Quality of Life Assessment

Quality of Life Models CURRENTLY

- The **Holistic Model** used in intervention in reabilitation, advocates a **systemic vision**, in which the **person** and his **environment** constitute a **whole**.
- In addition to individual **biological** particularities, they also include **social, psychological, environmental, cultural** and **justice** idiosyncrasies.
- The focus of intervention is **centered on the person**, in their physical, social and community environment.

Quality of Life

Based on Roberth Schalok's Model (1996):

Quality of life is defined 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

8 Dimensions: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion and rights.

Quality of Life in Disability

5 critical factors:

(i) multidimensional nature : **8 critical components of QOL** (Schalock, 1996): emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion and rights.

(ii) subjective satisfaction as a central measure of QOL: measuring the **level of satisfaction** of users with their different domains of life has been the most common indicator of measurement in the individual perception about their QOL.

(iii) **hierarchical nature** of the construct: first, QOL is subjective; second, its central dimensions are evaluated differently by individuals; and third, the value associated with each of the dimensions varies over the life cycle.

(iv) the use of **complex research designs** to analyze the significant correlations of a vast set of variables with QOL .

(v) the use of **multiple methods** to evaluate the individual perceptions about QOL.

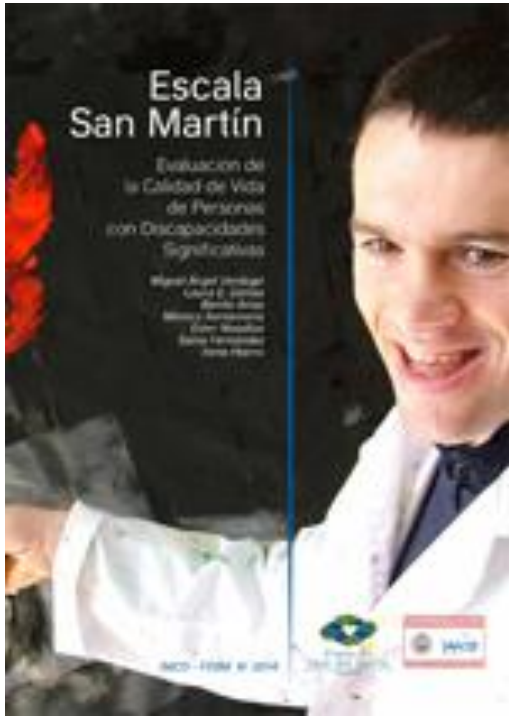
Quality of life conceptual and measurement model

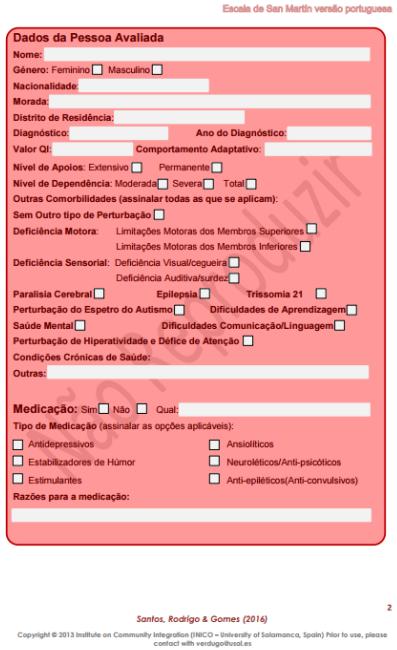
Factors	Dimensions	Exemplary indicators
Independence	Personal development Self-determination	Education status, personal skills, adaptive behavior Choices/decisions, autonomy, personal control, personal goals
Social participation	Interpersonal relations Social inclusion Rights	Social networks, friendships, social activities, interactions, relationships Community integration/participation, community roles, supports Human (respect, dignity, equality) legal (legal access, due process)
Well-being	Emotional well-being Physical well-being Material well-being	Safety and security, positive experiences, contentment, self-concept, lack of stress Health and nutrition status, recreation, leisure Financial status, employment status, housing status, possessions

Advantages of adopting Schalock and Verdugo's Model

- ✓It stands out for its increasing use and for the number of citations in the scope of the deficiency.
- ✓It extends throughout the **life cycle of people** with disabilities and guides the practice from early intervention, education, transition to active life, adulthood and aging.
- ✓It improves **planning**, developing models for person-centered programs evaluation, **assesses** the effects of services provided, and **guides** interventions to increase customer satisfaction.

