that indicated how adequate the structure was: $\chi^2 = 26676.694$; $p = 000$; RMSEA = .054; CFI = .984; TLI = .981; SRMR = .044 (Figure 2).

For more information about the psychometric properties of the tool and the results of the FCA, look at Verdugo et al. (2014).

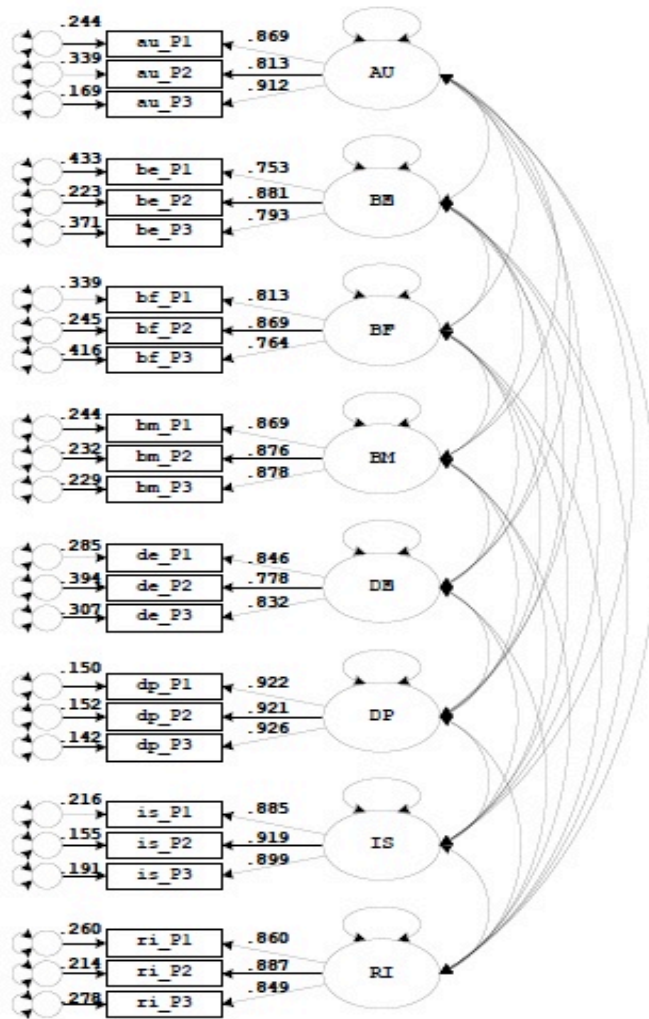


Figure 2. Eight correlated category model

1.5. APPLICATION MATERIAL

Aside from the present Application Manual, which must be read before carrying out the evaluation, a San Martin Scale Survey is necessary (Attachment B).

2

administration

2. ADMINISTRATION

2.1. THE SAN MARTIN SCALE

The San Martin Scale provides information about the most important areas of a person with a significant disability from a perspective of an external observer who knows them well. The tool consists of 95 items, divided into eight categories of quality of life which present the observable aspects and objectives of the quality of life. The scale includes:

(a) A table that gathers the data of the person who is being evaluated and two tables that gather the data of the informants.

(b) The 95 items, organized around the eight dimensions of the quality of life, with one single format. It presents a frequency oriented answer

divided into four options (never, sometimes, often, always).

(c) An open section in which any information considered relevant in terms of the assessment can be included.

(d) A summary table of the direct, standard and percentile scores completed.

(e) The outline of the quality of life in which the results of the assessment are presented graphically.

2.2. SCALE APPLICATION

In the following section, detailed instructions about how to complete each section of the San Martin Scale are presented. Please, before starting the administration process, read these instructions carefully.

2.2.1. Data about the evaluated person

The section of "Data about the evaluated person" refers to the data pertaining to the person with an intellectual disability whose quality of life is the object of investigation. Among the data that can be presented we can see the amount of support needed and the percentage of the disability.

