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QUALITY OF LIFE ASSESSMENT REPORT



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PROJECT CO-ORDINATION CONTACT:

Associação Portuguesa de Paralisia Cerebral de Faro
Rua da Guiné-Bissau n.º 2, 8005-203 Faro, Portugal
Website: www.appc-faro.org.pt

Ana Luísa Sousa
Telephone: +351289828814
E-mail: analuisasousa@appc-faro.org.pt





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PROJECT CO-ORDINATION

Associação Portuguesa de Paralisia Cerebral de Faro

Rua da Guiné-Bissau n.º 2, 8005-203 Faro, Portugal

Website: www.appc-faro.org.pt

Contact person:

Ana Luísa Sousa

Telephone: +351289828814

E-mail: analuisasousa@appc-faro.org.pt



PROJECT PARTNERS

Josefsheim gGmbH

Heinrich-Sommer-Straße 13

59939 Olsberg, Germany

Website: www.josefsheim-bigge.de

Contact person:

Martin Künemund

Telephone: +49 2962 800-400

E-mail: m.kuenemund@josefsheim-bigge.de



Istituto don Calabria

Via San Marco, 121

37138 Verona, Italy

Website: www.centrodoncalabria.it

Contact person:

Michele Fasoli

Telephone: +390458184111

E-mail: michele.fasoli@centrodoncalabria.it



Fundación San Francisco de Borja

C/ Barranquet nº 25.

03559 Alicante, Spain

Website: <https://csanrafael.org>

Contact person:

Ana Carratalá Marco

Telephone: +34649864522

E-mail: ana@csanrafael.org



European Platform for Rehabilitation

Avenue des Arts 8

1210 Brussels, Belgium

Website: www.epr.eu

Contact person:

Alicia Gómez Campos

Telephone:

E-mail: agomezcampos@epr.eu



1. THE PROJECT QOL4ALL

1.1. PROJECT DEVELOPMENT

Quality of Life for All (QoL4ALL) is an Erasmus + project that aims to improve the education of adults with disabilities through the provision of educational strategies that promote their quality of life. The project aims to improve the skills of adult education professionals working with people with profound and severe disabilities in the promotion of their quality of life.

QoL4ALL will analyse successful practices in the European Union regarding the quality of life of adults with severe and profound disabilities and promote the qualification and professionalism of service providers in the quality of life of these target group. The project will also aim at increasing the offer of intervention programs in adult education in regard to the promotion of their quality of life.

The target groups for this project are: clients, professionals, managers and stakeholders of education centres for adults with severe and profound disabilities or similar organizations; researchers from a research centre on education for the quality of life of people with disabilities; persons concerned with the quality of life of people with disabilities; and policy makers.

The consortium of the project is composed by: the [European Platform for Rehabilitation](#) (Bruxels, Belgium), the [Associação Portuguesa de Paralisia Cerebral de Faro](#) (Faro, Portugal), [Josefsheim gGmbH](#) (Olsberg, Germany), [Istituto Don Calabria](#) (Verona, Italy), [Centro San Rafael – Fundación San Francisco de Borja](#) (Alicante, Spain).

QoL4All has been developed from the idea that no matter our condition or situation we all have the right to have quality of life. Being aware of and respecting the rights of people with severe disabilities is crucial for staff members, carers and family members to contribute to their quality of life.

Policies and practices among people with disabilities are in the process of transformation, centred on change through innovation, reorganization of services and institutions and their effectiveness (Schalock, Verdugo, Bonham, Fantova & van Loon, 2008; Valdés, Soares & Frota, 2010; Verdugo, Navas, Gómez & Schalock, 2012). Intervention in the field of disability requires an application of the new paradigms through practices based on conceptual models and frameworks of human functioning and the provision of individual supports (Buntinx & Schalock, 2010).

PROJECT OBJECTIVES:

The main horizontal objectives of QoL4ALL are social inclusion and adult education. The project aims at improving the skills of adult education professionals working with people with profound and severe disabilities in the promotion of their quality of life.

This project intends to develop an education program to promote the quality of life of adults with severe and profound disabilities, defining strategies to be implemented with these people and their families, as well as identifying areas of training for employees and guidelines of organisational policies and practices. The aim is to improve the quality of the intervention through credible and sustainable practices based on a logical model that aligns the different levels of the systems (micro, meso and

macro) and which is based on the most recent international scientific guidelines on quality of life and disability, based on the principles established by international experts on this field.

THE PRIORITIES OF THE PROJECT AT NATIONAL (PORTUGUESE) LEVEL ARE:

- development of teaching/learning resources;
- training of adults, teachers, psychologists and technicians;
- development of tools to disseminate good practices.

PROJECT DELIVERABLES:

- Characterisation of the quality of life profile of adults with severe and profound disabilities;
- Identification of individual variables that are predictors of personal quality of life outcomes;
- Identification of good practices and successful experiences developed by partner organizations for improving the quality of life of adults with severe and profound disabilities;
- Design of an education program aimed at professionals working in the field of education of adults with severe and profound disabilities (benchmarking and benchlearning);
- Definition of curricular units and educational strategies to be integrated into the program;
- Definition of measures to be implemented among adults with severe and profound disabilities;
- Definition of strategies aimed at their relatives and informal caregivers;
- Definition of guiding principles, policies and organizational strategies based on a leadership style focused on the quality of life of disabled adults;
- Test the program;
- Evaluation of the impact, quality and effectiveness of the program.

INTELLECTUAL OUTPUTS:

- Quality of life assessment report;
- Guidelines to good practices and successful experiences;
- Education program for the quality of life of adults with severe and profound disabilities.

1.2. PROJECT PARTNERS

ASSOCIAÇÃO PORTUGUESA DE PARALISIA CEREBRAL DE FARO, PORTUGAL

The APPC Faro was founded in November 1982 by a group of parents and employees, to respond to the high number of children with Cerebral Palsy in the district of Faro (Algarve, Portugal), at the time

without specialized intervention in this area. With a team of 115 professionals and 12 volunteers, APPC Faro currently provides support to 611 clients in the Algarve region, with a total of eight social responses: early intervention, clinic, resource center for inclusion, professional rehabilitation unit, occupational activities center, residential home, independent residence and life support center.

Our vision is to be a national and international reference organization for providing quality services based on clients satisfaction, innovation and organizational transformation. Through our mission we intend to develop excellence responses in rehabilitation/habilitation, social and professional inclusion, to promote skills and quality of life for citizens with disabilities as full members of society that they integrate.

APPC Faro works in the prevention, diagnosis, evaluation and (re) habilitation of people with cerebral palsy, related neurological conditions and developmental disorders. As objective it has the prevention, qualification, participation, social inclusion and support to families of people with cerebral palsy and related neurological disorders.

Develops actions within Education, Health, Social Action, Housing, Vocational Training, Employment, Recreation and Sport and seeks to sensitize society and state structures to the problem of cerebral palsy.

The project covers the occupational and residential areas, where most people have multiple severe and profound disabilities, as well as some young people from the clinic who are in the process of transition into adult life.

The Occupational Activities Unit, is a structure that provides support for 56 adults with severe and profound disabilities, who do not meet conditions of employment, maximizing their independence and seeking their wellbeing, with respect for their special characteristics and needs, enabling better social inclusion.

The Residential Home is intended for accommodation of 19 young people and adults with severe disabilities on a permanent basis and 1 vacancy for temporary admission. Ensures the provision of personal hygiene, food and functional mobility services. Promotes well-being and quality of living conditions tailored to the needs of the residents.

