



# SELF-IN

SELF-MANAGEMENT  
LEARNING PROGRAMS (SLP),  
QUALITY OF LIFE,  
METACOGNITIVE PROCESSES  
AND MOTIVATIONAL ORIENTATION  
FOR PEOPLE WITH  
INTELLECTUAL DISABILITIES

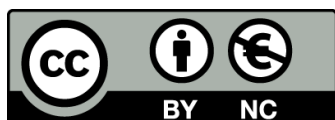
**Workbook for course designers and trainers**



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## INTRODUCTION.

SELF-IN (A Self-management learning model to foster the Independence of people with intellectual disabilities) is a "Cooperation for innovation and exchange of good practices" project developed within the key action "Adult Education" of the Erasmus+ programme. The association for the cooperation is formed by three partners: GROEP UBUNTU (Belgium); University of Padua (Italy); and the Valencian Institute of Social Services - IVASS (Spain).

This educational resource (Workbook) is intended as a didactic support for educators in the field of intellectual disabilities to design, implement and evaluate self-management programs from a meta-cognitive approach. That is to say, the SELF-IN project promotes the improvement of independence, self-determination, and social inclusion of People with Intellectual Disabilities (PwID) through the design and implementation of innovative self-management programs.

To this end, this workbook addresses, in its first two units, the relevance and scope of the concept of self-management in the field of intellectual disability, both from a theoretical and practical standpoint. The third didactic unit focuses on the inclusion of the metacognitive approach, as an educational methodology, within self-management programs.

Self-management programs are spaces where PwID meet, discuss, and learn how to take part in our society. Likewise, the concept of self-management (Sandjojo, 2019) refers to all the cognitions and actions of a person that deliberately influence his or her behavior with the aim of achieving previously selected outcomes.

The didactic unit 1 "Self-management, the Quality of Life model and independence of PwID" deepens, from a theoretical perspective, on those elements of the Quality of Life model of Schalock and Verdugo (2002 and 2012) with a greater link to the concept of self-management (independence factor and dimensions of self-determination, and social inclusion). In addition, other relevant concepts in the framework of self-management are explained, such as the context in which a person takes part, the differences between self-management and self-advocacy or the concept of independent living. Likewise, using "The European Framework for Personal, Social, and Learning to Learn Key Competence" (LifeComp, European Commission, 2020), the key competences needed (learning to

learn, growth mindset, empathy, communication...) to enable people with intellectual disabilities to fully participate in self-management programs are discussed in depth. Finally, Unit 1 explores the different methodologies for the evaluation of self-management programs and acquired competences, **including a competence evaluation tool produced by the project itself (Annex 1. SELF-INCA tool).**

The didactic unit 2 elaborates on the concept of a self-management program from a practical approach, explaining the different phases of implementation of a self-management program and including two real case studies (Annex 2. IVASS and Cercioeiras Case Studies)

The main innovation of this project is addressed in the didactic unit 3 and lies in the integration of metacognition methodologies as pedagogical reinforcements within the self-management programs with the objective of improving the key competences that PwID need to participate in the aforementioned activities. The concept of metacognition is understood as a person's ability to use his or her previous knowledge to plan a strategy to perform a task; applying the necessary steps to solve the problem; reflecting on and evaluating the results; and modifying, if necessary, the personal approach used (Flavell, 1976).

Finally, it should be remembered that this educational resource (PR1) is complementary to the other 3 SELF-IN products whose main features are summarized in the following table and can be downloaded for free at the project's website: [https://www.ivass.gva.es/es/Erasmus\\_SELF-IN/Educative\\_resources.html](https://www.ivass.gva.es/es/Erasmus_SELF-IN/Educative_resources.html).

**Table 0. Map of all intellectual products of the SELF-IN project.**

Name	Features	Target audience	Languages
<p><b>PR1</b> Self-management learning programs (SLP), quality of life, metacognitive processes and motivational orientation for people with intellectual disabilities.</p>	<p>Two sections:</p> <ul style="list-style-type: none"> <li>• Theoretical and practical content on the concept of self-management and meta-cognition.</li> <li>• Group dynamics.</li> </ul>	<ul style="list-style-type: none"> <li>• Educators and other direct care professionals in the field of intellectual disabilities.</li> <li>• Designers and coordinators of training actions and programs.</li> </ul>	<ul style="list-style-type: none"> <li>• English.</li> <li>• Spanish.</li> </ul>
<p><b>PR2</b> SELF-IN course for people with intellectual disabilities.</p>	<ul style="list-style-type: none"> <li>• 20 exercises to improve the skills needed to participate in self-management programs. Several exercises developed within the framework of meta-cognition are included.</li> <li>• Guide for the development of a 25-hour course using the 20 exercises.</li> </ul>	<ul style="list-style-type: none"> <li>• People with intellectual disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>• English.</li> <li>• Spanish.</li> <li>• Flemish.</li> </ul>
<p><b>PR3</b> SELF-IN conclusions.</p>	<p>Results of the impact achieved by the project on the participants, people with intellectual disabilities.</p>	<ul style="list-style-type: none"> <li>• Designers and coordinators of training actions and programs.</li> </ul>	<ul style="list-style-type: none"> <li>• English.</li> </ul>
<p><b>PR4</b> MOOC (Massive Open Online Course)</p>	<p>Recorded lessons and other educational resources produced by the SELF-IN project on self-management and meta-cognition.</p>	<ul style="list-style-type: none"> <li>• Educator and caregiver staff.</li> <li>• Social workers.</li> <li>• Occupational therapists.</li> <li>• Psychologists.</li> </ul>	<ul style="list-style-type: none"> <li>• English.</li> </ul>

