Best Practices and Successful Experiences
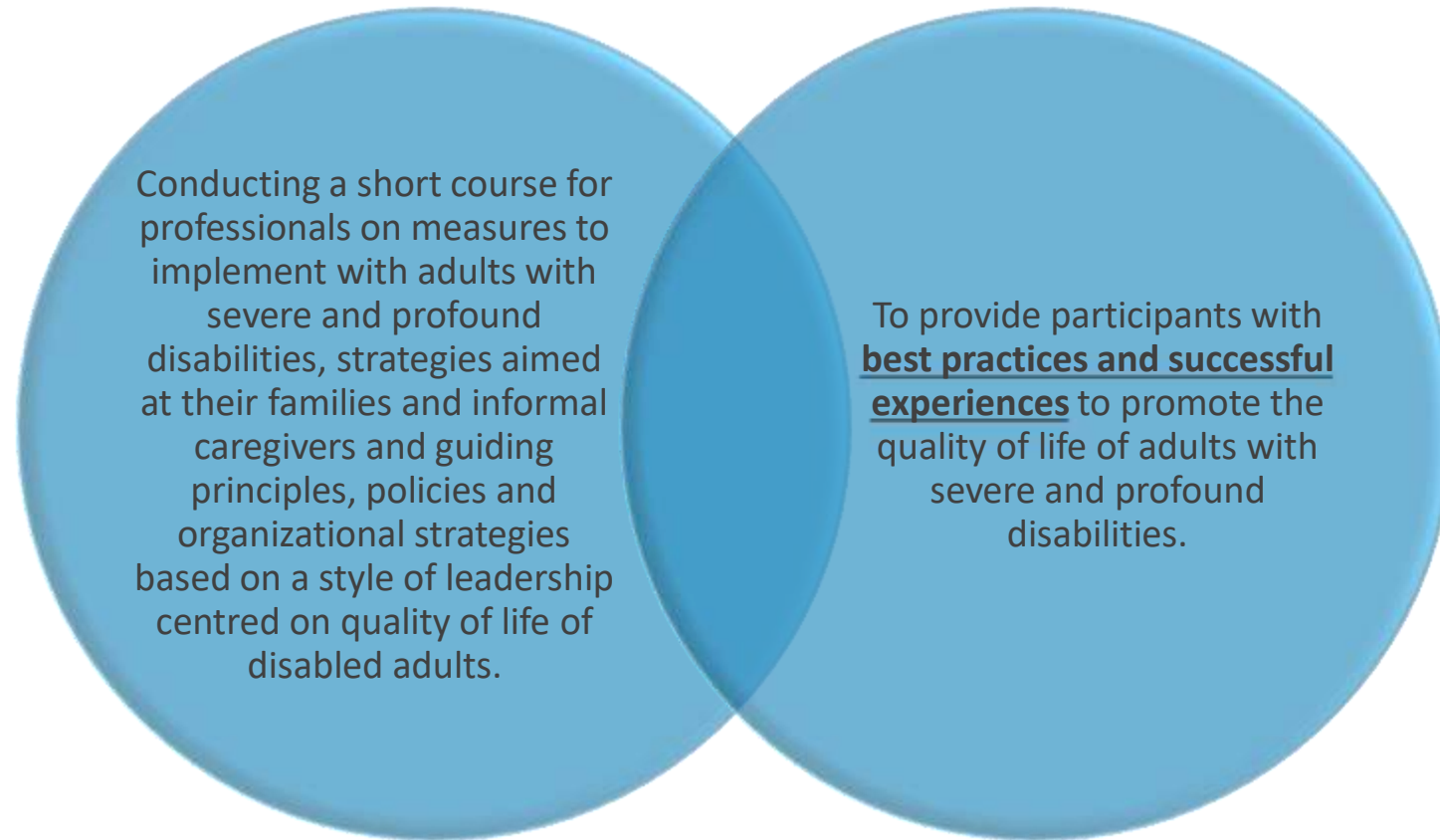
Learning/Teaching/Training Activities

General objectives of the training

Conducting a short course for professionals on measures to implement with adults with severe and profound disabilities, strategies aimed at their families and informal caregivers and guiding principles, policies and organizational strategies based on a style of leadership centred on quality of life of disabled adults.