JOSEFSHEIM GGMBH, GERMANY

The Josefsheim in Bigge is a rehabilitation centre and offers services to people with physical, sensory, learning and severe disabilities. Currently more than 1000 people are using the different services. The wide range of services is directed at people with disabilities of all age groups and covers the residential areas for children, teens and adults, a remedial kindergarten, the vocational training centre, the sheltered workshop and ambulant services.

The Josefsheim has around 800 employees with different backgrounds at the locations in Bigge, Lipperode and Sundern.

The special services, with their various skills, accompany the process with service planning and the delivery of separate services. The special services establish contact with the other specialised departments and thereby assure interdisciplinary work in all areas. The specialised departments are

social service, psychological service, the medical-therapeutic service, integration service and the special service for the hearing impaired. Medical, psychological and therapeutic services include equine, art and music therapy, therapeutic education, logotherapy, occupational therapy and physiotherapy as well as psychotherapy.

The project “Quality of Life for All” primarily covered the housing and working areas at the Josefsheim where most of the people with severe disabilities live and work: the working groups of the sheltered workshop for people with special needs and the care and living area. Over the past few years, the number of people with severe disabilities in these areas has increased.

In the sheltered workshop there are 420 jobs available for people with disabilities. The range of workplaces available is broadly defined in order to take into account and support each individual according to the nature and severity of their disability, performance and development opportunities.

The first stage in the entry procedure is to find out if the workshop can offer the appropriate support. The vocational training then follows. It should enable people with disabilities to take up employment in a sheltered workshop, in a vocational training centre, in the general labour market or to receive some work experience.

At Josefsheim Bigge there are living arrangements for 350 people of all age groups with disabilities. This number includes the living quarters that lie outside the main complex. There are another 51 places at the Josefshaus branch in Lipperode.

The Josefsheim offers diverse forms of accommodation. Depending on their requirements, people with disabilities can choose their own living arrangements. The open assistance completes the range of services with assisted living for non-residents, the outpatient service, family care, assistance services, individual care for people with severe disabilities and assistance with integration.

At European level the Josefsheim is certified in accordance with EQUASS Assurance (European Quality in Social Services). EQUASS enhances the social sector by engaging social service providers in continuous improvement, learning and development, in order to guarantee service users quality of services throughout Europe. Focus is placed on the concerns and interests of service recipients and other interest groups.

As a company of the JG Group, Josefsheim belongs to a Germany-wide holding which supports hospitals, care homes, youth centres and facilities for people with disabilities across 39 sites. As well as the JG Group, the Josefsheim Bigge is also a member of the Brüsseler Kreis and of the German Caritas Association.

ISTITUTO DON CALABRIA, ITALY

Istituto don Calabria (Congregation of the Poor Servant of the Holy Providence) is a worldwide organization with legal seat in Verona (Italy).

The Centro Polifunzionale don Calabria is an operative structure, in Verona, developed by the Istituto don Calabria to manage services in the social and health sectors. It works with a multifunctional vision, providing services for citizens in the fields of health, physical and neurologic rehabilitation, professional training and also social inclusion, education and assistance of people with disability. It

started its activities more than 70 years ago, always acting as a nonprofit organization, and it employs many different professionals for the provision of services.

Centro Polifunzionale Don Calabria has been recognized from 2013 to 2017, with EQUASS Quality Assurance in social services for Medialabor: employment access service for people with disabilities.

The centre works according to pathways of services which are either individualized or integrated with one another, aiming at the full development and expression of each individual's attitudes. This aim is carried out through a complete taking care of each person, in a professional cooperation between the different areas of the centre, according to the ICF system. It carries out rehabilitation, vocational training and retraining, job integration and promotion of social integration through distinct areas that interact in a connected system.

The integrated areas are: the rehabilitation area, the vocational-training area and the social area.

The centre also promotes innovative and complex projects in the above mentioned fields, always with the cooperation of public partners, universities and other organizations.

CENTRO SAN RAFAEL - FUNDACIÓN SAN FRANCISCO DE BORJA, SPAIN

The San Francisco de Borja Foundation is a private, social assistance foundation, which was established non-profit and indefinitely in 1996, to continue the work of the Association of the same name, established in 1980. Since its Con Origins in the 1980s, the Foundation has maintained an active commitment to defending the dignity and rights of people with intellectual disabilities, especially those with the greatest need for support.

Its mission is to generate opportunities and provide personalized support both in its services and programs and in the community, so that each person can develop their personal project and achieve a full and happy life.

This mission has been developed throughout its trajectory through the different services and programs it has managed. In 1982, he opened the first San Rafael residence to serve 40 people with intellectual disabilities who were in a serious situation of social exclusion. Today the residence provides residential support to 60 people with serious disabilities distributed in its five homes.

In 1998 the San Rafael Day Center was inaugurated, which currently offers specialized support to 42 people with intellectual disabilities. In 2001, and as a natural consequence of the application of the quality of life model, the Person-Centered Planning (PCP) approaches were introduced, an innovative methodology in our context, which creates the necessary conditions for the person with disability is the one that defines her own project of happiness and full life, supported by her circle of support, people whom she chooses from among her family, professionals and friends and who want to commit to her in order to achieve the results that she has defined as valuable in her life. The Foundation's experience in PCP has made it a benchmark for this approach in Spain. Consistent with the PCP, other equally innovative methodologies have been introduced, such as Positive Behavioral Support and Active Support, for which it has received recognition from the disability sector in Spain.

Guided by our vision of "Being generators of support for the construction of full lives, opening spaces for inclusion in our society", the Maldonado house was opened in 2005 and the Gómez-Trénor house

in 2015, offering an inclusive life model to women. 14 people with disabilities and widespread or widespread support needs living in them.

In 2018, the “Between Neighbours” project began as an inclusive day care alternative compared to traditional day centers. This service, the purpose of which is for young people with disabilities to continue their development in the community context to which they belong.

EUROPEAN PLATFORM FOR REHABILITATION, BELGIUM

The European Platform for Rehabilitation (EPR) is a network of service providers to people with disabilities committed to high quality service delivery. It is active at the European level in the fields of employment, education and training, vocational rehabilitation, social care, medical rehabilitation with cross-cutting expertise on co-production, quality of services, quality of life and mental health. The goal of EPR is to assist its member organisations to provide sustainable, high quality services through mutual learning and training activities. EPR has 25 members in 15 European Union (EU) countries (and 2 non-EU).

Members are not-for-profit or governmental leading service providers at local or regional level or national umbrella associations. EPR’s membership provides social inclusion, medical rehabilitation, employment and training services to over 130,000 persons every year, and over 20,000 rehabilitation professionals are employed in EPR’s members and their affiliates all over Europe.

Over the last 25 years, EPR has built up extensive practical experience in transnational cooperation in the fields of VET, employment, employment re-integration, research and development, innovation and ICT-based learning, and quality standards in the sector, among others. In this way, EPR strives to act as a laboratory of ‘good practice’ in the sector. From its very creation, EPR has focused on the development and training of professionals working with persons with disabilities.

As a consequence of its powerful membership base and established relationships of trust and cooperation at national and international level, EPR offers a unique forum for international benchmarking and bench-learning. In order to achieve its mission, teams of EPR experts develop methods and models of delivery that directly innovate and improve service delivery systems and programs for people with disabilities. EPR members co-create and pilot innovative tools and methods to better meet the needs of clients, employers and funders. EPR activities go beyond traditional mutual learning exchanges. Professionals from EPR members gather to benchmark and analyze effectiveness in service provision, improving quality of services and quality of life for clients, as well as positively impacting their daily work experience. Mental health is a key theme for EPR. The EPR Mental Health working group gathers experts on mental health issues from its membership to work together around a commonly agreed topic, developing resources and learning from good practices from their centers.

