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# GUIDELINES FOR GOOD PRACTICES AND SUCCESSFUL EXPERIENCES



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## IMPRINT

### IMPRINT:

This document was produced as part of the Erasmus+ project QoL4ALL.

### AUTHOR(S):

Project partnership QoL4ALL.



### LICENCE:

This document is a result of the European Commission funded Erasmus+ project QoL4ALL, grant number **2018-1-PT01-KA204-047468**, <https://ec.europa.eu/programmes/erasmus-plus/projects/eplu-project-details/#project/2018-1-PT01-KA204-047468> and is made available to the public free of charge under a Creative Commons licence CC-BY-SA 4.0 (<https://creativecommons.org/licenses/by-sa/4.0/>).

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## 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, is included in the intellectual output 2 of this Erasmus project, as a best practice.

## 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 came 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)<sup>1</sup> 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 Rights<sup>2</sup> 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 2010-2020<sup>3</sup> 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 2021-2030<sup>4</sup> 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

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<sup>1</sup> 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>

<sup>2</sup> [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](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)

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

<sup>4</sup> [https://ec.europa.eu/commission/presscorner/detail/en/ip\\_21\\_810](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 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. GUIDELINES FOR GOOD PRACTICES AND SUCCESSFUL EXPERIENCES

### 2.1. BACKGROUND INFORMATION ON SELECTING BEST PRACTICES

Before starting the process of selection of good practices, the consortium held a 'Workshop on identifying criteria for Best Practice in Quality of Life' (Josefsheim-Bigge, Olsberg, Germany), where the concepts of good, better and best practices were explored by the various partners with the aim to understand the concept of "Good Practice" and achieve a clear understanding of this concept.

As a result, it was considered that the success factors for selecting criteria for Best Practice in Quality of Life are:

<b>Knowledge on:</b>	<b>Balance between:</b>
Product information: the concepts of QoL;	Objective information (Facts);
Service users needs: the target groups;	Subjective information (Opinions);
The characteristics of social services.	Quantitative information (Numbers);
	Qualitative information (Written Text).

For professor Sarah Fraser in Petra Stienstra there are four levels:

1. A good idea: intuitively logical, but unproven and unmotivated;
2. Good practice: something that has demonstrably improved the results for the service provider;
3. Organization-bound Best Practice: proven results, considered optimal for a certain organization, but perhaps not for other service providers in the social sector;
4. Sector wide Best Practice: there is agreement that this is the best possible way of working, based on detailed benchmarking and analysis.

Two practical approaches from Prins (University Applied Science the Netherlands, 2008):

<b>Inspiring (practical) Examples:</b>	<b>Evidence Based "Good Practices":</b>
A (new) way of working that is more 'practice-based' than 'evidence-based'.	The quality of the innovative method is better substantiated.
A limited analysis has been made of process, effect and context, because it lacked resources, interest or expertise. The method of selection is mainly based on the opinion of experts and/or professionals themselves, who regard the approach in question as a 'better' approach. The external interested parties themselves have to check whether and how the working method can be applied in their own situation or can be made.	More (quantitative and/or qualitative) research has been done into the implementation, there is attention to implementation problems and effects. By the more extensive research orientation, the "evidence base" is better developed than with the category above, which also gives some insight into preconditions (such as money), transfer of success and failure factors.

## ASPECTS OF “BEST PRACTICES” IN QoL

### 1. Added Value

In general:

- Is the practice beneficial for care (organization/client/population of clients)?
- This added value must be proven by a qualitative study, or the added value must be recognized by clients or the professional group.

Client level:

- Immediately benefits a client population due to an improvement in QoL, a limitation in the QoL risks, or a visible improvement of QoL for clients in the care.
- Clients are involved in the realization of the QoL interventions or have a say in the evaluation of the implementation of the QoL practice.

Quality of life:

- It must be plausible that the QoL for individual clients is not worsened as a result of the application of the Best Practice. In addition, it must be plausible that the QoL is improved for the total client population.

Employee level:

- It benefits the working conditions of employees through, for example, an improvement in the efficiency and efficiency of the work and/or the motivation and pleasure in the work.

### 2. Theoretically well substantiated

- The QoL practice is clearly defined and it is plausible on the basis of theory and research that the QoL practice is effective. Context, purpose, target group, method, materials and preconditions must be well described.

### 3. Connected to strategic developments

- The QoL practice is in line with the strategic goals of the social service provider and responds to current relevant topics and needs. Fits within the policy of the social service provider in the field of qualitative care and is socially relevant.

### 4. Effect measurement

- The effect of the innovation is measured, or there is continuous registration and monitoring of the service users using the innovation.

### 5. Practice application

- The Best Practice must at least be successfully implemented.

a) Transferable content:

The QoL approach is described in terms of content in such a way that it can be understood by other institutions or organizations, and/or expertise is available to make this clear.

**b) Transferable change management:**

Expertise is available in writing and/or through consultation on how the QoL practice can best be implemented.

## 6. Applicability elsewhere

- It is possible to implement the QoL practice elsewhere given existing preconditions, such as financing structure, organizational structure and personnel functions.

## 7. Structural embedding

- The QoL practice is structurally implemented and is included in the quality policy of the institution.

## 8. Cost-effective

- It is plausible that the costs for implementing and structuring the QoL practice are in balance with the (health) profit that is achieved.

## INFORMATION FOR SELECTING BEST PRACTICE IN QOL

1. Is there a clear and solid approach on QoL? (documented)
2. Is the QoL approach systematic?
3. Is the approach based on up-to-date knowledge? (evidence)
4. Is the approach innovative ? (evidence)
5. Is the QoL approach based on the needs of service users?
6. Are the needs of service users assessed? If yes, in what way?
7. Is there verifiable data/evidence, to justify their need?
8. Are employees aware of the QoL approach?
9. Is the QoL approach put-into-practice by those employees who are involved in caregiving?
10. Does the QoL approach involve all those involved, as far as possible, in its design, implementation and evaluation of the interventions?
11. Are QoL objectives included in the Individual Plan of the service user?
12. Are service users/family members involved in the individual planning and adaptation of the interventions?
13. Is the QoL approach a key process of care?



14. Does the QoL approach contribute to:
  - a) Quality of life of service users?
  - b) Quality of service?
15. Is there verifiable data/evidence, to demonstrate QoL results?
16. Are the results demonstrated with relevant and valid indicators? What are the indicators?
17. Do QoL results of service users have positive trends?
18. Are the QoL approach, implementation strategy and results systematically compared with other organisations?
19. Has the QoL approach, implementation strategy and/or results been modified due to benchmarking?
20. Is the QoL practice sustainable (economically, organizationally and technically) in the long term?

#### Additional Information

1. Is the QoL approach based on the holistic perspective?
2. Have the employees improved competence in the QoL approach?
3. Are the employee/staff profile (based on criteria) taken into consideration in the QoL approach?
4. Does the organisation improve services based on QoL practice results?
5. Does the QoL practice contribute to positive change in society?
6. Does the QoL approach respond to the expectations/wishes/dreams of the service users?
7. Is it possible to transfer the QoL approach to other organisations/services?
8. Is there an increased satisfaction of QoL for users and family members?

At the end of the workshops, partners jointly reviewed the 20 items of information to select best practices and added some that they considered pertinent. They were evaluated for their relevance in terms of promoting quality of life, giving rise to the final version of criteria to select “Good Practices” presented below.

#### STEPS FOR SELECTING “GOOD PRACTICES”

<b>1</b>	Defining “Good Practice”;
<b>2</b>	Identifying criteria for a “Good Practice”;
<b>3</b>	Identifying information needed to selecting a “Good Practice”;



4	Designing instrument for collecting a “Good Practice”;
5	Designing instrument for assessing a “Good Practice”;
6	Collecting information about proposals for a “Good Practice”;
7	Assessing proposals for “Good Practices”;
8	Analysing results of assessing proposals for a “Good Practice”;
9	Selecting examples for a “Good Practice”.

## 2.2. SELECTING “GOOD PRACTICES”

### STEP 1: DEFINING “GOOD PRACTICE”

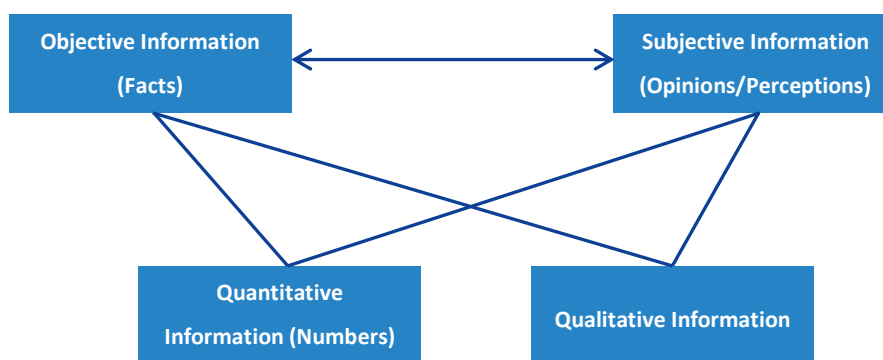
There is no universally accepted definition of “Good Practice”. Different organisations use different definitions and different criteria to assess whether an intervention, a practice or a method can be considered as “Good Practice”. “Good Practices” are often described as interventions that are innovative and that promote good quality care. The term “Good Practice” is often used to indicate that an approach has been successfully applied in an organisation and can be repeated or transferred.