**Source: SEF-IN project.**



## DIDACTIC UNIT 1

Self-management, QoL model and independence of PwID: a theoretical  
approach

University of Padua

## **1.1. UNIT OBJECTIVES**

1. Elaborating the self-management and QoL model: independence, independent living, social inclusion and self-determination.
2. Defining the influence of the context of PwID in the learning process related to self-management (independence, self-determination and social inclusion).
3. Defining the competences of PwID needed to take part in SLP. Framework (LifeComp: flexibility, growth mindset, critical thinking, and managing learning).
4. Elaborating the evaluation methodology and tools to assess the competences of PwID.
5. Elaborating the SELF-INCA competences assessment tool of PwID.
6. Specifying the references.

## 1.2. INTRODUCTION

The EU Strategy for the Rights of Persons with Disabilities 2021-2030 states the need to contribute to supporting persons with intellectual disabilities (PwID) to maximize their independence. Moreover, the UN convention on the rights of persons with disabilities states the respect for individual autonomy and independence, including the freedom to make one's own choices, to increase social inclusion.

Regarding disability, but not limited to it, the transition from assimilation and integration models to social inclusion models has been increasingly emphasized by several scholars and professionals in the field (Nota & Soresi, 2017). Integration has been emphasized from the idea of 'assimilation' of individuals with disabilities in regular schools and work contexts. Integration means to 'do it together with and involve services and specific professionals to support the permanence of people with difficulties inside everyday living contexts, respecting the characteristics of people with disabilities. The socio-economic changes associated with the increasing globalization and multi-diversity of most societies lead to the belief that a new change of pace and the need to move towards processes of social inclusion are needed (Soresi, Nota & Wehemeyer, 2011).

The new social paradigm of inclusion underlines the need to reflect on, analyze and expand the competences necessary to achieve the efficacious, fair, and cooperative inclusion of PwID in their different and natural life contexts while at the same time avoiding discrimination and forms of isolation (Soresi et al., 2011). Attention is also focused on the contextual characteristics and variables that, in the interaction with every individual's uniqueness, can determine different levels of social, civil, and professional participation (Shogren, Wehmeyer, Schalock, & Thompson, 2016). Inclusion, in this perspective, focuses on the context: it involves the ability to live in environments that allow everybody to participate actively and have a satisfying life (Soresi et al., 2011).

The concept of inclusion is related to the one of dignity. Inclusion involves the recognition of human dignity in all its expressions, as is stated by the Universal Declaration of Human Rights, adopted by the United Nations General Assembly on 10 December 1948. The Preamble states that the "recognition of the inherent dignity and the equal and inalienable rights of all members of the human family is the foundation of freedom, justice, and peace in the world." Therefore, human dignity is the founding value

of the global order, with the consequence that all Member States are obligated to promote the satisfaction of every person's fundamental rights (Griffo & Mascia, 2019). Applying the principles and values of human rights inclusion implies that every person, with no distinction and valorization of his/her uniqueness, can own and exploit all of the rights and fundamental freedoms underlined by the International Rights and the democratic constitutions. There is the involvement of civil, political, economic, social, and cultural rights, from the right to life to equality, freedom of thought, conscience and religion, work, health, education, and so on.

As maintained by Shogren and Shaw (2016), social inclusion processes should highlight the need to favour the participation, agency and freedom of choice in one's different life contexts of all individuals so that they may experience the quality of life, health and interpersonal relationships. In addition, for these authors, social inclusion processes require a careful analysis of any individual's strengths, such as those abilities and skills that can be used and implemented through person-environment interaction. Such strengths can favour outcomes linked to participation no longer understood as the mere presence of PwID in different contexts but rather as their satisfaction with the experience of active participation in their life contexts.

Within this perspective, increasing PwID's abilities to independently manage their affairs could enhance their quality of life, social inclusion, and participation (Dollar, Fredrick, Alberto, & Luke, 2012). Furthermore, it could reduce behavioural problems (García-Villamisar, Dattilo, & Matson, 2013) and the need for support from professionals and family members who often feel overburdened (Hermsen, Embregts, Hendriks & Frielink, 2014).

**Figure 1.1. Inclusion and self-determination process.**



***Inclusion is a complex process that involves*** the following:

- Ensuring the participation of people with vulnerabilities in community activities.
- Promoting the ability of all people with vulnerabilities to break down discrimination.
- Facilitating the inclusion of people with vulnerabilities in community settings.