2.2.2 Data about the informants

The informant is the person who must complete

the section of the data of the person who is being evaluated, as well as answering to the items that are included in the scale.

An adequate informant is a social services expert who has known the person for at least three months and who has the opportunity to observe them in different contexts during extended periods of time. Also, an informant can be a family member, legal guardian or close friends or acquaintance.

The scale can be completed by one or two informants. On page 2 of the San Martin Scale there are two identical tables so that the informant 1 (primary informant) and the informant 2 (another informant, a professional, family member or close friend or acquaintance with whom it is important to consult but never the person whose quality of life

is the object of evaluation).

2.2.3. Completion of the San Martin Scale

As it has previously been mentioned, the San Martin Scale must be complemented by a third party or external observer (e.g., professional, family member or close acquaintance) who knows the person with the intellectual disability well (for at least three months) and who has the opportunity to observe them in different contexts during an extended period of time. Its completion does not require previous preparation besides the thorough reading of the application manual as well as familiarity with the conceptual frame of the quality of life.

The scale has 95 items that are put into the third person, organized in terms of the eight categories of the quality of life, which can be answered according to four responses (never, sometimes, often and always). All items of one subscale must be completed before continuing on to the next and one must not forget to ask other informants in case there is a question, but one should never ask the person with disability who is being assessed.

In the following paragraphs, some recommendations are provided about the use of the possible response options.

“Never” is an adequate answer when the person never does or when the specific thing at hand never happens to him/her.

For example, to respond to the item “Choose how you spend your free time”, one should mark the option if the person evaluated never once during the week chooses how they spend their free time.

“Sometimes” is the appropriate answer if the person does or when a specific thing at hand happens sometimes but not on most occasions. For example, to respond to the item “Choose how you spend your free time”, one should mark the option of sometimes if, for example, this person chooses how to spend his/her free time 2 or 3 times per week.

“Often” is the perfect response for when the person does the specific activity in the item frequently; in other words, on most occasions. For example, to respond to the item “Choose how you spend your free time”, one should mark the response of frequent if, for example, the person chooses how to spend his/her free time between 4 or 6 days a week.

“Always” is the perfect response for when the person always does the specific activity in the item. For example, to respond to the item “Choose how you spend your free time”, one should mark the option of always if the person who is being evaluated always chooses how to spend his/her free time (even though there might be an exception in which he/she has not chosen).

In the case of activities that are not carried out every day, use criteria that is proportional and thinking in measure units that are larger (for example, monthly or annually).

3

correction

3. CORRECTION

In this section, the keys for correcting and interpreting the results of the San Martin Scale will be provided. In addition, an example of the process has been provided.

3.1 . SCALE CORRECTION

The points obtained in each one of the items are summed up in order to get a direct and total score for each category. These scores are for the completion of the table “Summary of Scores” and they have been transformed into standard and percentile scores, in order to obtain the “Outline of the quality of life” that is included at the end of the scale.

Direct Scores

To obtain the total and direct punctuation of each category one must add up the scores (1-2-3-4) of each one of the items as is shown in Figure 3. Similarly, the direct and total scores of the eight categories of the quality of life are calculated. These direct and total scores are used further on to complete the “Summary of Scores”.

Self-determination

		N	S	O	A
1	The people who offer them support take into account their preferences and choices	1	2	3	4
2	Participates in the creation of his own support plan	1	2	3	4
3	The staff in the centre supports his decisions	1	2	3	4
4	He chooses how to spend his free time	1	2	3	4
5	Certain measures are taken so that he can have a say in his environment (i.e., physical, material or social environment)	1	2	3	4
6	Certain measures are taken so that he can make decisions	1	2	3	4
7	He has the opportunity to say deny doing certain activities that are irrelevant to his health (e.g., partake in leisure activities, go to sleep at a certain time, wear the clothes that other choose)	1	2	3	4
8	He chooses the food or part of the food when there is variety	1	2	3	4
9	He decorates his room at his leisure	1	2	3	4
10	Supports that take into account his needs, desires and preferences (e.g., the people who provide services, being alone or in a group, places to be, time, pace) are provided.	1	2	3	4
11	If the person considers a decision to be unpleasant this one is reconsidered (e.g., during personal care, food, activities)	1	2	3	4
12	He has a daily program of activities that is suited to his preferences	1	2	3	4