For example, for Plena Inclusión (in Spain) a “Good Practice” is an action or set of actions that as a result of the identification of a need, are systematic, effective, efficient, sustainable, flexible, and are designed and implemented. These are carried out by the members of an organization with the support of its management bodies, which in addition to satisfying the needs and expectations of its customers, represent a clear improvement in service standards, always in accordance with the ethical and technical criteria, and aligned with its mission, vision and values. These “Good Practices” should be documented in order to serve as a reference for others and facilitate the improvement of the processes that are being put in place.

### STEP 2: IDENTIFYING CRITERIA FOR A “GOOD PRACTICE”

“Good Practice” should:	Information should be a balance between:
<ul style="list-style-type: none"> <li>- Be relevant for the target group;</li> <li>- Have tangible results of improving Quality of Life;</li> <li>- Meet needs and expectations of the service users;</li> <li>- Be an innovative way of working;</li> <li>- Prove satisfaction of service users and family members;</li> <li>- Have tangible results of inclusion of the service users.</li> </ul>	<ul style="list-style-type: none"> <li>- Objective information (Facts);</li> <li>- Subjective information (Opinions);</li> <li>- Quantitative information (Numbers);</li> <li>- Qualitative information (Written Text).</li> </ul>





**STEP 3: IDENTIFYING INFORMATION NEEDED TO SELECTING A “GOOD PRACTICE”**

Information	Evidence
<ol style="list-style-type: none"> <li><b>Name</b> of the “Good Practice” example.</li> <li><b>Argumentation why</b> the example has been put forward as a “Good Practice” example.</li> <li><b>Argument that</b> the example is ‘an <b>innovative</b>’.</li> <li>To which <b>dimensions</b> of QoL contributes the example?</li> <li><b>Information</b> about the <b>transferability</b> of the “Good Practice” example.</li> </ol>	<ol style="list-style-type: none"> <li><b>Evidence</b> that the practice increased the <b>satisfaction of the service users and family members</b>.</li> <li><b>Evidence</b> that the practice leads to <b>inclusion of the service users</b> with a profound disability.</li> <li><b>Evidence</b> about tangible results of <b>improving Quality of Life</b> of persons with a profound disability.</li> <li><b>Evidence</b> about tangible results of <b>meeting needs and expectations</b> of service users with a profound disability.</li> </ol>



**STEP 4: DESIGNING INSTRUMENT FOR COLLECTING A “GOOD PRACTICE”**

- What **name** would you give to this “Good Practice” example?
- Why** have you chosen this example to put forward as a “Good Practice” example?
- To which **dimensions** contributes the example?
- Have you **evidence** (proof) that the practice increased the **satisfaction of the service users**?
  - 4.1.** Please show how satisfaction is measured and the increased satisfaction score.



5. Have you **evidence** (proof) that the practice increased the **satisfaction of the family members**?
  - 5.1. Please show how satisfaction is measured and the increased satisfaction score.
6. Have you **evidence** (proof) about tangible results of **improving Quality of Life** of persons with a profound disability?
  - 6.1. Please show how this is determined?
7. Have you **evidence** (proof) about tangible results of **meeting expectations** of service users with a profound disability?
  - 7.1. Please show how this is determined?
8. **Why** are you considering the example as an **innovative way of working**?
9. In which way does the example lead to **inclusion of service users** with a profound disability?
  - 9.1. Please explain how you have understood and defined inclusion in this context.
10. What would be, in your opinion, the opportunities and challenges to **transfer the “Best Practice” example** to the partner organizations?

#### STEP 5: DESIGNING INSTRUMENT FOR ASSESSING A GOOD PRACTICE

Instructions how to score the proposals for “Good Practice”											
<b>1</b>	The file is a scoring file to administer <b>INDIVIDUAL</b> scoring for the proposals of “Good Practice” (so each person fills in his/her opinions by filling in this file)										
<b>2</b>	There are 13 proposals submitted for “Good Practice”										
	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 40%;">APPC - Faro</td> <td>3 proposals (APPC 1; APPC 2; APPC 3)</td> </tr> <tr> <td>San Rafael</td> <td>3 proposals (San Rafael 1; San Rafael 2; San Rafael 3)</td> </tr> <tr> <td>Instituto Opera don Calabria</td> <td>3 proposals (ODC 1; ODC 2; ODC 3)</td> </tr> <tr> <td>Josefsheim Bigge</td> <td>2 proposals (Josefsheim 1; Josefsheim 2)</td> </tr> <tr> <td>EPR</td> <td>2 proposals (EPR 1; EPR 2) <span style="float: right; font-size: small;">Note: The proposals submitted by EPR are coming from 2 members EPR</span></td> </tr> </table>	APPC - Faro	3 proposals (APPC 1; APPC 2; APPC 3)	San Rafael	3 proposals (San Rafael 1; San Rafael 2; San Rafael 3)	Instituto Opera don Calabria	3 proposals (ODC 1; ODC 2; ODC 3)	Josefsheim Bigge	2 proposals (Josefsheim 1; Josefsheim 2)	EPR	2 proposals (EPR 1; EPR 2) <span style="float: right; font-size: small;">Note: The proposals submitted by EPR are coming from 2 members EPR</span>
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EPR	2 proposals (EPR 1; EPR 2) <span style="float: right; font-size: small;">Note: The proposals submitted by EPR are coming from 2 members EPR</span>										
<b>3</b>	The file has 15 worksheets:										
<b>a.</b>	One worksheet with explanation how to score (worksheet 1)										
<b>b.</b>	One worksheet with persons who are eligible to express their opinion by filling in the scoring worksheets (worksheet 2)										
<b>c.</b>	13 worksheets for scoring (Each proposal has its own worksheet for scoring)										
<b>4</b>	The scoring of the proposals for “Good Practice” (QoL project) is an <b>INDIVIDUAL</b> activity										
<b>5</b>	Each individual (of the QoL project partner) is eligible to give a score										
<b>6</b>	Individuals cannot give a score to an example that is presented by his/her own organisation										



<b>7</b>	All items in the "relevance scale" and the "Yes – No scale" must be answered (you can give an answer by putting a "X" in the cell that represents your answer)
<b>8</b>	You give an answer by putting a "X" in the cell that represents your answer (for each item you are expected to give ONE answer)
<b>Concerning:</b>	
<b>a.</b>	The "Yes – No Scale": one example can contribute to more than one dimension of the model of Schalock – Verdugo. In these cases 'YES' must be answered.
<b>b.</b>	The "5-point relevance scale": Please mark one cell that is reflecting your personal opinion.

The Example:		Not Relevant	Less Relevant	No Opinion	Relevant	Highly Relevant
<b>1</b>	...is relevant for the target group: Individuals with a Profound Disability					
The Example:		YES		NO		
<b>2</b>	...contributes to the development of one (or more) QoL-dimensions of the model of Schalock & Verdugo					
<b>A</b>	...contributes to the QoL-dimension SELF-DETERMINATION (SD)					
<b>B</b>	...contributes to the QoL-dimension RIGHTS (R)					
<b>C</b>	...contributes to the QoL-dimension EMOTIONAL WELLBEING (EM)					
<b>D</b>	...contributes to the QoL-dimension SOCIAL INCLUSION (SI)					
<b>E</b>	...contributes to the QoL-dimension PERSONAL DEVELOPMENT (PD)					
<b>F</b>	...contributes to the QoL-dimension INTERPERSONAL RELATIONSHIP (IR)					
<b>G</b>	...contributes to the QoL-dimension MATERIAL WELLBEING (MW)					
<b>H</b>	...contributes to the QoL-dimension PHYSICAL WELLBEING (PW)					



The Example Presented:		No Valid Evidence	Less Valid Evidence	No Opinion	Some Valid Evidence	Much Valid Evidence
3	...has evidence of increased satisfaction of service users					
4	...has evidence of increased satisfaction of family members					
5	...has evidence of tangible results of improving aspects of Quality of Life					
6	...has evidence of meeting expectations of service users					
7	...has evidence of being an innovative way of working					
8	...has evidence of tangible results of Inclusion of service users					

**STEP 6: COLLECTING INFORMATION ABOUT PROPOSALS FOR “GOOD PRACTICE”**

All partners selected 2-3 examples of good practice from their own institution that contributed to improving the quality of life of people with severe disabilities, and in the case of EPR from its membership.