***Self-determined behaviours causes people:***

- Perceive that reality cannot be controlled in any way;
- Perceive a certain degree of control over the events that happen to them;
- Perceive that only others can control what happens to them.

***Generally, the more a person is self-determined:***

- The more it strives to achieve personal goals;
- The more he commits himself to show others how much he is committed;
- The more he strives to gain prestige and power.

***Self-management refers to the following:***

- Feel like protagonists of their own future;
- To think that you can do anything you want;
- To the fact that only very few people can accomplish what they want.

**Source: own elaboration from different sources**

### **1.3. THE SELF-MANAGEMENT AND QOL MODEL: INDEPENDENCE, INDEPENDENT LIVING, SOCIAL INCLUSION AND SELF-DETERMINATION.**

As mentioned above, to increase PwID's social inclusion and participation, particular emphasis and attention have been paid to the constructs of self-management, self-determination, and quality of life.

#### **Self-management.**

The concept of self-management refers "to a variety of activities related to deliberately changing or maintaining behaviours to achieve self-selected outcomes" (Sandjojo et al., 2018, p. 841). It can be conceptualized as an overarching term related to self-determination, autonomy, independence, and self-reliance.

Self-determination and autonomy are centred around having personal control over making choices and decisions to lead one's life according to one's interests, free from external influences (e.g., Tonkens & Weijers, 1999; Wehmeyer, Kelchner, & Richards, 1996). Independence and self-reliance include abilities to take actions to manage one's affairs and to provide for oneself, thereby relying on one's efforts, resources, judgement and abilities without requiring help and support from others (Sandjojo et al., 2018).

Self-management includes both making self-selected choices and having the capacity to shape one's behaviour to achieve the personally desired outcomes. What is valuable for PwID in terms of self-management is that they have to learn to do more by themselves, thereby becoming more independent. This should be the main goal, as this could enhance their overall quality of life and their participation and inclusion in social contexts (Dollar et al., 2012; Sandjojo et al., 2018).

#### **Self-determination.**

Self-management is strongly related to the concept of self-determination, which involves having personal control over making choices and decisions to lead one's life according to one's preferences without being wholly subjected to external influences (Sandjojo et al., 2020).

As Cottini (2016) reported, several definitions of self-determination can currently be found in the literature. One of the first was provided by Deci and Ryan (1985). They defined self-determination as an individual's ability to make choices after considering various prospects and using their choices to determine their actions. Deci and Ryan (1985, 2000) maintained that before the ability to achieve self-determination is a 'need' for independence, competence, and affiliation that has to be satisfied, and to be achieved, requires not only an individual to have a series of skills but also a favourable context and a range of social supports. The importance of considering personal and contextual aspects of self-determination was also maintained by Wehmeyer and Bolding (2001). By focusing his attention on the self-determination of individuals with and without disability, Wehmeyer (2006) defined self-determined behaviour as "volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (p. 117). Self-determined behaviours are expressed in different areas (future decisions, everyday activities, expressing feelings and ideas) and contexts (work, school, home, hospital) of an individual's life (Nota et al., 2007). Lastly, Shogren et al. (2015) defined self-determination as the tendency to act as the causal agent in one's life in service to own goals.

Researchers established a link between self-determined behaviour and adult life outcomes, including quality of life. For instance, Lachapelle et al. (2005) found that the essential characteristics of self-determination predicted quality of life in 182 PwID from four different countries (Canada, the United States, Belgium, and France). Nota et al. (2007) also confirmed this link for the Italian population, who studied 141 PwID and showed positive correlations between self-determination, social skills and quality of life. Shogren et al. (2015), involving 779 young adults with disability, found that self-determination predicted positive outcomes in achieving employment and community access. Wehmeyer and Palmer (2003) in a study with 94 young adults with learning and intellectual disability, observed that participants with higher levels of self-determination managed better multiple life categories, including employment (in terms of access and type of contract, part-time or full-time), financial independence and independent living. Wehmeyer and Schwartz (1997) showed that young people with learning and intellectual disability who presented higher levels of self-determination were likely to obtain employment more quickly and earn more than peers with lower levels of self-determination.