DIRECT TOTAL SCORE **28**

Figure 3. Calculation of the total and direct score of one category

Standard scores and percentiles of each category

In the attachment A there is a table with the necessary scale that allows for the changing of direct scores to standard scores. To do so, one must look at Table A and spot the standard score and the corresponding percentile to the direct and total score of each one of the categories. The results will be written down in the pertinent columns of the table "Summary of Scores" as is indicated in Figure 4.

Quality of Life Index and Percentile of the Index of the Quality of Life

In order to obtain the Index of Quality of Life one must first sum up the standard scores of the eight categories and write down the result in "Total Standard Score". This value becomes the Index of the Quality of Life (or Standard Compound Score) through table B which is included in attachment A. Find in this table the "Total Standard Score" in the same row, in the two right columns, you will find the Index of Quality of Life first and then its matching percentile. Following the example (Figure 4), the sum of the scores of the eight categories in "59" which would turn into an Index of Quality of Life of "84". The percentile of the Quality of Life in this case would be "14".

SUMMARY OF SCORES

SAN MARTIN SCALE

1. Write down the direct total scores of each one of the categories
2. Write down the standard and percentile scores
3. Write down the Index of the Quality of Life and its pertinent percentile

CATEGORIES	DIRECT TOTAL SCORES	STANDARD SCORES	CATEGORY PERCENTILES
SELF-DETERMINATION	28	8	25
EMOTIONAL WELL-BEING	27	6	9
PHYSICAL WELL-BEING	36	9	36
MATERIAL WELL-BEING	31	5	5
RIGHTS	35	7	25
PERSONAL DEVELOPMENT	30	8	25
SOCIAL INCLUSION	26	8	25
INTERPERSONAL RELATIONSHIPS	32	8	25

TOTAL STANDARD SCORE (SUM): 59

QUALITY OF LIFE INDEX (COMPOUND STANDARD SCORE): 84

FIGURE 4. Calculation of the Quality of Life Index

Quality of Life Outline

The Quality of Life Outline is in the last page of the survey. It provides a graphical representation of the standard scores obtained in the eight

quality of life categories, the Quality of Life Index and its respective percentiles. To obtain the outline one must circle the standard scores of each category and then connect them with a line (Figure 5).

AU	BE	BF	BM	DE	DP	IS	RI	ÍNDICE DE CV	PERCENTIL
16-20	16-20	16-20	16-20	16-20	16-20	16-20	16-20	>128	99
15	15	15	15	15	15	15	15	122-128	95
14	14	14	14	14	14	14	14	118-121	90
13	13	13	13	13	13	13	13	114-117	85
								112-113	80
12	12	12	12	12	12	12	12	110-111	75
								108-109	70
11	11	11	11	11	11	11	11	106-107	65
								104-105	60
								101-103	55
10	10	10	10	10	10	10	10	100	50
								98-99	45
								96-97	40
9	9	9	9	9	9	9	9	94-95	35
								92-93	30
8	8	8	8	8	8	8	8	90-91	25
								86-89	20
7	7	7	7	7	7	7	7	83-85	15
6	6	6	6	6	6	6	6	79-82	10
5	5	5	5	5	5	5	5	71-78	5
1-4	1-4	1-4	1-4	1-4	1-4	1-4	1-4	<70	1

Figure 5. Quality of Life Outline

3.2 EXAMPLE

In the following section, an example of a complete scale is presented for an invented case in order to demonstrate the process. All of the cases contained in the scale are not real. To assess the quality of life of Isabel Gutiérrez, a 37 year old

woman with cerebral palsy, Maite Menéndez, the psychologist of the centre provides support to people with disabilities and gave the following answers to the San Martin Scale.