Assessing Quality of Life	Digital Communication	Celebrating your Birthday	Participation Management	Personal Development in Community based Setting
Organisational Effectiveness and Efficiency	Development of Network and Alliances	Person Centred Planning	Persons Centred Planning	Communication without Speaking
	Promoting and Respecting Rights	Multisensorial Stimulation	Networking on Assistive Technologies	

**STEP 7: ASSESSING PROPOSALS FOR “GOOD PRACTICES”**

Total number of forms: 144 forms

Number of people: 12 persons

Number of proposals: 13 proposals

Each partner scored the 13 practices presented by completing the questionnaire constructed. This evaluation allowed us to select the 6 examples of good practices in which the teams of the partner institutions were trained.

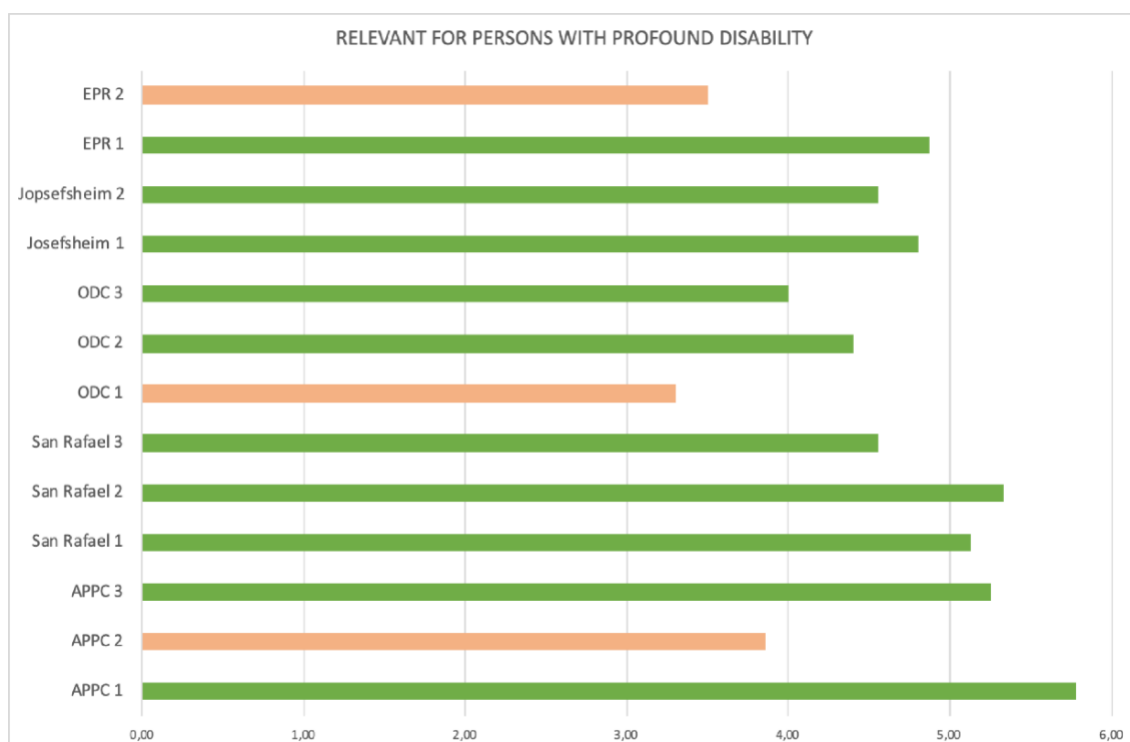
The individuals, who have been selected as eligible persons for expressing their opinion on the proposals for “Good Practice”, is based on the criteria: "The person has actively involved/participated in more than one international project meetings of the QoL project”.

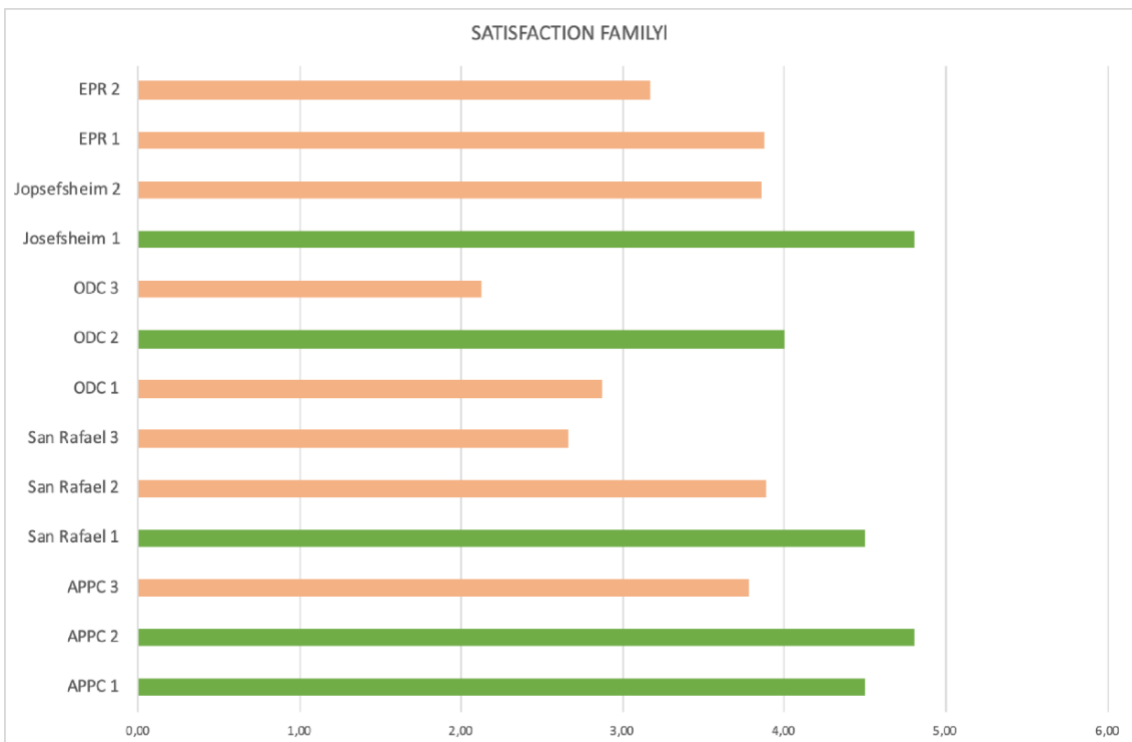
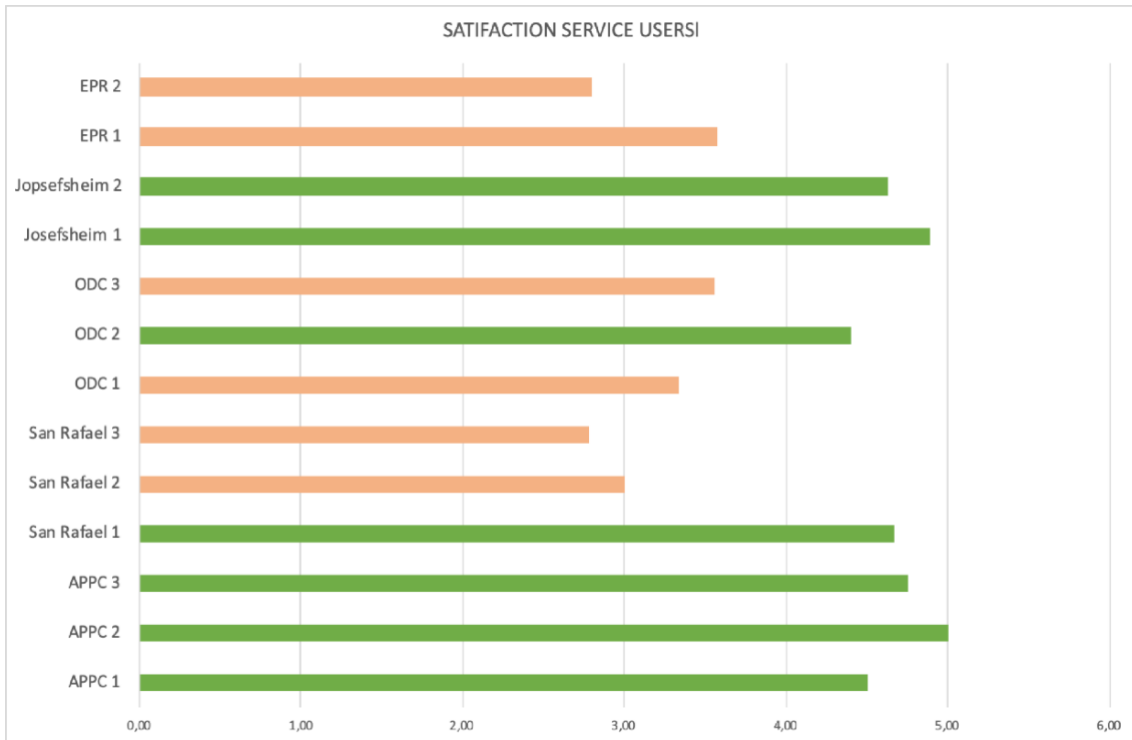
The examples of good practice have been selected taking into account the following aspects:

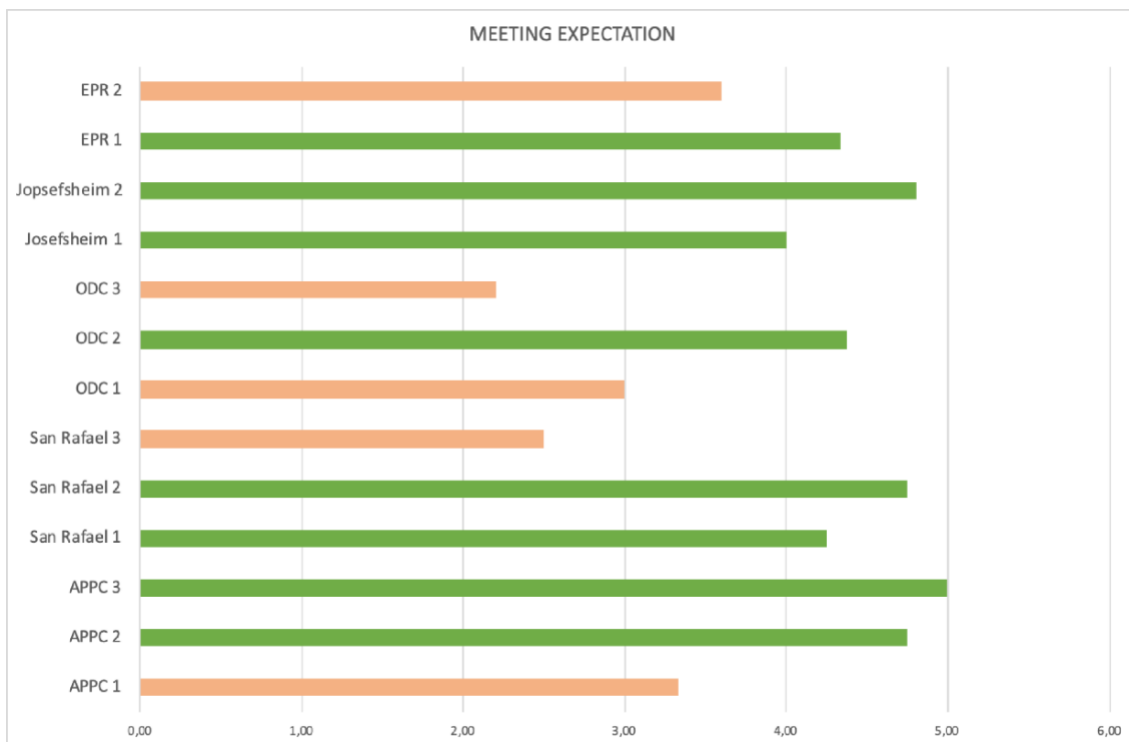
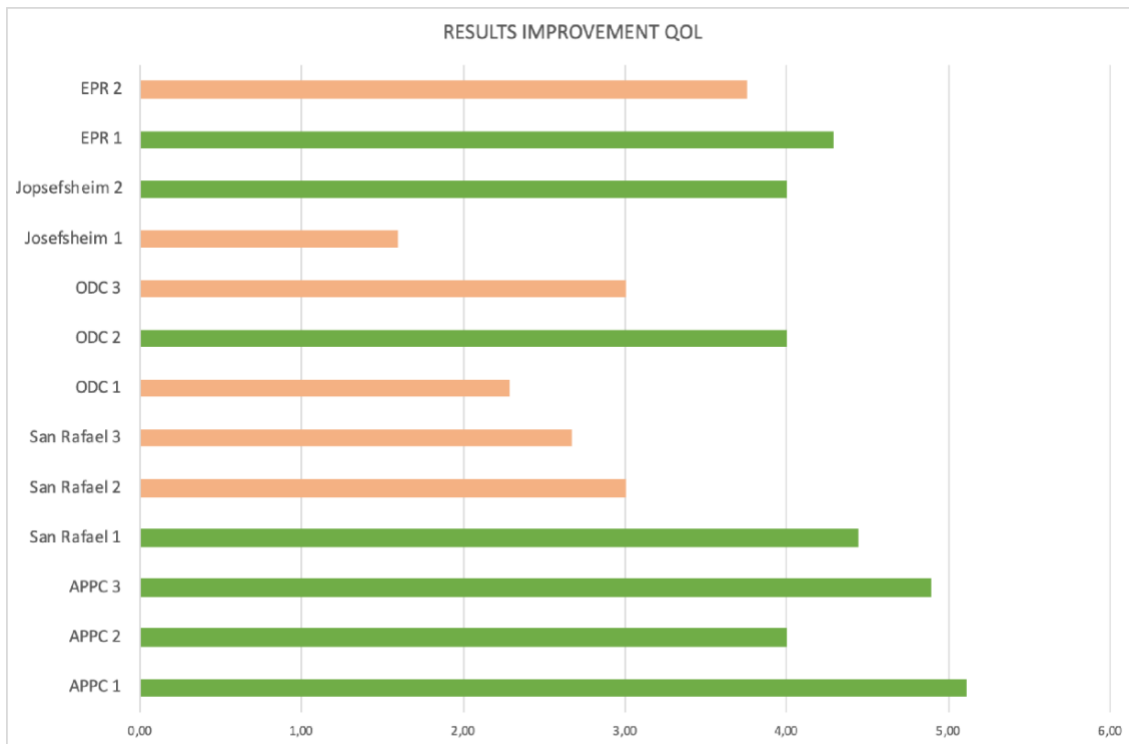
- Contributes to the development of one (or more) quality of life dimensions of the Schallock and Verdugo model;
- Increases service users and family member satisfaction;
- It has tangible results in improving aspects of quality of life;
- It responds to the expectations of service users;
- It is based on an innovative way of working;
- It has tangible results of the inclusion of users with severe disabilities.