SAN MARTÍN (Verdugo et al., 2014)





Escala de San Martín versão portuguesa

Dados da Pessoa Avaliada

Nome:
Género: Feminino ☐ Masculino ☐
Nacionalidade:
Morada:
Distrito de Residência:
Diagnóstico: **Ano do Diagnóstico:**
Valor QI: **Comportamento Adaptativo:**
Nível de Apoios: Extensivo ☐ Permanente ☐
Nível de Dependência: Moderada ☐ Severa ☐ Total ☐
Outras Comorbilidades (assinalar todas as que se aplicam):
Sem Outro tipo de Perturbação ☐
Deficiência Motora: Limitações Motoras dos Membros Superiores ☐
Limitações Motoras dos Membros Inferiores ☐
Deficiência Sensorial: Deficiência Visual/cegueira ☐
Deficiência Auditiva/surdez ☐
Paralisia Cerebral ☐ **Epilepsia** ☐ **Trissomia 21** ☐
Perturbação do Espetro do Autismo ☐ **Dificuldades de Aprendizagem** ☐
Saúde Mental ☐ **Dificuldades Comunicação/Linguagem** ☐
Perturbação de Hiperatividade e Défice de Atenção ☐
Condições Crónicas de Saúde:
Outras:

Medicação: Sim ☐ Não ☐ Qual:
Tipo de Medicação (assinalar as opções aplicáveis):
☐ Antidepressivos ☐ Ansiolíticos
☐ Estabilizadores de Humor ☐ Neurolépticos/Anti-psicóticos
☐ Estimulantes ☐ Anti-epiléticos(Anti-convulsivos)
Razões para a medicação:

Santos, Rodrigo & Gomes (2016)

http://sid.usal.es/libros/discapacidad/26729/8-1/escala-san-martin-evaluacion-de-la-calidad-de-vida-de-personas-con-discapacidades-significativas.aspx

SAN MARTÍN

- Multidimensional assessment of quality of life, based on the eight-dimensional model of Schalock and Verdugo (2002/2003).
- Developed by INICO and by Fundación Obra San Martín, authors Verdugo *et al* (2014).
- It offers an objective and subjective assessment of the quality of life of adults with intellectual, multiple and significant disabilities who require extensive and generalized support, with other associated conditions.
- It consists of 95 objective and observable items and is answered by social services professionals or others who have known the person for at least three months (family, close friends, legal guardians).
- Adults from 18 years of age (or 16 years, as long as they are outside the educational system).
- Higher standard scores mean a higher quality of life.

The San Martin Concept

- The **San Martín Scale** is an instrument that responds faithfully to the approaches of the **integral approach** to **quality of life**, which has become the main **conceptual reference** and **evaluation framework** to **promote improvements** in the lives of people with disabilities and, therefore, in the exercise of their right to a dignified life.

San Martin Scale AIM

- The concept of quality of life is a social construct that **guides practices** and **interventions** in services and is currently used as a key aspect in the **development of person-centred planning** and the **improvement of personal outcomes**, in the quality improvement strategies of service provider organisations and in the development of social policies.

San Martin Scale

✓**Personal outcomes** are important measures in the fields of education, health care, and social services that are being used not only for enhancing person well-being but also becoming very useful for assessing the **effectiveness of intervention programs**.

✓**Personal outcomes** are typically referenced to **eight core quality of life domains** that reflect an individual's self-determination (SD), emotional well-being (EW), physical well-being (PW), material well-being (MW), personal development (PD), rights (RI), social inclusion (SI), and interpersonal relationships (IR).

San Martin Scale

✓These **domains** can be **assessed** either through **self-reports**, **reports from other people**, or both.