About the person who is being assessed:

	DAY	MONTH	YEAR
Date of application	25	4	2013
Date of birth	15	2	1976

INFORMATION ABOUT THE PERSON WHO IS BEING ASSESSED

Name and Surnames: Ignacio Gutiérrez

Level of support needed: Extensive: Generalized: X

Level of recognized dependency

Grade I of moderate dependency

X Grade II of severe dependency

Grade III of great dependency

Percentage of disability : 89%

Year of expiration of the certificate: 2001

Other conditions that the person may have (write down all that apply)

X Physical disability

X Motor impairments in upper limbs

X Motor impairments in lower limbs

Sensory disability

Deaf

Visual

X Cerebral palsy

X Epilepsy

Mental health problems/emotional disturbances

Autism

Serious health problems

Others, specify

Down syndrome

Behavioural Problems

INFORMATION ABOUT INFORMANT 1

Name and Surname: Maite Menéndez

Amount of time you have been in contact with this person: 5 years and 6 months

Frequency of interaction with the assessed person:

X Many times a week

Once/ one week

Once/ two weeks

Once/month

Relationship with the assessed person:

X Professional

Mother/father

Brother/sister

Tutor/guardian

_____ Other (specify) _____

INFORMATION ABOUT THE INFORMANT 2

Name and Surname:

Amount of time you have been in contact with this person:

Frequency of interaction with the assessed person:

_____ Many times a week
_____ Once/ two weeks

_____ Once/ one week
_____ Once/month

Relationship with the assessed person:

_____ Professional _____ Mother/father __ Brother/sister _____ Tutor/guardian
_____ Other (specify) _____

INSTRUCTIONS:

In the following section a series of affirmations that pertain to the quality of life of the person who is being assessed are presented. Please, mark the response that BEST describes said person and do not leave any question in blank.

ANSWER KEY:

N: never S: sometimes O: often A: always

Self-determination

N S O A

		N	S	O	A
1	The people who offer them support take into account their preferences and choices	1	2	3	4
2	Participates in the creation of his own support plan	1	2	3	4
3	The staff in the centre supports his decisions	1	2	3	4
4	He chooses how to spend his free time	1	2	3	4
5	Certain measures are taken so that he can have a say in his environment (i.e., physical, material or social environment)	1	2	3	4
6	Certain measures are taken so that he can make decisions	1	2	3	4
7	He has the opportunity to say deny doing certain activities that are irrelevant to his health (e.g., partake in leisure activities, go to sleep at a certain time, wear the clothes that other choose)	1	2	3	4
8	He chooses the food or part of the food when there is variety	1	2	3	4
9	He decorates his room at his leisure	1	2	3	4
10	Supports that takes into account his needs, desires and preferences (e.g., the people who provide services, being alone or in a group, places to be, time, pace) are provided.	1	2	3	4
11	If the person considers a decision to be unpleasant the this one is	1	2	3	4

	reconsidered (e.g., during personal care, food, activities)				
12	He has a daily program of activities that is suited to his preferences	1	2	3	4

DIRECT TOTAL SCORE 28

Emotional well-being

N S O A

13	The people who provide support have a list of observable conducts that express his/her emotional state (e.g., maps, registers, etc.)	1	2	3	4
14	The person is previously informed about changes in the person that provides support (e.g., due to shifts, leaves, vacations, familial situations, etc.)	1	2	3	4
15	The people who provide support know his individual expressions of emotional well-being	1	2	3	4
16	The people who provide support know his individual expressions of angst	1	2	3	4
17	The people who provide support know how this person expresses his wishes	1	2	3	4
18	The people who provide support give special attention to facial expressions, looks, the direction of where they're looking, voice, muscular tension, posture, movement and physiological reactions	1	2	3	4
19	Has a personal record in which what he likes, what calms him, what he cannot stand and how he can react to this, is written down and all staff knows and must apply it	1	2	3	4
20	The guidelines and specific advice to help control his conducts are provided	1	2	3	4
21	The people who provide support have technique training in Positive Conduct Support	1	2	3	4
22	Love, affection and physical contact are provided when necessary	1	2	3	4
23	Specific measures are taken in order to improve the environment and the group ambiance	1	2	3	4
24	Specific measures are taken to ensure that his environment is recognizable and predictable (e.g., spaces, temporality, people who provide him support, activities, etc.)	1	2	3	4