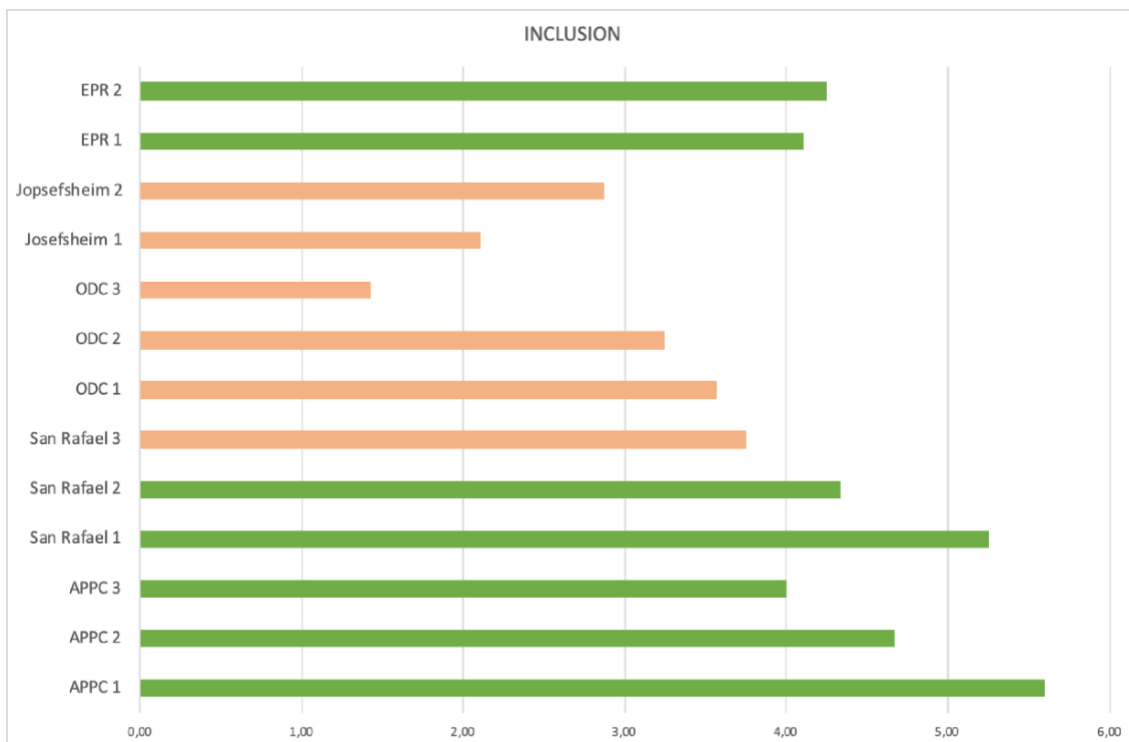
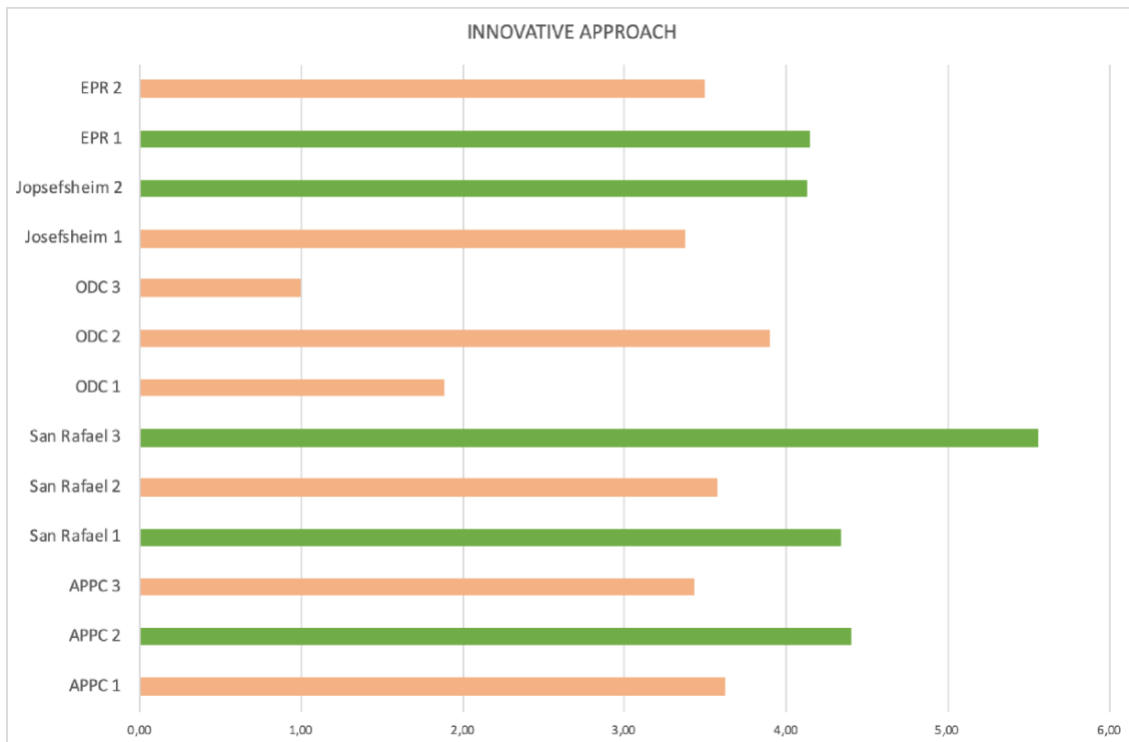
**Note:** Proposals for “Good Practices” submitted by an organization couldn’t be evaluated by workers working for that organization.

### STEP 8: ANALYSING RESULTS OF ASSESSING PROPOSALS FOR A “GOOD PRACTICE”











- Score: Above average of sum
- Score: Below average of sum

Point are given for each answer as follows:  
 Not Relevant: 0 points  
 Less Relevant: 1 point  
 No Opinion: no points  
 Relevant: 4 points  
 Highly Relevant: 6 points

	2		3		1		6		5		4		
	APPC 1	APPC 2	APPC 3	SAN RAFAEL 1	SAN RAFAEL 2	SAN RAFAEL 3	IODC 1	IODC 2	IODC 3	JOSEFSHEIM 1	JOSEFSHEIM 2	EPR 1	EPR 2
RELEVANCE	5,78	3,86	5,25	5,13	5,33	4,56	3,30	4,40	4,00	4,80	4,56	4,88	3,50
SATISFACTION SERVICE USERS	4,50	5,00	4,75	4,67	3,00	2,78	3,33	4,40	3,56	4,89	4,63	3,57	2,80
SATISFACTION FAMILY	4,50	4,80	3,78	4,50	3,89	2,67	2,88	4,00	2,13	4,80	3,86	3,88	3,17
RESULTS QOL	5,11	4,00	4,89	4,44	3,00	2,67	2,29	4,00	3,00	1,60	4,00	4,29	3,75
MEETING EXPECTATIONS	3,33	4,75	5,00	4,25	4,75	2,50	3,00	4,38	2,20	4,00	4,80	4,33	3,60
INNOVATIVE APPROACH	3,63	4,40	3,43	4,33	3,57	5,56	1,89	3,90	1,00	3,38	4,13	4,14	3,50
INCLUSION	5,60	4,67	4,00	5,25	4,33	3,75	3,57	3,25	1,43	2,11	2,88	4,11	4,25
Sum	32,45	31,47	31,10	32,57	27,88	24,47	20,25	28,33	17,31	25,58	28,84	29,19	24,57
Mean	4,64	4,50	4,44	4,65	3,98	3,50	2,89	4,05	2,47	3,65	4,12	4,17	3,51
SD	0,93	0,43	0,70	0,39	0,88	1,18	0,61	0,41	1,10	1,35	0,65	0,41	0,45

Sum Scores

- Score: Above average of sum
- Score: Below average of sum

Mean Scores

- Score: average 4,0 points of more
- Score: below average of 4,0 points

Cohesion (SD scores)

- Score: SD 0,60 or lower
- Score: SD more than 0,60

STEP 9: SELECTING EXAMPLES FOR A "GOOD PRACTICE"

The following projects/approaches have been selected as "Good Practice" examples:

	Name of the project/approach	Partner	Total	Score	Cohesion
1	Between Neighbours	San Rafael	32,57	4,65	0,39
2	Quality of Life Assessment	APPC	32,45	4,64	0,93
3	Rights	APPC	31,10	4,44	0,70
4	Digital communication for young adults with multiple disabilities	EPR <sup>5</sup>	29,19	4,17	0,41
5	SOKOOR-Project	JG Bigge	28,84	4,12	0,65
6	Person Centred Plan	IODC	28,33	4,05	0,41

Participants have been asked to rate the criteria for "Good Practice" by using the scale:

The scale: 1 = Not Relevant, 2 = Less Relevant, 3 = No Opinion, 4 = Relevant, 5 = Highly Relevant

Total: The sum of all eligible points given by those have given feedback

Score: The statistical average score of the criteria (Mean)

Cohesion: The statistical average of deviation on the mean (Standard Deviation)

Note 1: a standard deviation of less than 0,60 indicates a strong cohesion among the participants. Cohesion with a higher variation as 0,60 is marked with Red.

<sup>5</sup> The proposal of EPR was put forwarded on behalf of EPR member: Lykke Marie Home in Slangerup in Denmark

	“Good Practices”	Organisation	Content	Cohesion	Relevance	Cohesion
1	<b>Between Neighbours</b>	San Rafael	4,44	0,51	4,44	0,51
2	<b>Assessing Quality of Life</b>	APPC Faro	4,18	0,39	4,27	0,62
3	<b>Rights</b>	APPC Faro	4,06	0,75	4,29	0,77
4	<b>Digital Communication</b>	Marie Homes	4,38	0,62	4,13	0,72
5	<b>SOKOOR-Project</b>	JH Bigge	4,23	0,44	3,92	0,64
6	<b>Person Centred Planning</b>	ODC	4,36	0,48	4,36	0,61

**Score:** The statistical average score of the criteria (Mean)

**Cohesion:** The statistical average of deviation on the mean (Standard Deviation)

**Note 1:** a standard deviation of less than 0,60 indicates a strong cohesion among the participants. Cohesion with a higher variation as 0,60 is marked with **Red**.

	Selected “Good Practice”	About	QoL Dimensions
1	<b>Between Neighbours</b>	...individual support for personal development in a community based setting.	Interpersonal Relationships; Social Inclusion; Personal Development; Self-determination; Rights.
2	<b>Assessing Quality of Life</b>	...assessing, measuring and reporting Quality of Life of individuals with profound disabilities (San Martín Scale).	Emotional Well-being; Social Relationships; Material Well-being; Personal Development; Physical Well-being; Self-determination; Social Inclusion; Personal Rights.
3	<b>Rights</b>	...promoting and respecting the rights of persons with disability in provision of services.	Emotional Well-being; Social Relationships; Material Well-being; Personal Development; Physical Well-being; Self-determination; Social Inclusion; Personal Rights.