To provide participants with **best practices and successful experiences** to promote the quality of life of adults with severe and profound disabilities.

Learning objectives

KNOWLEDGE **+** UNDERSTANDING **+** AWARENESS **+** SKILLS **+** STRATEGIES **=** PRACTICES

Modules

Rights
APPC Faro

Disability

❖The most recent conception of disability (Schalock et al., 2010) refers to the mismatch between the competencies of a person and the demands of the environment.

❖ In contrast to the traditional deficits-based approach, the current paradigm leaves behind the limitations of the person and focuses on the supports and resources of the environment.

existence of new demands

involves new lines of work and research aimed at developing good assessment and planning practices, not only aimed at the diagnosis or classification of disability, but also aimed at planning support and improving the quality of life and self-determination of people with disabilities.

Main characteristics of the different perspectives in disability (Schalock, 2018)

Perspective	Main concepts used	Supposed "locus" of disability	Identified risk factors	Related interventions and supports	Typical elements of classification
Biomedical	- Etiology - Genetics - Organic	- Genetic-environment interaction - Health - Brain development	- Genetic or chromosomal anomalies - Cranioencephalic traumatism - Teratogens	- Special diets - Genetic modifications - Surgical procedures - Psychopharmacology interventions in mental health	- Etiology - Level of development
Psychoeducative	- Learning - Adaptive Behaviour - Intellectual functioning - Motivation	- Dynamic and reciprocal interaction between intellectual capacity, adaptive behaviour and participation	- Breeding - Absence of early intervention - Lack of opportunity for personal development and growth	- Parenting skills - Personal development strategies - Advice - Special Education - Support in making decisions - Information and support technologies	- Level of adaptive behaviour - IQ interval levels
Sociocultural	- Interaction person-environment - Social context - Attitudes of the society - Social interaction	- Functional limitations - Divergence between personal competence and the demands of the environment	- Attitudes of the society - Impoverished environments - Segregated environments	- Natural supports - Change in perceptions or attitudes of people - Enrichment of the environment - Adaptation of the environment	- Intensity of the necessary supports
Justice	- Discrimination - Legal rights - Human rights	- Organization of the society - Government structures	- Social inequality Injustice - Discrimination - Denial of rights	- Affirmation of rights - Person-centred planning - Judicial decisions	- Designation of: Capability/Incapability Suitable/Not suitable for the privileges of being a citizen

Inclusive responses to people with disabilities

According to Thompson et al. (2004), there are five trends that characterize inclusive responses to people with disabilities (Thompson et al., 2004):

1. changing expectations regarding people with disabilities;

2. a functional view of disability;

3. the experience of activities and situations typical of their age group;

4. the organization of consumer-centered support services;

5. the existence of support networks in the community.

What is Empowerment?

"Empowerment is an act of building, developing and enhancing power among individuals through cooperation and working together." (Rothstein, 1995)

"The process by which a person, or a group of people, uses their personal power inherent in their condition - for example: disability, gender, age, race - to make choices and make decisions, thus taking control of their life." (Sassaki, 1995)

"A process of recognition, creation and use of resources and instruments by individuals, groups and communities, in themselves and in the environment, which translates into an increase in power – psychological, socio-cultural, political and economic – that allows these subjects to increase the effectiveness of the exercise of their citizenship." (Pinto, 2001)

What is Empowerment?

➢ Beliefs and attitudes about whether the person

feels capable of defending himself and

expressing his own rights, interests, or opinions.

(Verdugo, 2021)

The Origin of Empowerment

Fight for Civil Rights, Feminist Movement and Social Action Ideology

1970s

Self-Help Movements

1980s

Community Psychology

1990s

Law and Citizenship

Empowerment Goals

GOALS

Strengthen **rights** and **participation** of **groups**, **people** or **populations** <u>subject to discrimination and exclusion</u>, and on the other hand oversee state powers and major economic interests, and fight oppression.

Promoting the effective **participation** of citizens in **social**, **economic**, **political** and **cultural life**, and a more equitable distribution of resources.