- **Self-report** forms assess the **individual's self-perception** of his/her status on the respective personal outcome and reflect the values underlying the quality of life concept (e.g., inclusion, empowerment, equity, and self-determination) as well as the principles underlying the disability rights movement.
- **Report of others assesses** the respondent's **perception about the person's status** on the respective personal outcome.
- Though the **most desirable measurement** is that involving **both kinds of reports**, it is **not always possible** to get reliable and valid self-reports from those **people with the lowest levels of functioning** and **highest support needs**.

San Martin Scale

- ✓There are a very considerable number of instruments to assess quality of life for people with intellectual and developmental disabilities, almost none of them are suitable for those with the **lowest levels of functioning** (significant limitations in adaptive behavior, or other significant conditions related to language limitation, significant motor dysfunctions, chronic and pain-related medical conditions, challenging behaviors, sensory impairments, or mental health problems).

- ✓None of the former instruments is suitable for those with the lowest levels of functioning who are frequently unable to communicate their feelings, thoughts, and preferences.

San Martin Scale

✓The San Martín Scale was developed with the goal of:

1. bridging this gap and satisfying the demands of practitioners that are interested on the implementation of evidence based practices to improve the quality of life of people through the provision of supports.;
2. to progress in the improvement of the quality of life of a group of individuals who, given the difficulty they present in terms of research, have received less attention from the scientific community;
3. developing a functional model of the quality of life for people with significant disabilities (also called people with multiple and severe disabilities).

San Martin Scale

- The scale makes reference to the **degree** in which people have **vital** and **valuable experiences**, it reflects the **dimensions** that contribute to a **full** and **interconnected life**; it takes into account the context of the **physical**, **social** and **cultural environments** that are **important to people** and it includes common human experiences, as well as unique vital ones.

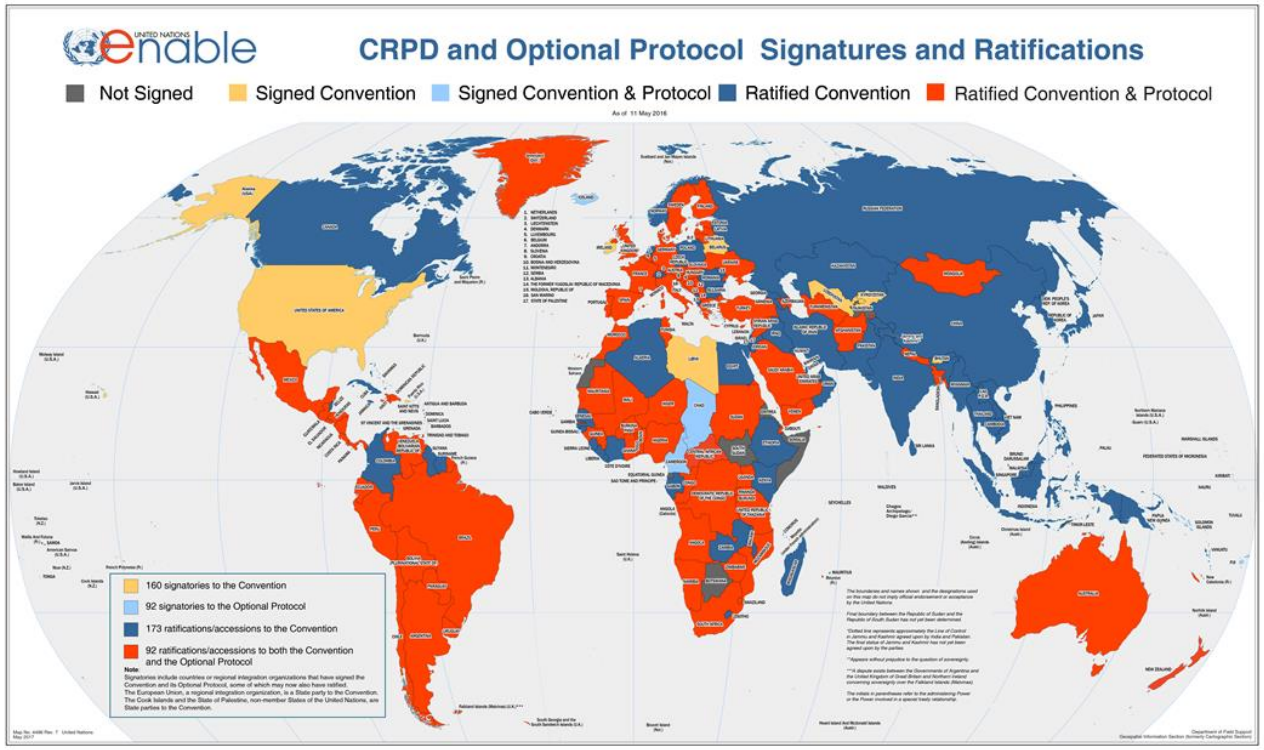
It allows professionals who work in providing services for people with significant disabilities to **plan interventions** and **provide support** that are focused on the individual; provide information that is relevant and from which they can straighten and improve the quality of the services; test out programs and develop organizational change.