<b>4</b>	<b>Digital Communication</b>	...the use of digital communication with persons who are not able to speak.	Self-determination; Personal Development; Interpersonal Relationships; Social Inclusion.
<b>5</b>	<b>SOKOOR-Project</b>	...enabling the service users to communicate to the best of their ability in their social area.	Emotional Well-being; Social Relationships; Material Well-being; Personal Development; Physical Well-being; Self-determination; Social Inclusion; Personal Rights.
<b>6</b>	<b>Person Centred Planning</b>	...the construction of a personalised program of activities based on a person's skills and interests .	Interpersonal Relationships; Emotional Wellbeing; Social Inclusion; Personal Development.

## 2.3. "GOOD PRACTICE" EXAMPLES

### Good Practice 1 – San Rafael Center, Spain

#### 1. What name would you give to this "Good Practice" example?

BETWEEN NEIGHBOURS: DAY CARE SERVICE IN THE COMMUNITY-BENISAUDET

#### Abstract:

In accordance with the vision of the San Francisco de Borja Foundation, which encourages us to "be the generators of support for the construction of full lives and opening spaces for inclusion in the community", in the year 2018 a new day care service was opened in the community to set that up.

Its purpose is to bring a response to the needs and expectations of people with intellectual disabilities with extensive or generalized support needs who are finishing their school years and for the ones who, due to their prolonged institutionalization, have greater difficulties in developing life projects in normalized and community environments.

This service, which is mainly developed in the Benisaudet neighbourhood of Alicante (although it is also present in other parts of the city according to the emerging opportunities), offers personalised support in community environments in a way that each person who participates can develop their personal project, developing their abilities, making valuable contributions to the community, establishing meaningful relationships with neighbours and enriching oneself's life and others.

In order to achieve these objectives, the centre has established alliances with community entities, such as neighbourhood associations, cooperatives, or the sports and sociocultural centres in the area, which

allow people to find a variety of options through which they can develop their personal projects, oriented from a person-centred approach.

The headquarters of the service is located in Calle Agustín Jiménez Navarraz, in an establishment of 100 m<sup>2</sup>: a multipurpose space in which eight users have a rest area, a kitchen, a dining room, two bathrooms and an activity area. As it was said before, it is located in the Benisaudet district of Alicante. This neighbourhood, recently built, is integrated into the city and surrounded by more traditional neighbourhoods. It has good communications with the city centre and other areas of Alicante. This allows us to have an extensive network of community resources that are available to provide a great variety of activities according to our users plans, tastes and preferences.

## **2. Why have you chosen this example to put forward as a “Good Practice” example?**

- a. This practice is an important step towards de-institutionalization. It brings services and supports within the community in order to facilitate and promote the inclusion and participation of people with intellectual disabilities.
- b. It avoids that people with disabilities who finish their school years necessarily have to access segregated services.
- c. With this project we are achieving a positive impact on the people we aid (by promoting their autonomy, empowerment and thus generating new opportunities for participation in the community), in the family (generating a vision of their family member as a full citizen able to make their own decisions and to have an active participation in the society, overcoming the initial fears that they may have), in the organization (generating a new style of support focused on the natural environment) and in the environment (making people with intellectual disabilities visible as active agents in society).

## **3. To which dimensions contributes the example?**

- a. Interpersonal Relationships;
- b. Inclusion;
- c. Personal Development;
- d. Self-determination;
- e. Rights.

## **4. Have you evidence (proof) that the practice increased the satisfaction of the service users? Please show how satisfaction is measured and the increased satisfaction score.**

- a. Among the 25 people with intellectual disabilities who have participated in the project, 24 have identified this resource as a priority for their personal support plan. The acceptance of the proposal on their part has been much higher than expected, as well as the satisfaction they express with the proposed activities. Also the most remarkable aspect of the project has been to discover that learning in natural environments is way more effective than trying to replicate everyday scenarios in special centres.
- b. An adapted satisfaction questionnaire will be passed in June 2020.

**5. Have you evidence (proof) that the practice increased the satisfaction of the family members? Please show how satisfaction is measured and the increased satisfaction score.**

- a. The satisfaction of the families has not been measured through the organization's satisfaction questionnaires, but it has been collected directly through interviews and written communications (some of the contributions of the families expressing their satisfaction can be consulted). In 2020 it will be included in the satisfaction evaluation along with other services of the Foundation.
- b. New users' families have prioritized this resource over the traditional and "special" resources.

**6. Have you evidence (proof) about tangible results of improving Quality of Life of people with a profound disability? Please show how this is determined?**

- a. We have an initial score of quality of life, which we will evaluate again in a year.
- b. It can be observed through the monitoring of the individual plans, which show an important increase of actions that have a special impact in the inclusion dimension.

**7. Have you evidence (proof) about tangible results of meeting expectations of service users with a profound disability? Please show how this is determined?**

- a. After interviews with the families who demand the resource and with the education centres from which the candidates for the service come, we have found that this more inclusive option is preferred to the traditional segregated solutions.
- b. Both the users who use this service and their families do not want to change the resource.
- c. The service contributes to increase personal experiences based on which users can identify as good life options that initially are not in demand, mainly due to lack of knowledge and experience. As the service develops, users identify valuable goals that we continuously incorporate into their individual support plan.

**8. Why are you considering the example as an innovative way of working?**

- a. The transformation of the support model from the institution to the community, moreover the avoiding of early institutionalization of young people with ID and extensive or generalized support needs.
- b. The move from closed to open areas of intervention in constant change.
- c. The methodology focuses on the basic principles of the PCP and the recognition of people's rights.
- d. Individualization of support based on the opportunities found in the community.
- e. The generation of positive dynamics with community agents that promotes a change in the view of people with disabilities.
- f. The capacity of self-management of the responsible team.

**9. In which way does the example lead to inclusion of services with a profound disability? Please explain how you have understood and defined inclusion in this context.**

The practice itself is an inclusive service for people with intellectual disabilities with high support needs. It is a service within the community that develops dynamics for a greater participation and contribution of the users as well as for a more frequent social interaction.

**10. What would be, in your opinion, the opportunities and challenges to transfer the “Best Practice” example to the partner organizations?**

- a. We have a common vision about the quality of life model and the relevance of inclusion.
- b. This service model doesn't require big investments nor infrastructures, so it is easily replicable in different community spaces. The project aims to advance in the transformation and redefinition of support models and centres for people with disabilities, from the right of people with great support needs to have an active participation in society and to enjoy a real social inclusion as an unavoidable way to develop their life project. Sharing this vision is the first step, available to all, to look for creative ways to achieve it.
- c. As an obstacle, we can highlight the difficulty in including this type of service in the regulations that can guarantee its sustainability. This may be attributable to the fact that the mental model of people with great support needs has not changed in politicians, professionals or families. This means that government initiatives are still not well-aligned with the principles and guidelines of the Convention.

## Good Practice 2 – APPC Faro, Portugal

**1. What name would you give to this “Good Practice” example?**

QUALITY OF LIFE ASSESSMENT

**Abstract**

APPC is committed to promoting the quality of life of people with disability, translating into a vector that guides practices and interventions within the scope of the services provided. It is about achieving equal opportunities, participation and excellence, in such a way that the clients can fully develop their potential, according to their specificities, providing individualized support based on a person-centred model.

**2. Why have you chosen this example to put forward as a “Good Practice” example?**

The institution's fundamental assumptions are based on the commitment to the quality of life of clients, in an ecological system of biopsychosocial development, seeking to respond to their life project, through individualized and person-centered support, prioritizing the natural, cultural, sporting context, educational, health and professional scope, services, support and routines available in the community, establishing an efficient structure, capable of interacting between the various stakeholders and involved in the provision of services, namely, family members, professionals, public and private entities, partners and entities funders and the community in general. APPC aims to achieve

high levels of clients satisfaction, for which it considers it essential to have measures that allow the assessment of their satisfaction, given the services provided, crucial for the development of the activities and programs developed by the institution, ensuring the complementarity of the services and responses available to promote the quality of life of clients and meet their individual needs and expectations.

**3. To which dimensions contributes the example?**

Emotional Well-being;

Social Relationships;

Material Well-being;

Personal Development;

Physical Well-being;

Self-determination;

Social Inclusion;

Personal Rights.

**4. Have you evidence (proof) that the practice increased the satisfaction of the service users? Please show how satisfaction is measured and the increased satisfaction score.**

Yes, we annually assess customer satisfaction, the development of individual support plans based on quality of life dimensions and verify that the results achieved are high and stable.

**5. Have you evidence (proof) that the practice increased the satisfaction of the family members? Please show how satisfaction is measured and the increased satisfaction score.**

Yes.

Satisfaction Questionnaire (Family).

Individual Plan Evaluation (Family).

Stable Results.

**6. Have you evidence (proof) about tangible results of improving Quality of Life of persons with a profound disability? Please show how this is determined?**

Results of QoL (San Martín Scale).

Results of client's improvement QoL (positive variation of San Martín Scale assessment).

**7. Have you evidence (proof) about tangible results of meeting expectations of service users with a profound disability? Please show how this is determined?**

Yes.

Determination of expectations and needs each year.