## **Independent Living.**

To be able to understand the concept of independent living, we should look back at how it started as a social movement. During the 1970s, Ed Roberts and other people with disability attended the University of California, Berkeley. These people lacked some of the privileges that other non-disabled students had, and as a result of this unfairness, Ed founded the independent living centre with the federal fund he got and developed it into an independent living movement via his work. From a historical standpoint, the concept of independent living can be defined as a movement that emerged in the late 1960s and early 1970s when people with disabilities began to play a larger role in the issues and decision-making mechanisms that affected their lives at the local, national, and international levels. When we use the term "independent living," we should keep in mind that it might signify different things and meanings to different people, organizations, and disciplines. The independent living (IL) field is one that allows persons with disabilities to live independently and regulate their own lives. The concept and approach have applications in rehabilitation, education, and other disciplines of human services. The concept implies that people with severe disabilities need to control their own life in order to become independent. While emphasizing a person's freedom, it refers not only to the individual's decisions or actions but also to the relevance of the person's society and environment." (Budde and Bachelder, 1986). Independent living is increasing in importance as a demand of disabled people's movements across the globe. Tarrant (2022) suggests that independent living complements the social model of disability to ensure that the 'we' of the people's with disability movement is able to retain a focus on the 'I' of the individual; and highlight the work of resistance and identity reconstruction that independent living performs. Tarrant (2022) argues that a fundamental aspect of independent living is its creation of 'repaired' social identities for people with disability which resist dominant narratives of otherness, deficiency and dependency and liberate people's agency.



## **Quality of life.**

Over the past two decades, the concept of quality of life has assumed an essential role in studies on PwID, as well as a construct that allows to verification of social policy, program support to individuals and groups, and public service (Schalock et al., 2002). Furthermore, it helps to develop environments that enable all people to access regular contexts and resources, emphasizing the crucial role of the work context (Schalock et al., 2002). As regards the meaning of the quality of life concept, Schalock et al. (2002) considered the term “quality” as related to human values, e.g. happiness, satisfaction and health, and the term “life” as referred to the essential aspects of human existence, e.g. health, family and work.

The QoL concept includes values related to equity, empowerment, self-determination, and inclusion (Schalock & Verdugo, 2012). This concept is also person-centred. From this perspective: (a) QoL needs to be discussed with the person (Reinders & Schalock, 2014); (b) personal development pertains not only to realized outcomes but also to the processes involved (Sen et al., 1997); and (c) nobody is excluded from the QoL enhancement process based on cognitive impairments (Brown et al., 2013; Mansell & Beadle-Brown, 2012; Nussbaum, 2006, 2009).

Regarding the concept of quality of life, as mentioned in the Consensus Document (2000), there is a lack of consensus among researchers regarding a universal definition of QoL (Brown & Keith, 2000); however, most definitions of QoL share these common features: general feelings of well-being, feelings of positive social involvement, and opportunities to achieve personal potential. Traditionally, domains frequently used to define QoL include physical well-being; emotional, psychological, or mental health/well-being; social relationships; productivity; social inclusion, and rights (Brown & Keith, 2000; Schalock, 2004).

According to Schalock, Verdugo and Braddock (2002), QoL is a multidimensional phenomenon. It includes eight dimensions: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being, and material well-being. Furthermore, thanks to cross-cultural data (Wang et al., 2010) and data obtained from Spain (Gomez, Verdugo, Arias, & Arias, 2011) they identify three higher-order factors. These are independence (consisting of personal development and self-determination: e.g., activities of daily living, choices, decisions, personal goals), social participation (composed of interpersonal relations, social

inclusion, and rights: e.g., social networks, friendships, social inclusion/community involvement, human rights), and well-being (formed from emotional, physical and material well-being: e.g., safety and security, health and nutrition status, financial status, employment).

**Figure 1.2. Conceptual model of individual Quality of Life**



*Figure 1.* A conceptual model of individual quality of life.

**Source: adapted from Schalock et al., 2016a**

The conceptual model of QoL theory presupposes a contextual understanding of disability as a condition that results from interacting individual and environmental factors. This approach mentions two kinds of factors: moderating and mediating. A moderator variable is a qualitative (e.g., gender or race) or quantitative (e.g., IQ or SES) variable that influences the direction or strength of the relation between a predictor and an outcome (Baron & Kenny, 1986). While a mediator variable affects the association between an independent variable and a result and shows indirect causation, connection or

relation (Baron & Kenny, 1986). The third component of this conceptual model involves enhancement strategies. They surround developing personal talents, maximizing personal involvement, providing personalised support, and facilitating individual growth opportunities.

The QoL framework emphasises the necessity to incorporate the systems perspective (Bronfenbrenner, 1979) because people live in several systems (micro, meso and macro) that influence the development of their values, beliefs and attitudes (Schalock, 2004). The micro-system refers to the immediate social context: family, home, peer groups and the workplace, which directly affects one person's life. The mesosystem includes the neighbourhood, community, service agencies and organisations that directly affect the functioning of the micro-system. Finally, the macro-system reflects the vast cultural patterns of culture, socio-political and economic systems. Only if we work in all these three areas we can reach our goal: improving the QoL of PwID.

Recently, also Wehmeyer (2013) stated that the quality of life is a multidimensional construct, conceptualized in the same factors and relationships between them, and in subjective and objective components, which refer to the possibility to meet the needs of people and the opportunity to pursue improvements in a major life activity setting. This conceptualization can be applied to all people, even to those with intellectual disabilities. In this project, in particular, we consider the subjective component of quality of life, i.e., life satisfaction.