EPR supports members in developing projects, giving guidance in finding project partners, in writing EU applications and organizing training sessions on accessing EU funding opportunities. Members have also the possibility to join projects developed by EPR. It supports members' networking and strategic growth by helping them to build connections with leading service providers across Europe, be part of a community of like-minded professionals, take part in exchanges and training on strategic issues and management.

EPR organizes online and in-person training sessions on innovative methodologies and tools in service provision to improve labour market integration and social inclusion.

EPR is recognised as an important player on the European scene. It has a seat on the EU's High-Level Group on Disability, and is also a member of major European umbrella structures such as Social Services Europe.

EPR also manages EQUASS (European Quality in Social Services), a tested system to enhance quality and excellence in social services provision in Europe. The overall objective of EQUASS is to enhance the social services sector by engaging service providers in quality and continuous improvement, and by guaranteeing service-users quality of services throughout Europe. The EQUASS department actively promotes benchmarking and bench learning as tools for improving the quality of life.

1.3. SITUATION IN THE PARTNERS COUNTRIES

SITUATION IN PORTUGAL

The Convention on the Rights of Persons with Disabilities (United Nations, 2006) ratified by Portugal on July 30, 2009, recognizes the right of all persons with disabilities to live in the community, on equal opportunities, and obliges States Parties to take effective and adequate measures to facilitate the full enjoyment of it by these citizens.

The legal system in Portugal has been part of this conceptual paradigm since Law No. 38/2004, of 18 August, which defines the general bases of the legal regime of prevention, authorization, rehabilitation and participation of people with disabilities, with guidelines for action by the State's central administration bodies.

Within the scope of the development of rehabilitation policies and reinforcement of social protection and inclusion in the area of disability, and with the objective of increasing levels of quality and effectiveness in the development of social responses aimed at this target audience, the State has been assuming as a priority the personal valuation and social and professional inclusion of these people, values that contribute to the exercise of their full citizenship.

Through Decree-Law No. 18/89, of January 11, the regime of occupational activities was established, aimed at people with severe disabilities, whose capacities did not allow them to the exercise of a productive activity.

On July 16, 1990, Order No. 52/SESS/90 approved the regulation for the implementation, creation and operation of services and equipment that develop occupational support activities.

The full inclusion of people with disabilities, as well as the recognition and promotion of their fundamental rights, is a priority assumed by the XXII Constitutional Government. So in 2021 the regulatory framework existing in Portugal is reviewed, streamlined and adjusted, concentrating legislation dispersed, and providing for a new regulatory framework based on a perspective that sees occupation as a process and instrument of training, training and development of skills of people with disabilities and incapacity with a view to their autonomy, from a perspective of social inclusion.

For this purpose, the intention is to create the Centre for Activities and Preparation for Inclusion, which from March 26, 2021 succeeds and replaces the Centre for Occupational Activities, as a community-based social response, with a regulation focused on new challenges, such as the promotion of autonomy, independent living, quality of life, personal and professional valuation and social inclusion, in the implementation of the principles and values advocated in national and international legal instruments that frame people's rights with disabilities.

It is intended to create a model of activities and services centred on facilitating and mediating learning and inclusion pathways, enabling greater access to the community, its resources and activities and the perspective that occupational activities are not an end in themselves, but rather, and as much as possible, a means of empowerment for inclusion, a response that empowers and maximizes the possibilities and opportunities for social and economic participation of people with disabilities, and that incorporates in its genesis the needs of people with disabilities, with different degrees of dependency and disability, which require different responses, more demanding from the point of view of qualifications and learning and more enabling from the point of view of the processes of empowerment and inclusion.

Considering that the objectives associated with the promotion of autonomy and inclusion bring new challenges to this type of structures, namely in terms of flexibility and organisation, it is important to update the structuring model of occupational support, adapting it to the objectives of the Convention on the Rights of Persons with Disabilities, and to safeguarding the existence of sequential responses to the exit from the education system, which ensure continuity of the support for people with disabilities and their families, promoting their autonomy and citizenship, facilitating decision-making processes and promotion of inclusion.

It is considered the Centre for Activities and Preparation for Inclusion, the equipment designed to develop occupational activities for people with disabilities, aiming to promote their quality of life, enabling greater access to the community, its resources and activities and that constitute as a means of empowerment for inclusion, depending on their needs, capabilities and level of functionality. This center is intended for people with disabilities, aged 18 years or over, who cannot, by themselves, temporarily or permanently, continue their training/academic path, or exercise a professional activity, or even if they are in the process of socio-professional inclusion, namely between work experiences (Decree Order No. 70/2021 of March 26 in Diário da República, 1st series, No. 60, page 23).

SITUATION IN GERMANY

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD - UN Disability Rights Convention) entered into force in Germany on March 26, 2009. Its aim is to affirm and concretize individual human rights in the context of the personal lives of people with disabilities. The implementation of the UNCRPD has created the basis for the effective and equal participation of people with disabilities in social, economic and political life.

The Federal Participation Act (Bundesteilhabegesetz/BTHG) serves to ensure the implementation of the requirements of the UNCRPD in German law and the associated implementation in practice, and thus to strengthen the participation and self-determination of people with disabilities. Along with this, the BTHG defines a new concept of disability, which is oriented towards the social understanding of an inclusive society according to the principles of the UNCRPD (Preamble and Art. 1 UNCRPD), the

transition from institution-centeredness to person-centeredness (Art. 19 UNCRPD), improvement to participation in education (Art. 24 UNCRPD) and in the workplace (Art. 27 UNCRPD), and the strengthening of consultation of persons with disabilities by persons with disabilities (Art. 26 UNCRPD (<https://umsetzungsbegleitung-bthg.de/gesetz/hintergrund>)).

On January 1, 2018, a new concept of disability was introduced, which is based on the understanding of the International Classification of Function, Disability and Health (ICF) of the WHO. Here the biopsychosocial model of the ICF stands in the center, at which individual participation restrictions are determined and brought in the interaction with the personal context factors (often environmental factors) and the desires and goals of humans into alignment. Thus, disability is to be understood as an interaction between impairment and environmental barriers.

The unrestricted participation in all aspects of life and the highest possible degree of self-determination are, among other things, in various studies and concept on the topic of quality of life within Germany, also the criteria that are important in the context of measuring the individual quality of life in general, but in particular in the quality of life of people with disabilities (Seifert, 2017). To elicit these objectively and to improve them in a targeted way, turns out to be very challenging, especially for the group of people with complex needs, as these people are mostly cognitively and/or physically unable to name their needs. Seifert (2001) uses and modifies five dimensions of well-being (psychological, social, material, activity-related and emotional) according to Felce and Perry (1997) in her qualitative study "Zielperspektive Lebensqualität" ("Target Perspective Quality of Life"). She approaches these using various scientific survey and observation methods. Seifert thus provides one of the few studies on the topic of quality of life for people with complex needs (<https://www.inklusion-online.net/index.php/inklusion-online/article/view/186/186>).

Therefore, with the project partner Josefsheim Bigge, the participation and involvement of a representing institution from Germany in the Erasmus + project Quality of Life for All was very important. In this project, with the involvement and participation of the various partner countries and based on the scientific findings of Schalock and Verdugo, a practical guide/training concept for determining and improving the individual quality of life for named target group was developed.

SITUATION IN ITALY

The Constitution of the Italian Republic, which come into force in 1948, already stated in Article 3 that: "all citizens have equal social dignity and are equal before the law, irrespective of sex, race, language, religion, political opinions, personal and social conditions. It is necessary for the Republic to remove the obstacles of economic and social nature, which, in fact, limiting the freedom and equality of citizens, prevent human person from fully cultivating themselves and participation effectively....".

In Italy, however, people with disabilities were attending separate school courses, special schools and differential classes. Only after Law No. 517/1977 these special schools were abolished and disabled pupils began to be integrated in ordinary classes with support teachers.