Questionnaire.

**8. Why are you considering the example as an innovative way of working?**

New generation of quality of life assessment.

**9. In which way does the example lead to inclusion of services with a profound disability? Please explain how you have understood and defined inclusion in this context.**

APPC promotes the full participation and active inclusion of clients and their representation at all levels of the organization and community.

**10. What would be, in your opinion, the opportunities and challenges to transfer the “Best Practice” example to the partner organizations?**

It's an opportunity for the partners to align their clients quality of life results in all levels of the organization performance (macro, meso and micro).

### Good Practice 3 – APPC Faro, Portugal

**1. What name would you give to this “Good Practice” example?**

RIGHTS

**Abstract:**

It is APPC's principle that all people have the right to free choice and control over decisions that concern them, including the services, programs and support products provided to them. APPC Faro is committed to promoting the defence of the rights of people with disabilities, in an accessible and practical translation of established laws and regulations, and in accordance with the institution's Code of Ethics based on the Convention on the Rights of Persons with Disabilities. APPC Faro follows its net political conduct, based on international conventions, legal guidelines and references that guide the rights and duties of people with disabilities, namely, the United Nations Convention on the Rights of Persons with Disabilities (2006); the Basic Law for the Prevention, Qualification, and Rehabilitation of Persons with Disabilities (2004); the Constitution of the Portuguese Republic (1976); and the Universal Declaration of Human Rights (1948).

**2. Why have you chosen this example to put forward as a “Good Practice” example?**

APPC Faro as a reference institution is committed to a strong alignment between their mission, their practices, the needs of its clients and a perspective of management and leadership sustained on teams with a strong collective spirit.

Mission.

Clients focus.

Adapt to the client's needs.



**3. To which dimensions contributes the example?**

Rights.

**4. Have you evidence (proof) that the practice increased the satisfaction of the service users? Please show how satisfaction is measured and the increased satisfaction score.**

Yes.

Satisfaction Questionnaire.

Individual Plan Evaluation.

Stable Results.

**5. Have you evidence (proof) that the practice increased the satisfaction of the family members? Please show how satisfaction is measured and the increased satisfaction score.**

Yes.

Satisfaction Questionnaire (Family).

Individual Plan Evaluation (Family).

Stable Results.

**6. Have you evidence (proof) about tangible results of improving Quality of Life of persons with a profound disability? Please show how this is determined?**

Results of Rights dimension (San Martín Scale).

Results of client's improvement of Rights dimension (positive variation of San Martin Scale assessment in Rights dimension).

**7. Have you evidence (proof) about tangible results of meeting expectations of service users with a profound disability? Please show how this is determined?**

Yes.

Determination of rights fulfill each year.

Questionnaire.

**8. Why are you considering the example as an innovative way of working?**

New generation of bio-psycho-social and justice disability models.

**9. In what way lead the example to inclusion of services with a profound disability? Please explain how you have understood and defined inclusion in this context.**

APPC promotes customer empowerment with the objective of enhancing equal opportunities, participation and inclusion.

## 10. What would be, in your opinion, the opportunities and challenges to transfer the “Best Practice” practice example to the partner organizations?

It's an opportunity to change practices and adapt to the scientific new model of disability (2018).

### Good Practice 4 – Marie Homes in Denmark (EPR, Belgium)

#### 1. What name would you give to this Best Practice example?

DIGITAL COMMUNICATION FOR YOUNG ADULTS WITH MULTIPLE DISABILITIES

#### 2. Why have you chosen this example to put forward as a “Good Practice” example?

‘Digital communication for young adults with multiple disabilities’ defines a practice, which covers most of the pedagogical work at the Lykke Marie Home in Slangerup in Denmark. It is one of our defined goals to become a leading provider of Augmentative and Alternative Communication (AAC), including digital communication for young adults with multiple, profound disabilities. It is a digital communication form that is based on high-tech solutions and research in artificial intelligence (AI). Individuals with very limited or no speaking ability need other means of communication than speech to be able to say what they want; when they want it; and to whom they want. Therefore, their access to AAC is crucial for their participation in and quality of life. As the Danish chapter of ISAAC (International Society of Augmentative and Alternative Communication) states:

*“It is in communication with other people that we get the opportunity to create our own ‘self’ – a ‘self’ that is different and separated from others. Being regarded as an independently thinking and acting human being is a fundamental human need – and thus a fundamental human right.”*

This shows how important it is to focus on communication working with people without speaking ability, which is the case for the young adults living in the Lykke Marie Home. Therefore, we prioritise AAC – especially the digital communication forms – as we have learned what positive effect this communication form has had on the young adults’ quality of life and influence in their own life.

#### 3. To which dimensions contributes the example?

Jonas Rønhøj is one of the young adults living at the Lykke Marie Home. In an article in the Danish magazine, *Socialpædagogen* (2019), his example clearly shows how the use of digital communication in everyday life is a success story that other social service providers in Europe should be inspired by. The use of digital communication contributes to the young adults’ quality of life in these dimensions: *self-determination, personal development, interpersonal relationships and social inclusion*. This is what young Jonas, his parents and network, and the staff around him at the Lykke Marie Home have learned using digital communication in practice.

Jonas is 24 years old and a resident of the Lykke Marie Home in Slangerup in Denmark. He has no speaking ability, reduced hearing ability and can only move one hand. Despite these disabilities, he is a competent user of social media and digital communication means. Jonas’ mother, Pia Rønhøj, has experienced these competences as a way to improve his quality of life considerably. Pia says: *“Jonas has a social network that he could never have had without these media. They provide him a way to*

*keep relations to the people that mean the most to him. He can call on his own to his family and former helpers. That he can reach out to the world by his own means is a huge gift.”*

Jonas uses his iPad to communicate. With the app *Avaz*, which is a symbol-controlled communication app to e.g. people with autism, Down’s syndrome and Asperger’s, he can tell his surroundings about his needs. *Avaz* is dialogue-based and encourages conversations between Jonas, his family and helpers. But he also uses independent video communication via the app FaceTime to call his family and friends; and he can put pictures and videos on Facebook by himself as well. Pia continues: *“We have reached contact with Jonas at a completely new level. The communication means have helped him to grow cognitively. Especially when we started using social media and FaceTime, we managed to build a new relationship with him.”*

It is examples like Jonas that make all of us at the Lykke Marie Home fully aware of the need to consistently work and practice with digital communication with all the residents. Because this communication form has such a huge influence on the young adults’ quality of life, it needs to be integrated in their day-to-day life as all other professional support and care tasks.

**4. Have you evidence (proof) that the practice increased the satisfaction of the service users? If so, please show how satisfaction is measured and the increased satisfaction score./ 5. Have you evidence (proof) that the practice increased the satisfaction of the family members? Please show how satisfaction is measured and the increased satisfaction score./ 6. Have you evidence (proof) about tangible results of improving Quality of Life of persons with a profound disability? Please show how this is determined?/ 7. Have you evidence (proof) about tangible results of meeting expectations of service users with a profound disability? Please show how this is determined?**

At the Lykke Marie Home we work in a value-based manner. Therefore, we haven’t yet prioritised collecting proof, results and/or quantitative measurements of the satisfaction level of the young adults, the relatives and staff on the implementation of digital communication and its effects on quality of life. But looking at the example of Jonas, his mother, Pia, and his helper, Eva, you can find qualitative data that are very clear. Digital communication for young adults like Jonas with profound, multiple disabilities and no speaking ability experience higher quality of life through self-determination, personal development, interpersonal relationships, and social inclusion. We therefore hope that the dissemination of our work with digital communication and the sharing of the success story of Jonas can inspire other European social service providers/ partner organisations in their work promoting communication and quality of life for people with disabilities.

#### **8. Why are you considering the example as an innovative way of working?**

Working with digital communication everyday at the Lykke Marie Home is certainly a very innovative way of working. Previously, other forms of AAC (like Signs to Speak (*Tegn Til Tale* in Danish) and pointing at symbols) were mostly used, but today digital communication is a good option. Complex flows of information, social media, platforms and new technologies fill up a central part of the everyday life of Danes today – and create new challenges and opportunities for both the individuals and the society at large. Therefore, digital communication solutions are important to integrate into the lives of people with (multiple) disabilities, as they also should have the option to become digitally literate and live in a way that reflects the day and age they are part of. It is highly important, though, to view digital communication as one of many augmentative and alternative communication forms. In order to

achieve as efficient a communication as possible, you need to use a broader array of augmentative and alternative communication strategies (ISAAC Denmark 2020). Digital communication can therefore in general not be the only tool you use – and can never replace the care, pedagogical support and communication that happens in the physical meeting between people. But the digital communication form is without a doubt an innovative approach that opens up many new roads in the pedagogical field in working with young adults with multiple disabilities, as it can provide space for communication and relationship building - independent from time and physical setting.