Life satisfaction refers "to a judgmental process, in which individuals assess the quality of their lives based on their own unique set of criteria" (Pavot & Diener, 1993). Although it does not represent the multidimensional nature of the concept, life satisfaction is a common measure of the quality of life and a means to assess the relative importance of individual quality of life domains (Schalock & Felce, 2004).

Stable and lasting life circumstances can affect life satisfaction (Diener & Biswas-Diener, 2002). Still, significant and recent life events like losing a job are more likely to strongly impact life satisfaction (Lucas, 2004). In addition, literature on life satisfaction found that having a favourable cognitive judgment of own life is positively related to better emotional, social, and behavioural health, enhanced social relationships, and social participation and inclusion (Sun & Shek, 2013).

Fortunately, societal views on the human rights of PwID have changed significantly over the last 40 years. In 2006, the United Nations Convention on the Rights of Persons with Disabilities substituted the Standard Rules (UNCRPD; United Nations 2006). These acts state the socio-political conditions for achieving equality, autonomy, non-discrimination, participation and inclusion in society. Before the UNCRPD, there were other Conventions that tried to re-affirm the rights of people with disabilities, but these never became international treaties and were not legally binding.

As matter of fact, this convention is crucial because it calls for rehabilitation, living independently, education, health, work and employment, and other measures to promote the independence and QoL of people with disabilities. It is consistent with the ecological model of disability proposed by the American Association on Intellectual and Developmental Disabilities (AAISS; Luckasson et al., 2002; Schalock et al., 2010). Indeed, the QoL conceptual and measurement framework provides that template and allows organisations and systems to implement QoL-related enhancement strategies that impact the desired results of the Conventions. The UNCRPD also encourages a powerful monitoring mechanism to ensure accountability for appropriate programme and policy planning.

**Figure 1.3. Sentences of satisfaction in life.**

<p><i>The following are some sentences related to satisfaction in life. There are no right or wrong answers; please, express your point of view exclusively.</i></p> <p><i>Read each statement carefully and indicate your agreement or disagreement.</i></p>	
<p>1. Often, the life of adults with disabilities with whom I operate is close to their ideal of life.</p>	<p>AGREE      DISAGREE</p> <p>Why?</p>
<p>2. The conditions of adults with disabilities with whom I operate are excellent.</p>	<p>AGREE      DISAGREE</p> <p>Why?</p>
<p>3. Most adults with disabilities with whom I operate are satisfied with their life.</p>	<p>AGREE      DISAGREE</p> <p>Why?</p>
<p>4. Most adults with disabilities with whom I operate so far have gotten the important things they want out of life.</p>	<p>AGREE      DISAGREE</p> <p>Why?</p>
<p>5. For most adults with disabilities with whom I operate, if they could relive their lives, they would change almost nothing.</p>	<p>AGREE      DISAGREE</p> <p>Why?</p>