In Italy, on the subject of disability the legislation has moved from a merely individual medical approach, based only on the impairment of which the subject is affected, to a broader definition of disability. The Law No. 482/1968 is the first organic law on "compulsory" job placement matter. The

Law No. 118/1971 introduced the concept of "civil invalidity" and the related monthly economic and retirement provisions have been introduced.

In 1978 the first health reform was adopted with the establishment of the National Health Service, open to all and free of charge.

Another significant law is the No. 104/1992, called "framework law for integration, assistance and rights of people with disability" where the definition of "person with disability" is reported such as "someone who presents a weakened physical, mental or sensorial condition, stabilized or progressive, which causes difficulties in learning, relationships or work integration and due to which a person undergoes a process of social disadvantage or marginalization".

The Law No. 68/1999 replaced and repealed the previous law on the right to work for people with disability. Article 1 of Law No. 68/99 states: "The purpose of this law is to promote the placement and work integration of people with disability through support services and targeted placement".

In Italy, the United Nations Convention on the Rights of People with Disability (UNCRPD) was ratified with Law No. 18/2009.

The article 3 introduced innovative principles and values: - respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons - non-discrimination - full and effective participation and inclusion in society - respect for difference and acceptance of persons with disabilities as part of human diversity and humanity - equality of opportunity - accessibility - equality between men and women - respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Another important Law is the No. 112/2016, that states "Provisions on assistance in favor of people with severe disabilities without family support", ("After Us, During Us"), to activate programs aimed at promote de-institutionalization and support paths to stay in homes or residential solutions that reproduce the living and relational conditions of the "family" and of the "home", implement innovative residential interventions for people with severe disabilities without parental support.

SITUATION IN SPAIN

In 1982, the Law on the Social Integration of the Handicapped (LISMI) was enacted in Spain, as the first legislative initiative after the 1978 Constitution, whose article 49 states that "The public powers shall carry out a policy of provision, treatment, rehabilitation and integration of the physically, sensory and mental handicapped (...). The LISMI arose with the intention of guiding a legislative development that would ensure the necessary resources for the exercise of the rights of these people for their complete personal fulfilment and their total social integration, and for the deeply disabled to receive the necessary assistance and guardianship.

Thus, in the second half of the 20th century, Spain experienced an important development of centers and resources for people with intellectual disabilities. It is noteworthy at this time the great effort made, especially by family associations, to make this group visible and generate proposals that tried to respond to the needs of these people and their families, through specific centers and resources, such as special education colleges, occupational centers, day centers, special employment centers,

residences, etc. The result was the creation of a network of services, assumed or supported by the Public Administrations, that took people out of their natural contexts to respond to their clinical or learning needs, including care from the medical or psychoeducational paradigm and that often segregated people from the community, especially those most seriously affected, whom only the law contemplated from the perspective of assistance and guardianship.

It was not until the last years of the twentieth century and the first of the twenty-first, when Spain began a transformation in the way of understanding people with intellectual disabilities and in the system of provision of support. New legislative initiatives arise, both from the Government of the nation and in the different autonomous communities that contribute to the advance in the recognition of citizenship of people with intellectual disabilities, although with an uneven development according to the territory.

The associative movement of the disability sector, as well as some academic institutions constituted an important engine of change in this advance, claiming the rights of people with disabilities and providing principles and approaches that would favor the transformation from the micro to the macrosystem.

In November 2007, Spain ratified the Convention on the Rights of Persons with Disabilities, which will allow an alignment of Spanish legislation on disability, although at different speeds depending on the Autonomous Community.

In 2013, Royal Legislative Decree 1/2013, of November 29, was published, approving the Consolidated Text of the General Law on the rights of people with disabilities and their social inclusion, which repeals the previous regulations and recognizes the desire for a full life and the need for personal fulfilment of people with intellectual disabilities without distinguishing their degree of affectation.

In the Valencian Community, territory to which the San Francisco de Borja Foundation belongs, the law on the "Statute of people with disabilities", currently in effect, was published in 2003 in order to regulate the actions of public administrations of the Valencian Community, through a coordinated action, aimed at the attention, promotion and protection of fundamental rights and freedoms, well-being and quality of life of people with disabilities.

In 2019, the Law of Inclusive Social Services of the Valencian Community is approved, which expands and makes its catalogue of benefits more flexible in order to adapt to the needs of each person, taking into account the principles of the 2006 Convention.

Despite this, people with greater support needs, the target group of this Erasmus project, present greater social vulnerability and greater disadvantage compared to other people with not so severe disabilities. According to the study "We all are all" (<https://www.plenainclusion.org/wp-content/uploads/2021/03/estudiotodosomostodosdef.pdf>) carried out by Plena Inclusión and INICO (University of Salamanca), in Spain there are 63,610 people with intellectual or developmental disabilities who have great support needs and who have other disabilities associated with their intellectual disability, such as mobility problems, mental health disorders or communication difficulties, among others.

The individual characteristics presented by this group exclude them from enjoying new service models; do not receive appropriate supports to meaningfully participate in activities of interest to them in

community settings; they present difficulties for their desires to be taken care of given the almost absolute dependence on others for; they are less likely to participate in an education that takes place within the ordinary system; they report lower scores than their peers with less severe ID in terms of subjective well-being; they have more limited social networks, in which the presence of professionals and relatives stands out, with less frequency of mutually satisfactory interpersonal relationships; they are more likely to remain in segregated environments; they find it more difficult to exercise their right to self-determination and, in general, they face greater situations of exclusion than their peers with less severe ID.

SITUATION IN EUROPE

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD or Convention)¹ was adopted in 2006 after decades of work by the United Nations to change attitudes and approaches to persons with disabilities. It marked a fundamental step in changing the view of persons with disabilities who are not considered anymore mere “objects” of charity, medical treatment and social protection, but they are “subjects” with rights, reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. The EU and its Member States are parties to the UNCRPD and as such are obliged to implement the Convention. The EU and its Member States are progressing with its implementation. To do that the EU has launched a series of initiatives that will help ensure the UN CRPD is fully implemented in Europe.

One of these main initiatives launched by the European Commission is the European Pillar of Social Rights² which serves as a compass for employment and social policies. It was jointly proclaimed in 2017 by the European Parliament, the Council, and the European Commission. It includes 20 principles and principle 17 of the Pillar underlines that persons with disabilities have the right to income support that ensures their living in dignity, services that enable them to participate in the labour market and in society and a work environment adapted to their needs.

The European Disability Strategy 2010-2020³ paved the way to a barrier-free Europe, fostering actions supported also by EU funds to make a difference for the life of approximately 87 million persons having some form of disability in the EU. The evaluation shows that it contributed to improving the situation in a number of areas, in particular accessibility for persons with disabilities and promoting their rights by putting disability high on the EU agenda.

In March 2021, the new Disability Strategy for the Rights of Persons with Disabilities 2021-2030⁴ was presented by the European Commission with the aim to build on the achievements of the previous ten years European Disability Strategy and to contribute to the implementation of the European Pillar of Social Rights. This new and ambitious strategy wants to achieve further progress in ensuring the full

¹ Full text of the Convention on the Rights of Persons with Disabilities:

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

² https://ec.europa.eu/info/strategy/priorities-2019-2024/economy-works-people/jobs-growth-and-investment/european-pillar-social-rights/european-pillar-social-rights-20-principles_en

³ <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=LEGISSUM%3Aem0047>

⁴ https://ec.europa.eu/commission/presscorner/detail/en/ip_21_810

participation of persons with disabilities, guiding the action of Member States as well as EU institutions. The main objective is to tackle the diverse challenges that persons with disabilities face, progressing on all areas of the United Nations Convention on the Rights of Persons with Disabilities, both at EU and Member State level.