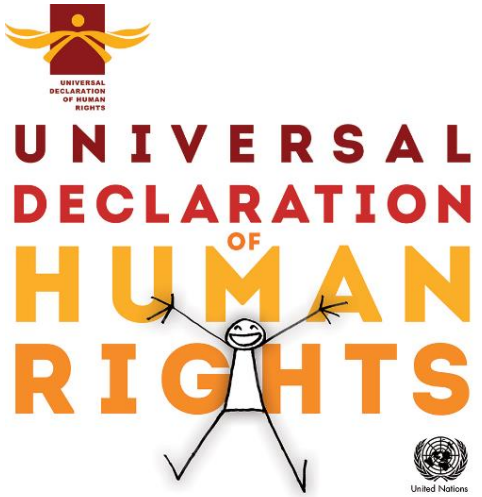
Participation of People with Disabilities

- Recent theoretical perspectives on human functioning (ICF, 2001 or AAIDD; Schalock et al, 2010) highlight the importance of a socio-ecological approach. This approach presupposes a functional and multidimensional conceptualization of disability, in which not the "defect" but the functioning of people is central.

- The shift of attention to the environment rather than on the person, explains a focus on social participation as a necessary dimension with regard to human functioning. Policies and political actions must therefore fundamentally focus on facilitating social participation in the daily lives of people with ID (Verdonschot et al, 2009).

The UN-Convention on the Rights of People with Disabilities (2006) has led to the international recognition, that it is the obligation of the society to guarantee the full Participation of People with Disabilities





Social Participation

- Speaking about social participation is speaking about quality of life. If QOL is an important goal for all people, this is also true for people with disabilities.
-
- Social participation as an inherent element of QOL.