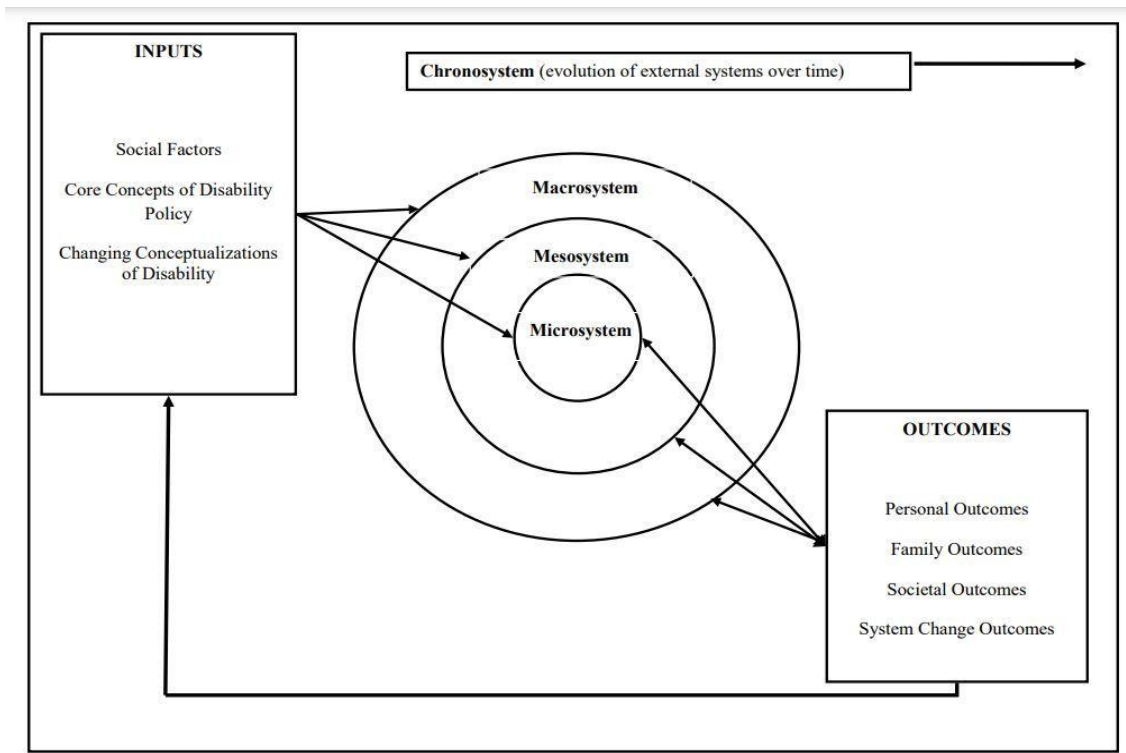
**Source: own elaboration.**

#### **1.4. THE INFLUENCE OF THE CONTEXT OF PWID IN THE LEARNING PROCESS RELATED TO SELF-MANAGEMENT**

While there is a growing view that people with intellectual disabilities should participate as fully as other members of society, our society is also becoming more complex. Social developments, such as higher demands at work, the digitalization of our society, globalization, the recent COVID-19 pandemic, environmental risks, etc., are related to the increasing difficulty of PwID to function independently and can negatively impact their possibility to have meaningful active life within their communities (Fesko et al., 2012; Netherlands Institute for Social Research, 2014). Altogether, this requires context involvement to make them more independent and self-determined. Recently, Shogren, Luckasson, and Schalock (2012) proposed a consensus definition of context, hoping to provide direction for beginning to think systematically about the influence of context on human functioning. The definition states: *“Context is a concept that integrates the totality of circumstances that comprise the milieu of human life and human functioning. Context can be viewed as an independent and intervening variable. As an independent variable, the context includes personal and environmental characteristics that are not usually manipulated, such as age, language, culture and ethnicity, gender and family. As an intervening variable, the context includes organizations, systems, and societal policies and practices that can be manipulated to enhance functioning. As an integrative concept, context provides a framework for describing and analyzing aspects of human functioning, such as personal and environmental factors, and supports planning and policy development”* (Shogren et al., 2014).

In this project, we focus on supporting staff to promote self-management in PwID. Indeed, there is a lack of research focusing on how to support staff can be trained to improve their clients' level of self-management and quality of life. For example, suppose support staff stimulates clients to do things themselves instead of taking over. In that case, this could reduce clients' dependency, passivity, and "learned helplessness" (Sigafos et al., 2005), regardless of whether someone has a mild or severe intellectual disability (Ramdoss et al., 2012).

**Figure 1.4. Context of human functioning: inputs and outputs.**



**Source: Retrieved by Shogren (2013).**

## 1.5. SELF-ADVOCACY

Over the past decades, special attention has been paid to the ability of people with intellectual disabilities to achieve social change through self-advocacy, contrasting oppression and discrimination experienced by them (Capri & Swartz, 2018; Goodley, 2000).

Van Reusen et al. (1995) defined self-advocacy as “the ability of an individual to effectively communicate, convey, negotiate, or assert one's interests, desires, needs, and rights. The term assumes the ability to make informed decisions. It also means taking responsibility for those decisions” (p. 6). More recently, Stodden et al. (2003) described self-advocacy as the ability to recognise and communicate one's needs and to choose how to achieve them. Perhaps, the development of self-advocacy is associated with the ability to make decisions, be independent and take responsibility (Ryan & Griffiths, 2015). It is also associated with self-management and self-determination, being a basis to foster active participation in social contexts (Burke et al., 2020; Shogren et al., 2022).

Starting from the definition of self-advocacy, Test et al. (2005) indicated four components of this construct: *knowledge of self*; *knowledge of personal and community rights*; *ability to communicate* one's interests, desires, needs and rights; *ability to be a leader*. As regards the *knowledge of self*, refers to the knowledge of one's disability in terms of strengths and limitations, as from this awareness, a person with a disability would have to articulate reasoning to achieve his or her wishes (Hartman, 1993). It is, therefore, a self-directed decision-making process: the individual knows what he or she wants and how to achieve it. Concerning the *knowledge of personal and community rights*, through speaking up and standing up for themselves and others in the same living conditions, self-advocacy by people with intellectual disabilities aims to redress inequalities and discrimination (Beart et al., 2004). As regards the *ability to communicate* interests, needs and rights, when people with intellectual disabilities make themselves heard they can be treated with respect because they show that they are able to think about their lives, make choices, and express opinions (Callus et al., 2022; Mineur et al., 2017). Moreover, self-advocacy fosters the ability to *lead* people with intellectual disabilities and facilitates the creation of a safe space where people can be together, support each other and create positive change (Caldwell, 2010; Ellem et al., 2021).