DIRECT TOTAL SCORE 27

PHYSICAL WELL-BEING

N S O A

25	Has a diet which is suitable for his qualities and needs	1	2	3	4
26	Does activities and physical exercise that is adequate for his qualities and needs	1	2	3	4
27	Eats and drinks the right amount of food and liquids to maintain good health	1	2	3	4
28	The preparation and presentation of the food is cared for (e.g. composition, taste, variety, temperature, etc.)	1	2	3	4
29	The people who provide support have the right training in terms of the specific health problems of the person assessed.	1	2	3	4
30	Has adequate hygiene (e.g., teeth, hair, nails, body) and self-presentation (e.g., clothes that are adequate for his age, for the occasion etc.)	1	2	3	4
31	He moves around different spaces (i.e., inside and outside)	1	2	3	4
32	Specific measures are taken to prevent or treat problems that result from	1	2	3	4

	physical disabilities				
33	Specific measures are taken in relation to his mobility to stimulate independence	1	2	3	4
34	Specific measures are taken to prevent or treat pain	1	2	3	4
35	Special attention is given to the diagnosis and treatment of the sensory disabilities that may be present	1	2	3	4
36	The people who offer support provide guidance in terms of his/her sexuality	1	2	3	4

DIRECT TOTAL SCORE 36

NUANCES

ITEM 35: If the person does not have a sensory disability, you must still give special attention to the prevention and control of it occurring.

MATERIAL WELL-BEING

N S O A

37	The belongings of the person are restored when they are deteriorated	1	2	3	4
38	The centre to which he/she attends to is suited for his qualities (i.e., sensory, cognitive, behavioural, physical)	1	2	3	4
39	The centre he/she attends to takes specific measures to avoid risks such as impacts, falls or escapes	1	2	3	4
40	Has a physical space with his personal belongings at hand	1	2	3	4
41	The technical aid that he/she needs has been suited on an individual basis	1	2	3	4
42	The effects of the technical aid are evaluated in the functioning and behaviour of the person	1	2	3	4
43	Has the technical aid that he/she needs	1	2	3	4
44	The people who provide support understand the alternative systems of communication that he/she needs	1	2	3	4
45	He/she has his own material possessions to entertain himself (e.g., games, magazines, music, television, etc.)	1	2	3	4
46	He has the material possessions he needs	1	2	3	4
47	Specific measures are taken to adapt the environment in which he/she lives to the capacities and limitations of the person (i.e., sensory, cognitive, behaviour, physical)	1	2	3	4
48	Specific measures are taken in order to adapt the environment in which he/she lives to his preferences and desires	1	2	3	4

DIRECT TOTAL SCORE 31

NUANCES

ITEM 38 AND 39: Centre means day, occupational, leisure and free time, etc. centre.

ITEM 44: In case of not needing them at all, mark "Always".

RIGHTS

N S O A

49	The people who provide support have information concerning the ethics and respect of the rights that the people with disabilities have	1	2	3	4
50	The people who provide support treat the person with respect (e.g., they talk them with an adequate tone, they don't treat him like an infant, they use positive terms, they avoid negative comments in public, they avoid talking about the person as if he/she were not present, etc.)	1	2	3	4
51	His/her rights are defended and respected (e.g. confidentiality, information about his/her rights as users, etc.)	1	2	3	4
52	The person is aware of his/her personal rights	1	2	3	4
53	His/her intimacy is respected in the centre to which he/she attends (e.g., knocking before entering, closing the door when he/she showers, when he/she goes to the bathroom or when they change his/her nappy etc.)	1	2	3	4
54	In the centre, the person has a space in which he/she can be alone if he/she so chooses	1	2	3	4
55	All of his/her personal, documents, supplies and assessments that belong to him by law are up to date	1	2	3	4
56	Specific measures are taken to respect his/her privacy (e.g. during personal care and hygiene, in terms of his/her sexuality, confidential information, etc.)	1	2	3	4
57	He/she is treated with respect in his/her environment	1	2	3	4
58	In the centre which he/she attends, his/her possessions and right to property are respected	1	2	3	4
59	His/her rights are respected in the centre which he/she attends	1	2	3	4
60	Information privacy is respected in the centre (e.g. spreading of images, personal data, etc.)	1	2	3	4