According to the new Strategy “persons with disabilities still face barriers in access to healthcare, education, employment, recreation activities, as well as in participation in political life. They have a higher risk of poverty or social exclusion (28,4%) compared to persons without disabilities (18,4%). Over half of persons with disabilities say they felt personally discriminated against in 2019. Furthermore, the Covid-19 pandemic and its socio-economic consequences contributed to amplifying obstacles and inequalities. “Persons with disabilities living in residential care experience higher infection rates and at the same time they suffer from isolation due to social distancing rules. Those living in the community and at home are affected by restricted personal service delivery, which can put independent living in jeopardy”.

People with severe disabilities have complex and specific needs often overlooked by major disability policies. This project has raised awareness of them during the final conference to European policymakers.

1.4. PROJECT DESCRIPTION

This project was based on a previous experience developed at APPC Faro (Portugal) in the framework of a doctoral study in Education at the Autonomous University of Madrid (Spain) on the design of an education program to promote the quality of life of adults with multi deficiency, validated by international experts through a Delphi study. It's was felt the need to bring together the best practices developed at European level in this area, to promote the qualification and fairness of the services available to these citizens.

Given the evolution of the concept of disability over the last decades, based on the principle of inclusive education and with the ratification of the United Nations International Convention on the Rights of Persons with Disabilities, a new perspective is inherent with this population, implying a greater dignification of their quality of life and a greater commitment to a theoretical/practical framework of reference that is adequate to the fulfillment of the values of citizenship and inclusion of these citizens as full members of the society that they are part of.

In international terms, this theme has been widely analyzed and implemented, both in rehabilitation and in special education. The concept of quality of life is used universally to evaluate the results of policies, practices and personal evolutions. In 2002, Schalock and Verdugo described quality of life as a desired state of personal well-being that: (a) is multidimensional; (b) has universal properties and properties related to culture; (c) has objective and subjective components; and (d) is influenced by personal characteristics and environmental factors. Today, the model of Schalock and Verdugo is internationally accepted as a valid and reliable framework to discuss the quality of life of an individual (Gómez, Verdugo, Arias & Arias, 2011), since it is based on a validated model in cultural terms , with robust psychometric properties, translating into personal results based on evidence, constituting itself as the theoretical reference of this project.

Regarding education for the quality of life of people with disabilities, it is aimed at focusing on an educational system of multidimensional and multidisciplinary nature that respects diversity, individuality and development, aiming at a culture of cooperation and collaboration problem solving, maximizing the potential of each individual with disability and providing an improvement in the educational response.

It should be noted that, with severe and profound disabilities, there are marked limitations in their body functions and structures (by reference to the ICF, i.e. the International Classification of Functioning, Disability and Health), which put their development at serious risk, leading them to experience serious difficulties in the process of learning and participation in the various contexts in which they are inserted.

The main objective of this project is to improve the education of adults with disabilities through the provision of educational strategies that promote their quality of life. The aim is to analyze successful practices in the European Union regarding the quality of life of adults with severe and profound disabilities. To promote the qualification and professionalism of service providers in the quality of life of these people. And to increase the offer of intervention programs in adult education with regard to the promotion of their quality of life.

This project intends to develop an education program to promote the quality of life of adults with severe and profound disabilities, defining strategies to be implemented with these people and their families, as well as identifying areas of training for employees and guidelines of organizational policies and practices. The aim is to improve the quality of the intervention through credible and sustainable practices based on a logical model that aligns the different levels of the systems (micro, meso and macro) and which is based on the most recent international scientific guidelines on quality of life and disability, based on the principles established by international experts in this regard.

The QoL4ALL project lasted 36 months, with the application approved for 24 months and with an extension of another 12 months. As part of the project partnership, tasks were distributed so that each partner could make appropriate contributions at several points in the project.

The project began with training in assessing the quality of life of people with severe and profound disabilities (LTT1) with the aim of training the participants in the application of the quality of life assessment tools and their results quotation. Also, promote an understanding of various concepts, models and topics connected to quality of life. Previously, each institution in the consortium selected the professionals who could assume the role of external observer to evaluate the target group. These professionals (23) took part in training courses on assessing the quality of life of people with severe disabilities (partnership's consortium team with qualifications and knowledge). Each professional identified their training needs, presented a letter of motivation and expression of interest and their resume. The consortium asked the authors of the San Martín Scale to use the versions made available in the languages of the consortium's countries (except in German - unofficial translation). The assessment was carried out by 19 professionals from the institutions of the partnership consortium, and each institution completed the instrument to twenty people with severe disability (n = 80). The data collected from the assessment of quality of life were introduced into a computer application adapted for this purpose (belonging to Centro San Rafael) and statistically analyzed with the aim of determining the characterization of the quality of life profile of adults with severe and profound disabilities and identifying variables predictors of personal quality of life results.

The results of this study were an input for the design of the educational program to promote the quality of life of people with severe and profound disabilities built by the partnership.

The second phase of the project consisted in the identification of good practices and successful experiences developed by partner entities in terms of adequacy, quality, strength and relevance for improving the quality of life of adults with severe and profound disabilities.

At the same time, the partners designed an education program aimed at professionals working in the field of adult education with severe and profound disabilities, based on the comparison of the quality of life assessment results achieved by the sample of each partner institution (benchmarking and benchlearning). The curricular units and pedagogical strategies to be included in the program were defined, based on measures to be implemented among adults with severe and profound disabilities, in the definition of strategies aimed at their families and informal caregivers, in the definition of guiding principles, policies and organizational strategies based on a leadership style focused on the quality of life of adults with disabilities.

In the third phase of the project, the education program for the quality of life of people with severe disabilities was tested through a training course (LTT2) prepared by the partners and aimed at professionals who work directly with adults with severe and profound disabilities, with the aim of providing educational strategies that promote the quality of life of adults with severe disabilities. Subsequently, the impact, quality and effectiveness of the program were evaluated.

In the last phase of the project, a “Best Practices and Successful Experiences” training (LTT3) was held in order to share with the participants the best practices and successful experiences to promote the quality of life of adults with severe disabilities.

2. QUALITY OF LIFE ASSESSMENT REPORT OF ADULTS WITH SEVERE AND PROFOUND DISABILITIES

ABSTRACT

The purpose of this article is to present the results of the assessment of the quality of life of adults with severe and profound disabilities who participated in the European project “Quality of Life for All” of the Erasmus+ program, contributing to the development of an education program for the promotion of the quality of life of adults with severe disabilities.

In this framework, an investigation was developed based on a descriptive methodology.

The main objective of the research carried out was to characterize the quality of life of these people in order to determine which domains and dimensions are considered most significant for the improvement of their quality of life, using a sample consisting of N = 80, belonging to four institutions of the project's consortium, namely, Cerebral Palsy Portuguese Association of Faro (Faro, Portugal), Josefsheim gGmbH (Olsberg, Germany), Istituto Don Calabria (Verona, Italy) and Centro San Rafael – Fundación San Francisco de Borja (Alicante, Spain).

In this study, the questionnaire survey was used as a data collection technique, using the San Martín Scale. The collected data were analysed using Excel and SPSS software.

The results obtained from this investigation indicate that the lowest quality of life dimensions for the studied population, according to their families and professionals, are social inclusion, self-determination, personal development and emotional well-being, constituting the centre of the program to promote the quality of life of adults with severe disabilities.

Keywords: Quality of Life, severe and profound disabilities, San Martín Scale.