To achieve this goal there must be also a process of power distribution

Operationalization of the Concept

The definition and operationalization of the term empowerment can be guided by three characteristics:

| 1st | access and control to necessary resources; |

| 2nd | decision-making process and problem solving skills; |

| 3rd | acquisition/modification of behaviours. |

Guiding Principles

1st	Establish a partnership relationship on the basis of equality, which implies:
	• hear what people have to say and start from that point;
	• give all the information that the professional has;
	• create a relationship of exchange, give and receive;
	• ask both to the professional and the person with disability;
	• maintain a balance of power between the professional and the person with disability.
2nd	Always contextualize the individual situation in the individual environment.
3rd	Focus on expanding the capabilities/resources of the PwD and their environment.
4th	Respect the pace of the person or the group and maintain the continuity of the process.
5th	Base the actions on the preferences and needs of the persons or the groups.
6th	Always encourage active person with disability participation in all decisions and actions.

Stages of Empowerment Process

The empowerment process requires time and opportunities to exercise skills and rights, and to learn new attitudes. Therefore it takes place in several phases:

Awareness by the individuals or groups in situations of exclusion from their lack of power	**Identification with other** individuals or groups in a similar situation	**Survey of skills and resources** needed to a better control in their lives	**Decision to act** in concrete areas

Key Concepts in Empowerment

Autonomy as a condition of dominance in the physical and social environment, preserving the privacy and dignity of the person who exercises it as much as possible;
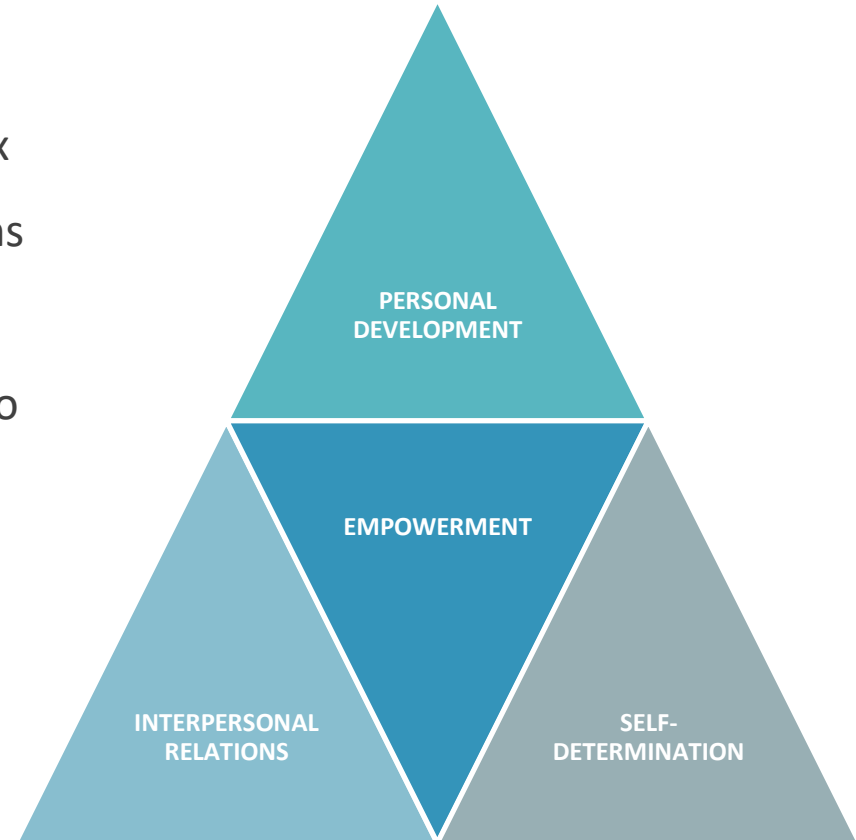
Suspension of the disbelief in the capacities of people and groups. Avoid negative ratings and customer infantilization.