DIRECT TOTAL SCORE 35

SELF-DEVELOPMENT

N S O A

61	Has an activities program with things he/she likes and which contribute to his/her personal development	1	2	3	4
62	The activities he/she partakes in allow him/her to learn new skills	1	2	3	4
63	He/she is taught things that interest him/her	1	2	3	4
64	He/she learns things that make him/her more independent	1	2	3	4
65	He/she is provided with new instructions and models to learn new things	1	2	3	4
66	He/she has the opportunity to demonstrate his/her abilities	1	2	3	4
67	He/she has the ability to develop activities independently	1	2	3	4
68	Specific measures are taken to preserve his/her skills and abilities	1	2	3	4
69	Specific measures are taken to show him/her new skills	1	2	3	4
70	His/her development is stimulated in different areas (e.g., cognitive, social, sensory, emotional, motor)	1	2	3	4
71	The stimulation of his/her development is carried out respecting his/her pace and preferences (e.g., avoiding over and under stimulation)	1	2	3	4
72	Acquires new skills or experiences in participating in different activities	1	2	3	4

DIRECT TOTAL SCORE 30

SOCIAL INCLUSION

N S O A

73	Has the opportunity to get to know other places that are different from the one where he/she lives (i.e., travel, field trips, tourist routes, etc.)	1	2	3	4
74	Can enjoy vacations in inclusive environments (e.g., hotel, park, rural homes, beach, mountain, SPA, theme parks, etc.)	1	2	3	4
75	Has a record of specialized support that all staff knows well and must carry out	1	2	3	4
76	Participates in activities outside of the centre with people who do not belong to his/her support circle	1	2	3	4
77	Participates in inclusive activities that are appropriate for his/her mental and physical conditions	1	2	3	4
78	Participates in inclusive activities that interest him/her	1	2	3	4
79	The activities in which he/she participates take into account the leisure and culture facilities of the area	1	2	3	4
80	Specific measures are taken in order to provide the most variety of activities possible (e.g., new activities depending on the preferences of the person)	1	2	3	4
81	Participates in social activities outside of the centre where he/she receives support	1	2	3	4
82	Specific measures are taken to encourage the participation of the person in the community	1	2	3	4
83	He/she uses community facilities (e.g., restaurants, cafes, libraries, pools, cinemas, parks, beaches, etc.)	1	2	3	4

DIRECT TOTAL SCORE 26

NUANCES

The support context can include family members, professionals, volunteers, centre colleagues, friends, etc.

INTERPERSONAL RELATIONSHIPS

N S O A

84	The people who provide support know the communication system that he/she uses	1	2	3	4
85	In the centre they identify the best way to communicate with him/her (i.e., visual, touch, hearing, smell, taste)	1	2	3	4
86	In the centre they design activities that facilitate the personal interactions among other people	1	2	3	4
87	In the centre information about how the person interacts when he/she meets new people is provided	1	2	3	4
88	Important events are celebrated (e.g., anniversaries, birthdays, etc.)	1	2	3	4
89	In the centre they plan out activities and support that lead to social interaction	1	2	3	4
90	When one interacts with the person, one must leave time for him/her to respond	1	2	3	4

91	When he/she shows a specific conduct one must always find a meaning for it	1	2	3	4
92	The people who provide support check to see if the person understands them correctly through an analysis of his/her reactions	1	2	3	4
93	Specific measures are taken to improve his/her communication abilities	1	2	3	4
94	He/she has the opportunity to meet people outside from the support group	1	2	3	4
95	Specific measures are taken to maintain and expand his/her social networks	1	2	3	4

DIRECT TOTAL SCORE 32

Nuances

ITEM 94: The support group can include family members, professionals, volunteers, colleagues, friends, etc.