2.1. INTRODUCTION

This project is based on previous experience developed at the institution Cerebral Palsy Portuguese Association of Faro (Portugal), in the framework of a doctoral study in Education at the Autonomous University of Madrid (Spain) on the design of an education program to promote the quality of life of adults with multi disability, validated by international experts through a Delphi study. Thus arises the need to bring together the best practices developed at European level in this area, to promote the qualification and fairness of the services available to these citizens.

Given the evolution of the concept of disability over the last decades, based on the principle of inclusive education and with the ratification of the United Nations International Convention on the Rights of Persons with Disabilities, a new perspective is inherent with this population, implying a greater dignification of their quality of life and a greater commitment to a theoretical/practical framework of reference that ensures the fulfillment of the values of citizenship and inclusion of these citizens as full members of the society that they are part of.

In international terms, this theme has been widely analyzed and implemented, both in rehabilitation and in special education. The concept of quality of life is used universally to evaluate the results of policies, practices and personal evolutions. In 2002, Schalock and Verdugo described quality of life as a desired state of personal well-being that: (a) is multidimensional; (b) has universal properties and properties related to culture; (c) has objective and subjective components; and (d) is influenced by personal characteristics and environmental factors. Today, the model of Schalock and Verdugo is internationally accepted as a valid and reliable framework to discuss the quality of life of an individual (Gómez, Verdugo, Arias, & Arias, 2011), since it is based on a validated model in cultural terms, with robust psychometric properties, translating into personal results based on evidence.

Regarding education for the quality of life of people with disabilities, it is aimed at focusing on an educational system of multidimensional and multidisciplinary nature that respects diversity, individuality and development, aiming at a culture of cooperation and collaborative problem solving, maximizing the potential of each individual with disability and providing an improvement in the educational response.

This study is part of a European project, "Quality of Life for All" of the Erasmus + program, within the scope of adult education. This project intends to develop an education program to promote the quality of life of adults with severe and profound disabilities, defining strategies to be implemented with these people and their families, as well as identifying areas of training for employees and guidelines of organizational policies and practices. The aim is to improve the quality of the intervention through evidence-based and sustainable practices based on a logical model that aligns the different levels of the systems (micro, meso and macro) and which is based on the most recent international scientific guidelines on quality of life and disability, based on the principles established by international experts in this regard. The main objective of this project is to improve the education of adults with disabilities through the provision of educational strategies that promote their quality of life. The aim is to analyze successful practices in the European Union regarding the quality of life of adults with severe and profound disabilities. To promote the qualification and professionalism of service providers in the quality of life of these people. And to increase the offer of intervention programs in adult education with regard to the promotion of their quality of life.

This research appears as a first part of the project "Quality of Life for All", as it intends to characterize the quality of life profile of adults with severe and profound disabilities through the San Martín Scale - Assessment of Quality of Life in Persons with Significant Intellectual and Developmental Disabilities, and identify individual, service and community variables that are predictors of personal quality of life outcomes.

Policies and practices among people with disabilities are in the process of transformation, centered on change through innovation, reorganization of services and institutions and their effectiveness (Schalock, Verdugo, Bonham, Fantova & van Loon, 2008; Valdés, Soares & Frota, 2010; Verdugo, Navas, Gómez and Schalock, 2012).

Intervention in the field of disability requires an application of the new paradigms through practices based on conceptual models and frameworks of human functioning and the provision of individual supports.

Since the 1990s, the concept of quality of life has become an important research topic in social sciences and education, especially in the area of disability. The use of this concept has allowed for a better understanding of the intervention practices of services that support the population with disabilities and has contributed to evaluating and improving policy development, enabling and planning of these services (Schalock, 1996). The investigations carried out in recent decades, underlying the theme of Quality of life, cover different populations: users of health services (Schalock, 2000; Schalock, Bonham & Marchand, 2000; Velanovich, 2001); people with serious illnesses (Bullinger et al., 1996), genetic or hereditary illnesses (Bullinger et al., 2002; Kuhnle, Bullinger & Schwarz, 1996; Mancuso, Peterson & Charlson, 2001) or chronic and lethal illnesses (Almeida & Loureiro, 2000; Sabaz, Cairns, Lawson, Bleasel & Bye, 2001; Vickery et al., 2001; Stockler, Osoba, Corey, Goodwin & Tannock, 1999); and, more recently, research reflects the quality of life of older people (Berglund & Ericsson, 2003).

The interest in the concept of quality of life led the World Health Organization (WHO) in 1995 to define the concept of quality of life, through three fundamental assumptions: subjectivity, multidimensionality and the presence of positive and negative dimensions.

Quality of life is effectively a multidimensional construction that has both objective and subjective characteristics (Costanza et al., 2008; Cummins, 1997; 2005; Verdugo, Schalock, Keith & Stancliffe, 2005). Objective components are external conditions that can be observed and measured within the public domain, including culturally normative values. Subjective characteristics exist only within an individual's private consciousness; reflect satisfaction with life domains weighted according to their value to the individual.

In this context, this research has as its background the Schalock & Verdugo model (2002; 2007) operationalized through dimensions, indicators and personal results that are organized into different levels.

It should be noted that, with severe and profound disabilities, there are marked limitations in their body functions and structures (by reference to the ICF, i.e. the International Classification of Functioning, Disability and Health), which put their development at serious risk, leading them to experience serious difficulties in the process of learning and participation in the various contexts in which they are inserted. These limitations and their level of functionality result from the interaction between their health conditions and environmental factors. In other words, people with multiple

disabilities can present very different characteristics, essentially determined by the combination and severity of the limitations they present, the age at which they appear and the experiences they have had. Their limitations and difficulties make them understand the world in a different way, they need to have more significant experiences to maintain the skills already developed and they need to experience identical situations in different contexts that facilitate the generalization of skills. The barriers to their participation and learning are very significant and make them need intensive support both in carrying out daily activities and in learning; partners who accept them as active participants and are responsive; identical experiences in different environments; common environments where there are significant opportunities to participate in multiple diverse experiences; opportunities to interact with people and significant objects. Consequently, these people need specific supports, in their natural contexts, whenever possible, in order to respond to the specific needs of their needs. These supports must be embodied in your individual development plan.

They are, therefore, a very heterogeneous group and, consequently, have unique and exceptional learning needs that show a complex picture, requiring permanent support in carrying out most daily activities, such as food, hygiene, mobility, dressing and the undressing.

Although they are a heterogeneous population, it is common to manifest severe limitations in terms of some mental functions, as well as many difficulties in terms of communication and language (referring difficulties in understanding and producing oral messages, in verbal interaction with others, in conversation and access to information) and at the level of motor functions, namely mobility (for example: walking and moving, changing body positions, moving objects and fine motor skills).

They may also present limitations in visual or auditory functions, and serious physical health problems often coexist, namely, epilepsy and respiratory problems.

In fact, and regarding the activity and participation of these people, their greatest difficulties are located in the level of interaction processes with the environment (people and objects); understanding the surrounding world (difficulties in accessing information); the selection of relevant stimuli; understanding and interpreting the information received; the acquisition of skills; of concentration and attention; of thought; making decisions about your life; and, problem solving.

It should also be noted that the quality and quantity of information received and perceived is usually limited and distorted, partly due to their limitations but also to the fact that they have few significant experiences (Amaral, 2002).

These limitations and difficulties make them understand the world in a different way, they need to have more significant experiences to maintain the competences already developed and they need to experience identical situations in different contexts that facilitate the generalization of competences.