Advocacy and negotiation of the rights of persons or groups excluded or diminished in power. At the beginning of the process the professional has a more active role, but then must delete himself so that customers take into his hands his own representation.
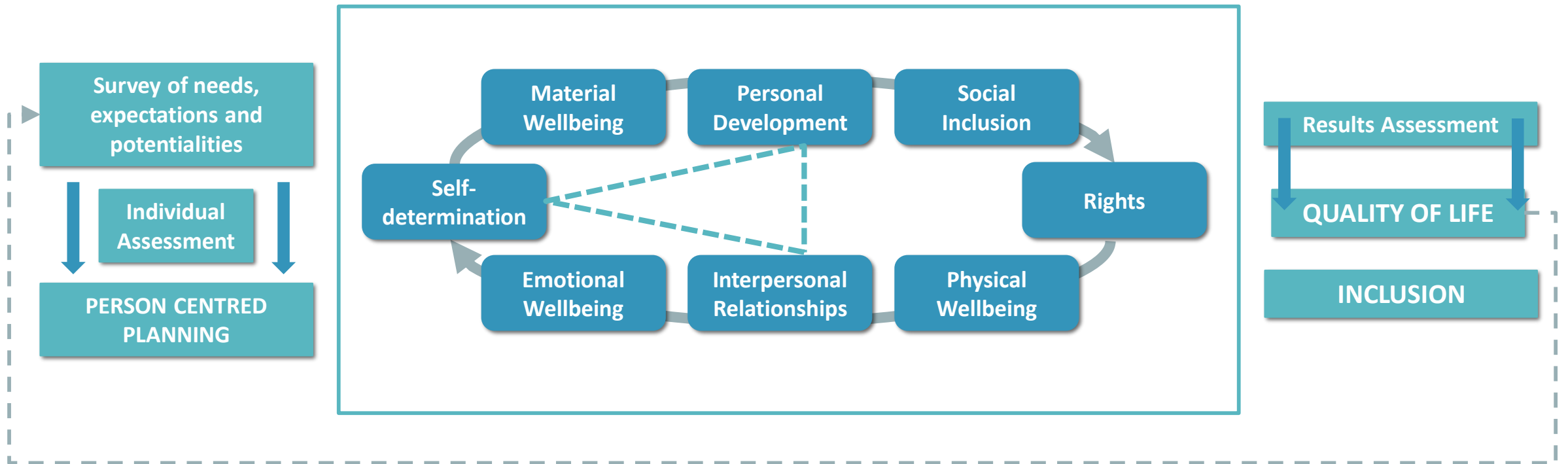
Validation, recognition of the capabilities of expression of the needs and interests of people by themselves and from there to any other aid process.

Empowerment and Quality of Life in APPC

With regard to the assessment of measures to promote empowerment, this is established through its effectiveness index based on the weighted average of the following three dimensions of quality of life: Self-determination, Personal Development and Interpersonal Relations, since the increase in autonomy, ability to choose, decision-making, personal skills and competence, based on relationships of equality and power sharing, lead to a higher rate of individual success.

The Empowerment Process in APPC Faro

Empowerment is a **multidimensional social process** through which **people gain control over their own lives**.

It is a process of recognition, creation and use of resources and instruments by **individuals, groups and communities**, **in themselves and in the environment**, which translates into an **increase in power - psychological, socio-cultural, political and economic -** which allows these subjects to **increase the effectiveness of the exercise of their citizenship**.

It is based on three perspectives:

- influencing the thinking of others (**power over**);
- making decisions and making choices, with access to resources and assets (**power to**);
- resist the illegitimate power of others (**power of**).

Environment of Empowerment

The institution ensures an environment of empowerment through the systematic training of its human resources in this area, more specifically, through the dissemination of associated strategies and recommendations:

- ✓ Encourage customers' self-confidence;
- ✓ Promote the ability to choose and make decisions;
- ✓ Share responsibilities;
- ✓ Support whenever necessary;
- ✓ Recognize attitudes and behaviors;
- ✓ To positively reinforce customer achievements.

Operationalization of the Model at APPC

Through **person-centered planning**, where in a systematic way we seek to promote a **vision of the person with disabilities as an active element of the society** that integrates, we develop concrete actions in the contexts in which the person is inserted.