If you wish to make a remark that you see as relevant in to the assessment please do so in the following section:

PHYSICAL WELL-BEING	36	9	36
MATERIAL WELL-BEING	31	5	5
RIGHTS	35	7	25
PERSONAL DEVELOPMENT	30	8	25
SOCIAL INCLUSION	26	8	25
INTERPERSONAL RELATIONSHIPS	32	8	25

TOTAL STANDARD SCORE (SUM): 59

QUALITY OF LIFE INDEX (COMPOUND STANDARD SCORE): 84

PERCENTILE OF THE QUALITY OF LIFE INDEX: 14

OUTLINE OF THE QUALITY OF LIFE

AU	BE	BF	BM	DE	DP	IS	RI	ÍNDICE DE CV	PERCENTIL
16-20	16-20	16-20	16-20	16-20	16-20	16-20	16-20	>128	99
15	15	15	15	15	15	15	15	122-128	95
14	14	14	14	14	14	14	14	118-121	90
13	13	13	13	13	13	13	13	114-117	85
								112-113	80
12	12	12	12	12	12	12	12	110-111	75
								108-109	70
11	11	11	11	11	11	11	11	106-107	65
								104-105	60
								101-103	55
10	10	10	10	10	10	10	10	100	50
								98-99	45
								96-97	40
9	9	9	9	9	9	9	9	94-95	35
								92-93	30
8	8	8	8	8	8	8	8	90-91	25
								86-89	20
7	7	7	7	7	7	7	7	83-85	15
6	6	6	6	6	6	6	6	79-82	10
5	5	5	5	5	5	5	5	71-78	5
1-4	1-4	1-4	1-4	1-4	1-4	1-4	1-4	<70	1

3.3 . *INTERPRETATION OF RESULTS*

Even though the correction of the test is fairly easy, the interpretation of results requires a detailed analysis that will allow us to obtain the maximum efficiency of the results. In the following section, some rules are set out in order to interpret the results obtained in the scale.

Standard scores

The direct scores that we have obtained in the items which are a part of each category are summed up in order to obtain the direct and total score. This direct total score must be transformed into a standard score by using Table A which is included in the attachment A of this manual. In order to interpret the standard scores, one must take into account that they have a distribution with an average of 10 and a standard deviation of 3. Higher standard scores mean a higher quality of life.

Quality of Life Index:

The Quality of Life Index also called "Standard Compound Score" presents a distribution with an average of 100 and a standard deviation of 15. This is a distribution with which the evaluators are familiar with, so its interpretation is fairly easy. To obtain the Quality of Life Index you must add the standard scores of the eight categories and write down the result in the "Standard Score Total" of the Score Summary Table. This value is then transformed into the Quality of Life Index (or Standard Compound Score) through Table B which can be found in

attachment A. For this, the Standard Total Score must be spotted, and in the same row, to the right, the Quality of Life Index can be seen as well as its percentile.

Percentiles

Percentiles indicate the percentage of people who have a superior or inferior score. The bigger the percentile the greater the quality of life is. As it has previously been mentioned, the percentiles of the standard scores can be found in Table A and the percentiles of the Quality of Life Index can be found in table B (attachment A).

Quality of Life Outline

The Quality of Life Outline can be found in the last page of the scale. It shows a graphical representation of the standard scores that have been obtained by people in the categories of the quality of life along with their respective percentiles. To draw it, circle the standard scores that have been obtained for each category and connect the circles with a line (see example in the previous section). The obtained outline will immediately allow one to differentiate in a simple manner which are the categories with higher scores and those with lower scores providing useful information in terms of personal results related to the quality of life that can be used for plans which are centred on the person.