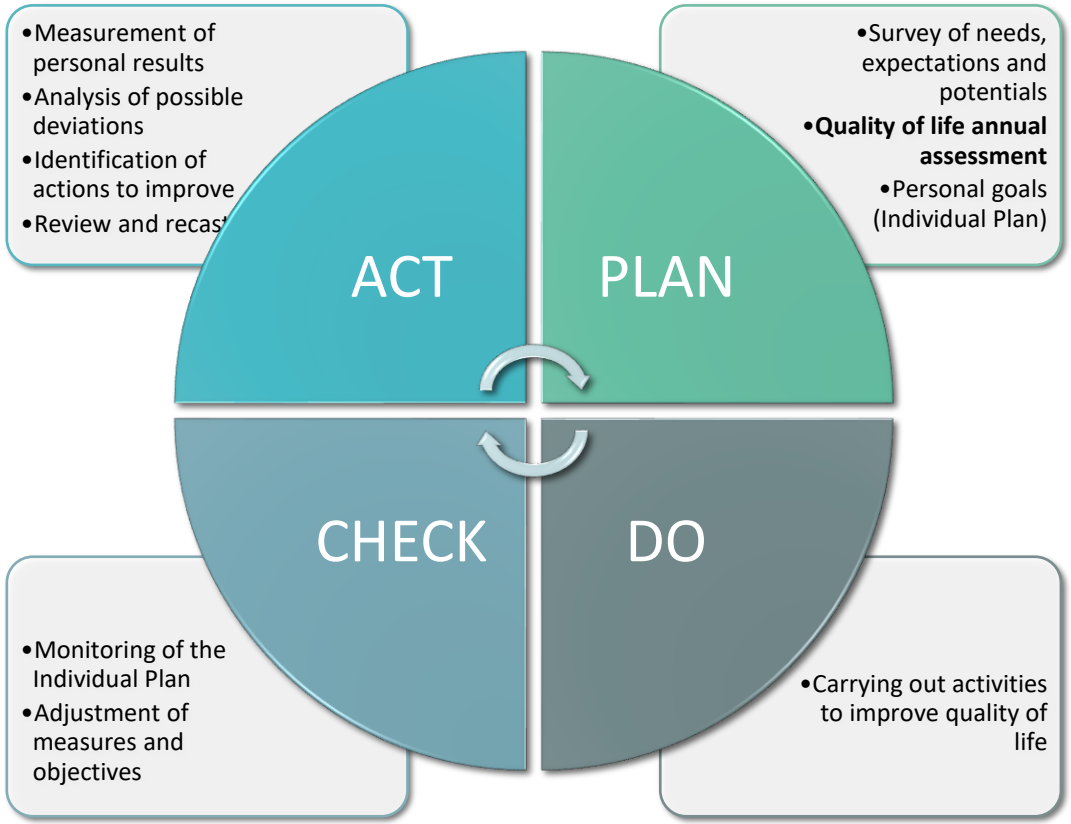
- Empirical research shows that often social participation is prevented for persons with disabilities, but especially for people with severe multiple disabilities.

How do individuals with disabilities experience social inclusion?

In a study by Hall (2009) six themes were being identified:

- being accepted,
- relationships,
- involvement in activities,
- living accommodations,
- occupation and
- support systems

Continuous improvement in quality of life



Continuous quality improvement

Continues Quality Improvement		
Evaluation	Survey of Needs, Expectations and Potentialities of the Person with Disabilities	Holistic Approach Biopsychosocial Model Ecological Sistemic Model **Quality of Life Model**
Planning	Individual Development Plan (Personal Objectives and Goals and Individualized Support)	Person Centered Planning By Reference to the ICF (WHO) Alignment with the Schalock **Quality of Life Model**
Implementation	Semiannual Monitoring Annual Review	Individual Results Collective Results
(Re) Evaluation	Annual Quality of Life Assessment (Scales)	Individual Benefits Collective Benefits Impact of Services
		Restructuring of Individual Plans Definition of Key Areas for Improvement

Improving QOL of service users

- Quality of Life domains are a way of measuring the degree to which a person enjoys the possibilities of his/ her life given the person's unique opportunities and limitations.
- The domains describe personal and environmental factors that influence quality of life.

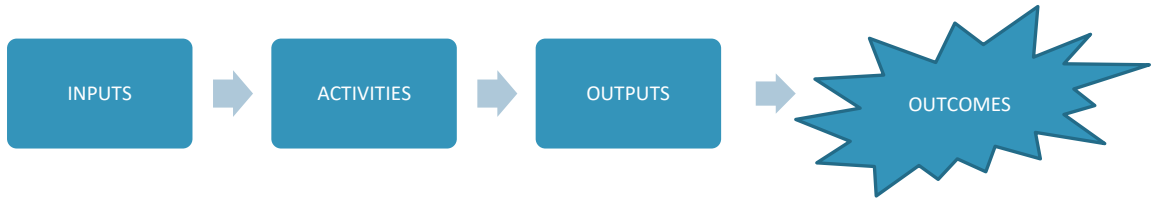
1. Identify the Individual's Goals and Strengths for the **Individual Plan**.
2. Select **Support Needs** that are important to and for the Individual.
3. Align Support Needs to **Outcome** Categories.
4. **Monitor** the Status of Support **Objectives**.