Our guiding principles are:

a) the central role of the person in defining the planning process and identifying the goals to be achieved;

b) the systematic involvement of the family;

c) the emphasis on the individual's abilities and potentials and not on his limitations and disabilities;

d) and the focus on contexts, services, support and routines available in the community.

In this way, the planning and organization of the services provided are developed in a support system that seeks to promote social inclusion and the quality of life of customers.

Rights of Persons with Disabilities

People with disability represent a particularly vulnerable group in terms of defense and guarantee of rights.

Traditionally, it has experienced situations of exclusion that constitute a clear violation of the rights contained in the Convention on the Rights of Persons with Disabilities (UN, 2006).

EVERYONE HAS THE RIGHT TO ALL RIGHTS AND FREEDOMS, WITHOUT DISTINCTION OF ANY NATURE.

Universal Declaration of Human Rights (1948, United Nations)

PRINCIPLES

They recognize the dignity and inherent value of all members of the human family and their equal and inalienable rights as the basis for the foundation of freedom, justice and peace in the world.

Rights of the Person with Disability

https://www.youtube.com/watch?v=7i_ZJxVhdhU

How can we support adults with a profound disability to promote awareness of their rights?

Strategies for creating awareness about the Rights of the Person with Profound Disability

We can use some strategies to increase the awareness about Rights for people with profound disability:

- ✓ Rights letter with symbols;

- ✓ Photographs;

- ✓ Videos;

- ✓ Drafting individual plan with the family/ individual person;

- ✓ Delivery of letters of rights;

- ✓ Educational activities;

- ✓ Roleplaying activities;

- ✓ …

Strategies for respecting the Rights of the Person with Profound Disability

→ Staff has specific training on ethics and respect for the rights of persons with disabilities;

→ Staff treat the person with respect:

- Speaking with a proper tone;

- Avoiding infantilizing the PwD;

- Avoiding negative comments in public;

- Not talking about the PwD as if they were not present.

→ The rights of the person are respected;

→ The person knew their rights.

Strategies for respecting the Rights of the Person with Profound Disability

→ Staff respect the intimacy of the PwD:

- Knocking on the door before entering;

- Closing the door during the hygiene activities;

- Having a space to be alone if they want;

→ The PwD material goods are stored in a personal space;

→ The sharing of information and image is respected according to the will of the person;

→ It is provided all the legal documentation, subsidies and benefits to which they are entitled

by law.

Promotion of awareness about fundamental Rights with Adults with a Profound Disability

https://www.youtube.com/watch?v=1slaf-Ut_4U#action=share

APPC's Examples

Client Charter of Rights and Duties:

- Simplified chart (more simple language)

- Pictographic chart (with Augmentative & Alternative Communication symbols)

Right e.g.:

- Confidentiality of all mine clinical information and

    identifying elements that respect me.

- Keeping it secret about my information.

APPC's Examples

Access:

- Available in all rooms of the institution;

- In the institution's structural documents:

  - Rules of Procedure

  - Service contracts

  - Individual Plan.

APPC's Examples

Strategies:

- Daily Activities;

- Self-Determination and Self-Representation Group Sessions;

- Individual Meetings.

Exercise

Working in small groups based on concrete practical assignments (per country group) - **90 minutes**

Through your experience:

1. Give two examples of your organization's strategies to promote the rights of people with disabilities.

2. Explain how the person with a disability is empowered in the examples given above.

3. How does your organization apply the results obtained by promoting the rights of people with disabilities to promote a more fair and inclusive society (give an example)?

Empowerment vs. Power

Power comes from a variety of sources: social, economic, political and cultural
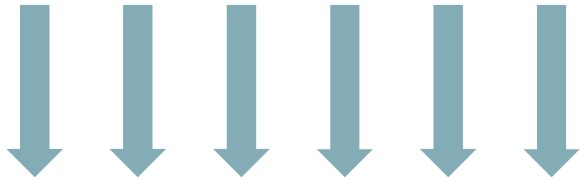
Power Redistribution

Dominating/Dominated Interaction

Static View of Power

Domination/Submission

"To Deny People Their Human Rights Is To Challenge Their Very Humanity."

-Nelson Mandela