**9. In which way does the practice lead to inclusion of service users with a profound disability? Please explain how you have understood and defined inclusion in this context.**

'Newer' digital tools give completely new opportunities for communication and thus opportunity to expand or just maintain one's social contacts. Most people can contact whomever they want, but it is the opposite for people with profound disabilities. This group is often dependent on others to take initiative (LEV 2019). Most of our work with digital communication is still based on the staff of the Lykke Marie Home taking the communication initiative, but there is today a better chance of social inclusion as the young adult himself/herself can contact friends, family and others, as we saw in Jonas' example. Digital communication is thus also a way of diminishing social isolation of people with profound disabilities. Likewise the young adult has gained larger influence in her/his own life where the young adult can express and act on her/his own needs and wishes – in a way that was not possible earlier.

**10. What would be, in your opinion, the opportunities and challenges to transfer the "Good Practice" example to the partner organizations?**

There are both opportunities and challenges in transferring/ implementing digital communication in practice to other European partner organisations/ service providers. As previously stated, we live in a digitalised society with many accessible technologies. The opportunities of getting an iPad and being connected to the Internet is possible in most parts of Europe. The high-tech solutions are also becoming cheaper – compared to earlier when technology was markedly more expensive, and people's motivation to work with new technologies is often that it is innovative and exciting to communicate in this way. We have learned that when a staff member has tried this communication form, then the staff also realizes that it gives access to the young adult's inner universe in a completely new way. Eva Benning who is a trained social worker and Jonas' helper at the Lykke Marie Home says,

*"Digital communication is very interesting, as it is very obvious to see what difference it makes for the young adults. I am motivated to use these tools, because I get the feeling that I in this way get into the resident's world."*

The main challenges in implementing digital communication are that this communication form can never stand alone, as AAC should always involve the tool, the AAC user and the surroundings, and these 3 factors have to be coordinated, before it can become meaningful (ISAAC Denmark 2020). It is therefore not a solution to just purchase an iPad as a support tool and believe that digital communication will then function.

The young adult has to be motivated and involved in using this form of communication in her/ his everyday life. In this regard, it is crucial that the relatives and staff seek to uncover the young adult's needs and wishes for using digital communication. The surrounding environment (e.g. relatives and

staff) also has to embrace the new technology with sincere interest and active participation. They have to help the young adult become a member of the various social networks – e.g. by creating a technical set-up where the social networks can be built, expanded and maintained. It is also important that the relatives and staff members have a lot of faith and patience in the young adult succeeding in using digital communications. It takes time for all of us to learn new skills – both for the young adult, the relatives and the staff. We also experience at the Lykke Marie Home that not all staff members are equally interested in the digital world. We have had to accommodate these differences as we are all unique individuals. And the less digitally minded colleagues can instead contribute with other important pedagogical interventions – until they at a later stage grow interested in the digital world. As long as there is a continued focus on the importance of digital communication and an acknowledgement of its potential, your organization develops in the right direction.

On the other hand, digital communication can also be challenging for the working environment, as computers and eye-sight-controlled programmes set high standards for the individual staff member's technical competences. It is therefore necessary to have a consistent focus on education of all staff members, if digital communication is to be implemented successfully. The management of the Lykke Marie Home has among other initiatives made sure that all employees have been trained in AAC. This included an introduction to all digital communication opportunities for people without any speaking abilities. Even if you as an organization are fully aware of the necessity of training the staff in digital communication, it is another challenge that technology is evolving at such high speed that it can be difficult to keep pace with the developments of the best use of it. Tomorrow there might be a newer technology or a better computer programme on the market. Therefore you have to accept as a user of digital communication that this communication form is constantly changing – and that you should keep on learning more and seek to acquire the newest developments in this field. At the Lykke Marie Home, we are therefore still not fully completed in making the tools a totally integrated part of everyday life yet, but we are very focused on getting there, so we consider it an on-going process that will always be part of our development.

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## Good Practice 5 – Josefsheim Bigge, Germany

### 1. What name would you give to this Best Practice example?

SOKOOR-Project (communicative and integrated participation in one's social area).

### 2. Why have you chosen this example to put forward as a Best Practice example?

It's a relatively new project but it has already proved most successful in enabling the service users to communicate to the best of their ability in their social area.

### 3. To which dimension contributes the example?

The SOKOOR-Project contributes to enabling the service users to participate in social life.

The example contribute to the following core dimensions:

- Emotional Well-being;
- Social Relationships;
- Material Well-being;
- Personal Development;
- Physical Well-being;
- Self-determination;
- Social Inclusion;
- Personal Rights.

### 4. Have you evidence (proof) that the practice increased the satisfaction of the service users? Please show how satisfaction is measured and the increased satisfaction score.

We measure the increase in satisfaction of the service users by the higher degree of independence and self-determination as well as by the positive reaction of the service users. All of which are documented.

### 5. Have you evidence (proof) that the practice increased the satisfaction of the family members? Please show how satisfaction is measured and the increased satisfaction score.

We offer regular contact with the family members or representatives to achieve feedback and they are free to contact us any time. The information we receive is then documented.

### 6. Have you evidence (proof) about tangible results of improving Quality of Life of persons with a profound disability? Please show how this is determined?

An example of improving the quality of life of a person with a profound disability is that he has been supplied with an environment control.

The improvement is monitored and evaluated in both examples.

**7. Have you evidence (proof) about tangible results of meeting expectations of service users with a profound disability? Please show how this is determined?**

In the case of the SOKOOR-Project, there is the additional aspect: the service-users become more independent, e. g. they choose their own food which they select from a menu and even order by themselves.

**8. Why are you considering the example as an innovative way of working?**

This project enhances living skills which means that the service users are less dependent on personnel; it widens their competence and makes them more independent. Their disability is also compensated by the technical assistant.

**9. In what way lead the example to inclusion of services with a profound disability? Please explain how you have understood and defined inclusion in this context.**

In the example, it is the service-user who selects and determines what is done. The service user also selects his support team by himself.

**10. What would be, in your opinion, the opportunities and challenges to transfer the Best Practice example to the partner-organizations?**

Opportunities:

- Environment control;
- Self-determination;
- Skills improvement,
- Inclusion,
- Less barriers.

Challenges:

- Technical equipment;
- Development of a new project;
- Time requirement;
- Financial support;
- Crowdfunding.

## Good Practice 6 – Istituto don Calabria, Italy

**1. What name would you give this Best Practice example?**

PERSON CENTRED PLAN

**2. Why have you chosen this example to put forward as a Best Practice example?**

Because the intent is to maintain the skills achieved by the person and to develop the residual potentialities through a facilitating life context, the construction of a personalized program (by choosing activities that are built and negotiated starting from the person's skills and interests) and by proposing activities oriented to the emotional and affective sphere.

**3. To which dimension contributes the example?**

- Interpersonal Relationship;
- Emotional Wellbeing;
- Social Inclusion;
- Personal Development.

**4. Have you evidence (proof) that the practice increased the satisfaction of the service users? Please show how satisfaction is measured and the increased satisfaction score.**

Questionnaire about general satisfaction (compiled by person and/or family members/caregivers).

Attendance/Desire to attend the daily centre.

Desire to replay activities.

Observation of emotions/face expressions.

Observation of attention and waking times (for people with very profound disabilities).

**5. Have you evidence (proof) that the practice increased the satisfaction of the family members? Please show how satisfaction is measured and the increased satisfaction score.**

Questionnaire about general satisfaction (compiled by person and/or family members/caregivers).

Periodic talks/meetings with family members.

**6. Have you evidence (proof) about tangible results of improving Quality of Life of persons with a profound disability? Please show how this is determined?**

Sharing with people of every kind of activity.

Observation and analysis of emotions and face expressions.

Investigation about life before accident/trauma/disease (for people with acquired disability).

The quality of life is determined by observation, discussions and meeting with the person, families, caregivers and professionals.

**7. Have you evidence (proof) about tangible results of meeting expectations of service users with a profound disability? Please show how this is determined?**

Depth of communications and kind of requests.



Compliance between the person and operators.

Number of activity.

Observation of attention time.

Observation of waking times.

**8. Why are you considering the example as an innovative way of working?**

Because SAO is a daily service dedicated to adults with acquired disabilities: investigating about life before trauma (hobbies, choices, wishes, thoughts) helps to recognize what could increase quality of life.

Speaking with frankness could help a person to feel treated with respect; it gives them the opportunity to decide with as much freedom as possible about their choices.

**9. In what way lead the example to inclusion of services with a profound disability? Please explain how you have understood and defined inclusion in this context.**

Sharing and negotiating the most choices as possible allows persons to be in the middle of their own life and to be leaders of themselves.

**10. What would be, in your opinion, the opportunities and challenges to transfer the Best Practice example to the partner-organizations?**

The best challenge is to share the need of allow to every man to decide for himself to the best of his ability and live a meaningful life.