Exercise (90 minutes)

Working in small groups based on concrete practical assignments (per country group)

Through your experience, how to use the results of the San Martin assessment to generate changes in :

- each person with severe disability
- the organization
- the society



System Levels		Input	Process	Results	
				Output	Outcomes
MICRO	Individual				
MESO	Organization				
MACRO	Society				

Selected outcome – Measurement terms

Inputs are resources a program uses to achieve program objectives. Examples are staff, volunteers, facilities, equipment, curricula, and money. A program uses inputs to support activities.

Activities are what a program does with its inputs – the services it provides – to fulfill its mission. Activities include the strategies, techniques, and types of treatment that comprise the program's service methodology.

Outputs are the direct products of program activities and usually are measured in terms of the volume of work accomplished – for example, the numbers of training, counseling sessions conducted, educational materials distributed, and participants served. Outputs have little inherent value in themselves. They are important because they are intended to lead to a desired benefit for participants or target populations.

Outcomes are benefits for participants during or after their involvement with a program. They are influenced by a program's outputs. Outcomes may relate to knowledge, skills, attitudes, values, behavior, condition, or status. They are what participants know, think, or can do; or how they behave; or what their condition is, that is different following the program.

Outcome indicators are the specific items of information that track a program's success on outcomes. They describe observable, measurable characteristics or changes that represent achievement of an outcome.

Outcome targets are numerical objectives for a program's level of achievement on its outcomes. After a program has had experience with measuring outcomes, it can use its findings to set targets for the number and percent of participants expected to achieve desired outcomes in the next reporting period. It also can set targets for the amount of change it expects participants to experience.

Benchmarks are performance data that are used for comparative purposes. A program can use its own data as a baseline benchmark against which to compare future performance. It also can use data from another program as a benchmark. In the latter case, the other program often is chosen because it is exemplary and its data are used as a target to strive for, rather than as a baseline.

Component	Perspective		
	Individual	***Organization***	***Society***
Practices in question	Evaluation, Diagnosis, Interventions, Individualized supports	**Quality strategies:** Person-centered planning Support system Staff support techniques Program options Clients participation	Public policies to people with disabilities
Indicators of evidence	Behavioral indicators (change) Physical indicators (change) QOL scores Psychological indicators (change) Relevant instruments scoresAlignment of the objectives with the measuresConsistency among diagnosticians	**Organizational results:** Effort measures Efficiency measures Staff measures Program options Network indicators Personal results	Government Rules (e.g. Education, Economy) Community Impacts (e.g. Attitudes, Opportunities, Participation) Education and Training Strategies (e.g. Professional Practices, Mental Models, Curriculum) Resource location pattern
Evidence collection strategy	Random studies Multiple baseline studies Unique Case designs Qualitative approaches Users researches Scales development Stories	Experimental-control Quasi-experiments Multivariate designs Qualitative designs Clients researches	Meta-analysis Experimental control Multivariate designs Clients researches
Interpretation guides	Quality of the evidenceSturdiness/hardiness of the evidenceRelevance of the evidence		

Evidence-based practice measurement approach (Schalock, Verdugo and Gómez, 2011)

Why measure outcomes?

To see if programs really make a difference in the lives of people

…there is an even more important reason: **To help programs improve services.**

Outcome measurement provides a learning loop that feeds information back into programs on how well they are doing. It offers findings they can use **to adapt**, **improve**, and become more **effective**.

Results of outcome measurement show not only where services are being effective for participants, but also where outcomes are not as expected. Program managers can use outcome data to:

- Strengthen existing services.
- Target effective services for expansion.
- Identify staff and volunteer training needs.
- Develop and justify budgets.
- Prepare long-range plans.
- Focus board members' attention on programmatic issues.

APPC Faro

System Levels		Input	Process	Results	
				Output	Outcomes
MICRO	Individual	Personal goals and needs of each person	Provision of individualized services	Personal results	Quality of Life Index Fulfilment of needs Personal Achievements (Individual Plan)
MESO	Organizacional	Stakeholder needsShort-term Opportunities Occurrences	Implementation of improvement actions	Impact of improvement actions	Compliance Rate for Improvement Actions Effectiveness Index
MACRO	Society	Value-based policiesResources	Development of Key Processes Management strategies	Total organization results Transformation indicators in the system	