Beauchamp and Kiewra (2004) pointed out that ‘self-advocacy skills are very important for students with disabilities and are essential for students to be successful in life after high school’ (p. 165). Indeed, self-advocacy has been studied since the middle school or high school period (Barrie & McDonald, 2002; Battle, Dickens-Wright, & Murphy, 1998; Zickel & Arnold, 2001); over time, studies have shown that self-advocacy correlates with academic success, performance, persistence, and higher levels of adaptation to college (Adams & Proctor, 2010; Getzel & Thoma, 2008; Hadley, 2006; Murray et al., 2014; Thoma & Wehmeyer, 2005). Self-advocacy impacts also on the subjective perception of well-being and, specifically, on their external conditions in terms of new friendships and expanded social networks, opportunities for paid or non-paid work, and access to information and resources (Tilley et al., 2020). Focusing on new friendships and social networks, Bear et al. (2004) found that the positive social environment provided by self-advocacy fosters the creation of new relationships, becoming a new source of emotional support for people with intellectual disabilities. Moreover, self-advocacy could help people to cope with difficult phases in their life, providing a support network (Power & Bartlett, 2018).

Self-advocacy evolves over time, depending on external factors that regard contexts and the availability of suitable staff (Henderson & Bigby, 2016). One of the problems that many people with intellectual disabilities experience is the need for support in doing what they would like to do (Callus et al., 2022). In particular, Daly-Cano et al. (2015) found that the basis of self-advocacy skills is family, educators, and peers. Several authors support the hypothesis that the development of self-advocacy can be fostered by the family (Dowrick et al., 2005; Murray et al., 2014; Murray & Naranjo, 2008). Family influence can be positive, encouraging the student to succeed, but it can also discourage goal achievement due to overprotection (Dowrick et al., 2005; Janiga & Costenbader, 2002). In a study by Murray and Naranjo (2008) with students with disabilities, the results also underlined the influence of educators in the development of self-advocacy.

Following the social model of disability (Oliver & Barnes, 1998), people who have been given a disability label are seen as the ablest people to explain the effects of a disabling society and, in this way, self-advocacy becomes a continually progressive and emancipatory activity (Goodley, 1997). Indeed, hearing about the experiences of other people with disabilities who have performed certain actions and activities is an important aspect of self-advocacy (Callus et al., 2022).

In this framework, the peer groups can influence the development of self-advocacy, through the observation of patterns (Dowrick et al., 2005). In a study, Anderson and Bigby (2017) found that participating in self-advocacy groups allows group members to have respectful relationships, interesting activities, and a sense of belonging and control. Related to this aspect, self-advocacy allows people with intellectual disabilities to have more sense of control in their life (Callus et al., 2022). Furthermore, it has been observed that self-advocates can challenge stereotypes through a power shift and by exerting more control over narratives that are told about people ascribed to the label of intellectual disability (Fenn & Scior, 2019). In this way, there could be a spillover effect that broke the social stigma associated with intellectual disability (Anderson & Bigby, 2017). Finally, self-advocacy groups provide a safe psychological space for people with disabilities, that can experience different social identities, peer support and opportunities for teamworking, supporting a sense of connectedness (Fenn & Scior, 2019; Goodley, 1997; Strnadova et al., 2018).

## **1.6. COMPETENCES TO TAKE PART IN SELF-MANAGEMENT PROGRAMS: LIFECOMP FRAMEWORK.**

Personal and social competences, such as collaboration and active participation, called Life Skills by WHO (World Health Organization), appear also in the Key Competences for Lifelong Learning framework updated in 2018 within the European Council Recommendation (EU, 2018). Therefore, the frameworks of digital competences (DigComp), competences for entrepreneurship (EntreComp), and individual, social and learning-to-learn competences (LifeComp) were developed. The drafting of the LifeComp framework began with an in-depth exploration of the framework of future-oriented competences to cope with complexity, uncertainty, and change in global contexts that had a number of definitions: Life Skills, Soft Skills, Socio-Emotional and Non-Cognitive Skills, Transversal Skills, 21st Century Skills, Skills for 2030. Furthermore, for the definition of LifeComp, a preliminary mapping of the common ground of the different definitions was conducted in relation to the 2018 Council Recommendation, including identifying overlaps with DigComp and EntreComp (Caena, 2019).

The LifeComp framework refers to individual, social and learning-to-learn skills understood as a whole and applicable to all areas of life. Competences that could be acquired through experiences of formal, informal and non-formal learning and that could foster the growth of 21st-century citizens (Sala, Punie, Garkov, & Cabrera, 2020). This framework involves three areas consisting of three competences to which as many indicators are assigned (Masseroni&Ravotto, 2021) (Figure 1.5.).

In particular, the framework describes nine competences (P1-3, S1-3, L1-3) that are structured in 3 intertwined competence areas (Caena 2019; Sala et al. 2020):

- Personal,
- Social, and
- Learning to learn.

Personal, Social and Learning to Learn competence can be broadly defined as the ability to reflect upon oneself, effectively manage time and information, work with others in a constructive way, remain resilient and manage one's learning and career.