The International Classification of Functioning, Disability and Health (ICF) proposed by the World Health Organization (WHO), describes human functioning based on a biopsychosocial model, contrary to the biomedical perspective previously defended by the International Classification of Impairments, Disabilities, and Handicaps (WHO, 2004). This has generated two conceptual models that tend to be understood as antagonistic: the “medical model” and the “social model”. While the first considers disability as an individual's problem, a direct consequence of disease, trauma or other health problem, requiring medical assistance, in the form of individual treatment, by professionals, with a view to total cure or, if this is not possible, to the individual's adaptation to their new condition, the second

considers disability as a problem created by society, focusing on the full integration of the individual in the same society, in which disability is understood not as an attribute of the individual, but rather a complex set of conditions, created essentially by the social environment (WHO, 2004). Thus, if in the medical model, the emphasis is placed on the side of medical care where, at a political level, the main response is the modification or reform of health policies, whereas in the social model, the solution to the problem is limited to a social action, being society's collective responsibility to carry out the necessary environmental changes for the full participation of people with disabilities in all areas of social life. In this way, it is an attitudinal or ideological issue that requires deep social changes, that is, at the political level, it is a human rights issue (WHO, 2004).

The ICF arises from the integration of these two opposing models, which serve as the basis for its conceptualization, using a "biopsychosocial" approach, in which the human being is considered as a whole, that is, it is understood that the individual is the result of interaction between intrinsic factors (body functions and structures) and the influence of the context in which it is inserted (at an environmental and personal level). According to the WHO (2004, p.22), "the ICF tries to arrive at a synthesis that offers a coherent vision of the different perspectives of health: biological, individual and social".

2.2. METHOD

2.2.1. PARTICIPANTS

With regard to those providing information (i.e., report of others), two selection criteria were employed, informants could be social services professionals who have known the person for at least three months and if necessary they could be relatives/proxies who know the person well.

In reference to the individual being assessed, this person needed to: (a) show an intellectual disability and extensive or pervasive support needs (i.e., people with intellectual disability and a low level of functioning, for instance, due to a profound or severe intellectual disability, multiple disabilities or chronic and severe health conditions); (b) be currently receiving supports and services from the institutions of the partnership consortium; and (c) be 16 years old or older and not currently engaged in the education system.

The San Martín Scale was applied to a convenience sample composed of 80 people who met the above criteria. The assessment was carried out by 19 professionals from the institutions of the partnership consortium. Other respondents were relatives ($n = 17$; 21%) and other professionals (79%).

Each institution of the partnership consortium's respondent applied the instrument to twenty people. People that completed the assessment had known the person for more than two years in most of the cases (83.1%), more than a half (52.5%) knew the person for more than ten years, and 17.5% for between twenty and thirty-six years. The great majority (81%) had a frequency of contact with the assessed person of several times per week.

Regarding the people with disabilities assessed, the number of men ($n = 43$; 53.75%) was slightly higher than the number of women ($n = 37$; 46.25%). The age of the participants ranged between 21 and 90 years old ($M = 46.68$; $SD = 16.49$).

All the individuals being assessed required extensive (26.67%) or pervasive (71.67%) support needs. Although there was no specific measurement of intellectual and adaptive functioning available for most of the people, respondents estimated that 1% had mild intellectual disability, 14.49% moderate, 52.17% severe, and 31.88% profound. In addition, 80% had other associated verified conditions, such as speech/language impairment (77.5%), mental health problems/emotional disturbance (47.5%), cerebral palsy (36.25%), epilepsy (33.75%), visual impairment/blindness (27.5%) or challenging behavior (26.25%). Most of them (81.25%) were taking medication, especially antiepileptic/anti-seizures and anxiolytics.

2.2.2. INSTRUMENT

Given that quality of life assessment tools for people with intellectual disabilities in general do not assess those with lower levels of functioning, the San Martín Scale was recently developed (Verdugo et al., 2013; Verdugo et al., 2014). Through this scale, an assessment of the most important aspects of the life of a person with significant intellectual disability can be carried out, based on the concept of an external observer, who assumes the role of an informant about the assessed individual thanks to their proximity and perspective of the individual. In this sense, it must be completed by a third person, who knows the subject with a significant disability very well and who has the opportunity to observe it in different contexts over prolonged periods of time (Verdugo et al., 2013).

The scale consists of 95 items distributed over the eight quality of life dimensions of the Schalock and Verdugo (2002/2003) model: emotional well-being; interpersonal relationships; material well-being; personal development; physical well-being; self-determination; social inclusion; and rights. It is intended for adults over the age of 18 (or children over the age of 16, whenever they are outside the education system) with significant disabilities, that is, people with intellectual disabilities who require extensive and generalized support, with other possible associated conditions. It has four response options on a Likert-type scale (never, sometimes, often, and always). The scale can be filled in by one or more informants, preferably by a professional from the services that support the person being assessed and who have known him or her for at least three months. However, these can also be family members, legal guardians, close friends or significant others who know the person in different contexts of their life. The score of this scale is determined from the following elements: the instrument has a scale that allows transforming the raw results (direct scores) into standard scores ($M = 10$, $SD = 3$) and percentiles for each of the eight dimensions, which they can be graphically represented in a quality of life profile that facilitates the interpretation of the scores by clearly illustrating which areas the person has the greatest strength and which are those in which he/she has the greatest difficulties and needs for support (Verdugo et al., 2013). The estimated time of administration of the scale is 30 minutes.

The San Martín Scale was developed using a systematic and rigorous method, according to international recommendations for instrumental studies (Carretero - Dios & Perez, 2007, cit. in Verdugo et al., 2013). It was evaluated and validated by experts to be applied to the groups mentioned above, having gone through several phases until reaching its current form. This instrument allows the identification of a person's quality of life profile, with evidence of validity and reliability, for the implementation of evidence-based practices and the design of individual support plans. It is an approximation to the individuals that constitute the population of this study, as well as to the context in which they live (Verdugo et al., 2013).

2.2.3. PROCEDURE

Initially, each institution in the consortium selected the professionals who could assume the role of external observer/informant taking into account the defined criteria (informants could be social services professionals who have known the person for at least three months and if necessary they could be relatives/proxies who know the person well). These professionals took part in training courses on assessing the quality of life of people with severe and profound disabilities, given by members of the partnership's consortium with qualifications and knowledge for this purpose. Each professional identified their training needs, presented a letter of motivation and expression of interest and their resume. Twenty-three professionals from the consortium institutions participated in this training, where they had the opportunity to understand the quality of life concept and models, learn about the San Martín Scale, receive training on its application and interpretation results, as well as understand the opportunities and limitations of applying it.

Subsequently, the consortium asked the authors of the San Martín Scale to use the versions made available in the languages of the consortium's countries (except in German - unofficial translation). Informed consents were obtained from all participants and the evaluation was carried out, guaranteeing the anonymity and confidentiality of the data collected.

The personal data and the results of the San Martín Scale were filled in by members of the partnership on an online platform provided by the Spanish partner.

2.3. RESULTS AND DISCUSSION

According to the authors of the San Martín Scale, the direct scores obtained can be transformed into standard scores, taking into account that they have a distribution with a mean equal to 10 and a typical distribution equal to 3, with high standard scores showing greater quality of life (Verdugo et al., 2014).

Table 1

Average of scores obtained in the dimensions of quality of life (San Martín Scale)

	Total Direct Scores SD	Total Direct Scores RI	Total Direct Scores EW	Total Direct Scores SI	Total Direct Scores PD	Total Direct Scores IR	Total Direct Scores MW	Total Direct Scores PW
M	31,400	40,338	35,44	27,850	32,063	36,075	40,813	37,825
N	80	80	80	80	80	80	80	80
SD	7,305	3,170	5,126	7,785	6,902	6,243	4,413	4,3726

Note: SD = self-determination; RI = rights; EW = emotional wellbeing; SI = social inclusion; PD = personal development; IR = interpersonal relationships; MW = material wellbeing; PW = Physical wellbeing; M = mean; N = sample; SD = standard deviation.