The background is a dark blue gradient with several overlapping, semi-transparent circles of varying shades of blue. A thin white vertical line is positioned to the right of the number '4'.

4

references

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Table A. Scale of the San Martin Scale

PUNTUACIÓN ESTÁNDAR	AU	BE	BF	BM	DE	DP	IS	RI	PERCENTIL
20									>99
19									>99
18									>99
17	48								99
16	46-47						>44		98
15	43-45	47-48	48		48	47-48	43-44	47-48	95
14	41-42	45-46	46-47	48	46-47	45-46	40-42	45-46	91
13	39-40	43-44	44-45	46-47	44-45	42-44	38-39	43-44	84
12	36-38	41-42	42-43	44-45	43	40-41	35-37	41-42	75
11	34-35	38-40	40-41	42-43	41-42	37-39	33-34	39-40	63
10	31-33	36-37	38-39	40-41	39-40	35-36	30-32	36-38	50
9	29-30	34-35	36-37	38-39	37-38	32-34	28-29	34-35	37
8	27-28	32-33	34-35	36-37	36	30-31	25-27	32-33	25
7	24-26	30-31	32-33	34-35	34-35	27-29	23-24	30-31	16
6	22-23	27-29	30-31	32-33	32-33	25-26	20-22	27-29	9
5	20-21	25-26	28-29	30-31	30-31	22-24	18-19	25-26	5
4	17-19	23-24	26-27	28-29	29	20-21	15-17	23-24	2
3	15-16	21-22	24-25	25-27	27-28	17-19	13-14	21-22	1
2	13-14	19-20	22-23	23-24	25-26	15-16	11-12	19-20	<1
1	<14	<20	<22	<23	<25	<15	<11	<19	<1

Note:

AU = Self-determination

BE = Emotional well-being

BF = Physical well-being

BM = Material well-being

DE = Rights

DP = Personal Development

IS = Social inclusion

RI = Interpersonal relationships

Table B. Quality of Life Index and Percentile

Total Standard Quality of Life Percentile			Total Standard Quality of Life		
Score	Index	Percentile	Score	Index	Percentile
122	132	98	90	107	68
121	131	98	89	107	67
120	130	98	88	106	65
119	129	97	87	105	63
118	128	97	86	105	61
117	128	97	85	104	59
116	127	96	84	103	57
115	126	96	83	102	55
114	125	95	82	101	53
113	125	95	81	101	51
112	124	94	80	100	50
111	124	94	79	99	47
110	122	93	78	98	45
109	122	93	77	98	43
108	121	92	76	97	41
107	120	91	75	96	39
106	119	90	74	95	37
105	119	89	73	95	35
104	118	88	72	94	34
103	117	87	71	93	32
102	116	86	70	92	30
101	116	85	69	91	28
100	115	84	68	90	26
99	114	82	67	90	23
98	113	81	66	89	22
97	113	80	65	89	22
96	112	78	64	88	20
95	111	77	63	87	19
94	110	75	62	86	17
93	110	74	61	85	16
92	109	72	60	85	15
91	108	70	59	84	14

Total Standard Score Quality of Life Index Percentile

58	83	13
57	82	12
56	82	11
55	81	10
54	80	9
53	79	8
52	79	8
51	78	7
50	77	6
49	77	6
48	76	5
47	75	5
46	74	4
45	74	4
44	73	3
43	72	3
42	71	3
41	70	2
40	70	2
39	69	2
38	69	2
37	68	2
36	67	1
35	67	1
34	66	1
33	65	1
32	64	1
31	63	1
30	62	1
29	62	1
28	61	<1
27	60	<1

Total Standard Score Quality of Life Index Percentile

26	59	<1
25	58	<1
24	58	<1
23	57	<1
22	57	<1
21	56	<1
20	55	<1
19	54	<1
18	53	<1
17	52	<1
16	52	<1