From the analysis of the table above, it can be seen that the dimensions of quality of life with direct scores with lower mean values are social inclusion, self-determination, personal development, emotional well-being and interpersonal relationships.

Table 2

Global average of standard score, percentile and quality of life index (San Martín Scale)

	Total Standard Score	Quality of Life Index Percentile	Quality of Life Index
M	76,350	42,688	97,075
N	80	80	80
SD	13,20	22,59	10,02

Note: M = mean; N = sample; SD = standard deviation.

Table 3

Percentile for the eight dimensions (San Martín Scale)

	Percentile SD	Percentile RI	Percentile EW	Percentile SI	Percentile PD	Percentile IR	Percentile MW	Percentile PW
M	47,463	55,350	43,525	38,088	37,675	47,075	52,775	47,238
N	80	80	80	80	80	80	80	80
SD	30,790	20,349	25,875	29,723	26,813	27,769	24,903	22,806

Note: SD = self-determination; RI = rights; EW = emotional wellbeing; SI = social inclusion; PD = personal development; IR = interpersonal relationships; MW = material wellbeing; PW = Physical wellbeing; M = mean; N = sample; SD = standard deviation.

Table 4

Standard scores for the eight dimensions (San Martín Scale)

	Standard Scores SD	Standard Scores RI	Standard Scores EW	Standard Scores SI	Standard Scores PD	Standard Scores IR	Standard Scores MW	Standard Scores PW
M	9,638	10,475	9,363	8,725	8,663	9,638	10,188	9,663
N	80	80	80	80	80	80	80	80
SD	3,199	1,816	2,357	3,110	2,846	2,838	2,220	2,191

Note: SD = self-determination; RI = rights; EW = emotional wellbeing; SI = social inclusion; PD = personal development; IR = interpersonal relationships; MW = material wellbeing; PW = Physical wellbeing; M = mean; N = sample; SD = standard deviation.

The total scores demonstrate that the average quality of life index of the sample is 97,075.

By reading the table below, it can be seen that the institution with the highest average quality of life index is Josefsheim-Bigge and the lowest is APPC.

Table 5

Global average of standard score, percentile and quality of life index for each partner institution (San Martín Scale)

	Total Standard Score	Quality of Life Index	Quality of Life Index Percentile
TOTAL	76,350	97,075	42,688
Josefsheim Bigge	79,950	99,800	47,400
Don Calabria	75,400	96,450	41,750
APPC	71,900	93,700	35,800
San Rafael	78,150	98,350	45,800

The total scores of the quality of life assessment were analyzed in order to verify if there are statistically significant differences in relation to the specific characteristics of the study sample (differentiating factors) through non-parametric tests, such as the Mann-Whitney U and the H of Kruskal-Wallis, specific for small samples and containing two or more independent groups. To obtain the meaning of the relationships between the variables, the significance level <0.05 was used.

The table above shows that the quality of life index of the sample is 97.08, corresponding to a relatively low percentile of 42.69.

It should be noted that only statistically significant relationships (sig. ≤ 0.05) were found in the variables: level of intellectual disability, level of dependence and level of support needs which are presented in the tables that follow.

Table 6

Kruskal Wallis H test that relates the total standard score, percentile and quality of life index (San Martín Scale) with the variable level of intellectual disability

	Total Standard Score	Quality of Life Index Percentile	Quality of Life Index
Chi-Square	15,145	15,210	15,785
df	3	3	3
Asymp. Sig.	,002	,002	,001

Table 7

Kruskal Wallis H test that relates the total standard score, percentile and quality of life index (San Martín Scale) with the variable level of dependence

	Total Standard Score	Quality of Life Index Percentile	Quality of Life Index
Chi-Square	24,789	24,893	24,854
df	2	2	2
Asymp. Sig.	,000	,000	,000

Table 8

Kruskal Wallis H test that relates the total standard score, percentile and quality of life index (San Martín Scale) with the variable level of support needs

	Total Standard Score	Quality of Life Index Percentile	Quality of Life Index
Chi-Square	27,595	27,603	28,293
df	1	1	1
Asymp. Sig.	,000	,000	,000

The average of global quality of life scores showed lower values in the dimensions of social inclusion, self-determination, personal development and emotional well-being, these results may be directly linked to the fact that variables with statistically significant differences, especially the level of intellectual disability, which, according to the quality of life model that supports this study, are integral indicators of these dimensions. The highest values were found in the material well-being dimension, which may be due to the fact that the subjects in the study sample are all institutionalized, which may contribute to promoting the necessary measures of material well-being, for example, guaranteeing the social benefits to which the person is entitled, and ensuring the provision and access to support products (wheelchairs, communicators, etc.).

It is also important to mention that, when analyzing the aggregated results of the administration of the San Martín Scale, it was found that half of the average scores reached the theoretical midpoint of the scale (M=10 in the case of standard scores), and the rest are all found below this score, which means that the overall average score obtained by adults with severe disabilities assessed overall was low.

The dimensions that reached the highest percentile were interpersonal relationships and material well-being. The dimensions with the lowest percentile were the dimensions of social inclusion and personal development. These results show that the quality of life of adults with severe disabilities assessed is substantially lower than the average obtained by 1788 people with significant disabilities who constituted the sample that formed the validation of the San Martín Scale (Verdugo et al., 2014). On the other hand, when these results are compared with the results achieved in other studies, it can be seen that the results achieved by the present study are superior, as, for example, in the study

“Evaluación de la calidad de vida en personas con discapacidades significativas: aplicación de la Escala San Martín en la Fundación Obra San Martín” (Hierro et al., 2015), where the aggregated data of 85 people, presented standard scores below the theoretical midpoint of the scale ($M=10$) and the dimensions they presented the highest percentile ($P=25$) were self-determination and physical well-being, and the dimensions with the lowest percentile ($P=6$) were social inclusion and interpersonal relationships. This can lead to critical questions about variables that may be involved in the differences presented.

2.4. FINAL CONSIDERATIONS

From the administration of the San Martín Scale, it was found that the average quality of life index of adults with severe disabilities assessed was 97, which corresponds to the 43 percentile. Just over half of the average scores reached the theoretical midpoint of the scale ($M=10$ in the case of standard scores), and the rest are all below this score, which means that the overall average score obtained by the adults assessed in general was low. The dimensions with the lowest values were social inclusion and self-determination.

It would be interesting for further studies to broaden the universe of the statistical sample, as well as to contemplate other age groups in addition to those considered. It would be also important that not only professionals and family members were involved but also other institutions. It would be relevant to complement this study in the future, with new valid methods to understand the individual perspective of people with severe and profound disabilities regarding the importance given to the different factors that contribute to their own quality of life.

It is highlighted that the dissemination and use of the information produced could facilitate the development of educational policies that ensure the promotion of actions aimed at adults with severe disabilities, their families and professionals, with the goal of improving their quality of life.

Among other answers and solutions, the importance of establishing plans for local action to promote the quality of life of adults with severe multiple disabilities is reinforced, taking into account that social realities are largely determined in each community, or ecological space, and the different forms of interaction of factors such as physical and technical resources. For example, it would be interesting to implement initiatives centered on improving personal resources, such as personal skills, supporting participation in the community in leisure activities, or addressing issues such as self-determination and social participation in an environment guided by interaction between the various protagonists. It must be emphasised that at all stages of these initiatives (planning, implementation, evaluation) and the active participation of adults with multiple disabilities should be a basic principle, in order to ensure the relevance and usefulness of the programs.

Regarding this research, it is hoped that it can, in some way, contribute to and arouse interest in research in the field of education for the quality of life of adults with severe disabilities. It is also expected to increase the understanding of the importance of practices with these human beings, which aim to promote their development and learning with respect and educational attention through the recognition of their individual potential.

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