As regards the interdependence of LifeComp framework areas and components, the Personal, Social and Learning-to-Learn key competence is grounded on positive, resilient attitudes towards one's personal, social and physical well-being (personal area) and lifelong learning (learning-to-learn area) (Sala et al. 2020). This requires knowledge about what makes for healthy minds, bodies, and lifestyles (personal area), and awareness of one's own learning needs and processes (learning to learn area). It entails identifying and planning goals (learning-to-learn area) and self-motivating (personal area), seeking necessary support (learning-to-learn area), coping with stress and handling obstacles (personal area) (Caena, F., & Vuorikari, 2022). It builds on a desire to apply prior learning and experience, and curiosity about opportunities to learn and develop in a variety of contexts (learning to learn area). It includes learning and working autonomously (learning to learn area) and together (social area), as well as communicating constructively (social area): respecting and valuing the uniqueness of others, beyond prejudice and towards compromise (social area) (Ibidem). A complete view of LifeComp areas, components and descriptors can be found in Figure 1.6.

As a consequence, the inclusion of twenty-first-century competences in the community context or educational training context with people with disability (including Personal, Social and Learning-to-Learn) becomes ever more necessary. These competences are inherently transversal to subjects (Caena 2019; Griffin, Care, and McGaw 2012); promoting them needs a joint, coordinated action for alignment of policies, practices, tools and assessment across teacher teams and education systems. Recent curricular reforms in compulsory education in Europe (e.g., in Ireland and Finland) are striving towards this goal, which requires educators to be prepared to develop and model these transversal competences in the first place (Caena 2019).

## **Personal área**

- P1 self-regulation - awareness and management of emotions, thoughts and behaviour.

Self-regulation could be considered a multi-dimensional phenomenon (Pintrich, 2000). In general, it refers to ongoing interaction between the individual, the environment, and the task and includes self-generated thoughts, feelings, and actions that are planned and adapted to attain personal goals (Zimmerman, 2000). Managing feelings and emotions plays an important role in personal development by predisposing people to be open or closed to change (Deakin Crick et al., 2015). It also plays a crucial role in a person's active involvement in learning how to learn, and it is necessary for the development of other key competences (Sala et al., 2020). Moreover, self-regulation from a personal growth perspective includes persistence and grit in facing challenges and changes (Hochanadel & Finamore, 2015). It refers to the control of mental functions including emotional, social and motivational elements and the overriding of unwanted reactions to an impulse, rather than eliminating the impulse itself (Baumeister & Heatherton, 1996; Whitebread and Pino Pasternak 2010).

- P2 flexibility – the ability to manage transitions and uncertainty, and to face challenges.

Flexibility is the human ability to adapt cognitive processing strategies to face new and unexpected conditions in the environment (Cañas et al. 2003). It could imply a process of learning, that is, it could be acquired with experience and it involves the adaptation of cognitive processing strategies (Canas, 2006). Al-Atoum (2017) use the term cognitive flexibility suggesting that it is an important component of creative thinking and indicates the automatic cognitive state by changing the situation or its characteristics. This means the ability to produce various ideas about a specific problem or situation and the shift from a certain type of thinking to another when responding to a stimulus that challenges the individual's thinking (Ahmad & Khasawneh, 2021). In addition, flexibility refers to the competence of making decisions when the results are uncertain, the information available is ambiguous or there is a risk of unintended outcomes (Bacigalupo, Kamylylis, Punie & Van den Brande, 2016). Being flexible means adapting to new situations and making adjustments to face changes. It requires an acceptance attitude of complexity, contradictions, and lack of clarity (Council of Europe, 2016).

- P3 well-being – the pursuit of life satisfaction, care of physical, mental and social health, and adoption of a sustainable lifestyle

Well-being could be defined as “the engaged participation in the activities that are deemed desirable and valued in a cultural community and the psychological experiences that are produced by such engagement” (Weisner, 2014, p.90). The pursuit of life goals directly associated with the satisfaction of basic needs (affiliation, personal growth and community) is linked to well-being (Ryan et al., 1996). By adopting a systemic understanding that takes account of the interaction of multiple factors, well-being can be characterised as emerging from the dynamic integration of and relationships between the physical, cognitive, emotional, social, existential, and environmental factors (Sala et al., 2020). This includes the satisfaction of three innate psychological needs (Ryan & Deci, 2000): autonomy, the need to feel responsible for one’s own; competence, the need to produce a desired result and experience mastery; and relatedness, the need to feel connected to others.

### **Social area**

- S1 empathy - the understanding of another person’s emotions, experiences and values, and the provision of appropriate responses.

Empathy comprises three aspects (Derntl & Regenbogen, 2014; Hoffman, 2003): the ability to recognise emotions and mental states in others (cognitive empathy); to cognitively take the perspective of others and share emotional states with them (perspective change); and the ability to offer an appropriate response to others’ emotions and mental states (emotional empathy). It is critical for deploying other social and emotional competences, and building positive relationships (Cefai et al., 2018; Cefai & Cavioni, 2014) and it can be found at the root of all pro-social behaviours, providing a basis for coping with stress and resolving conflicts (Kremer & Dietzen, 1991). As an enabler of effective interaction and collaboration, empathy represents a core foundation for intercultural competences and active citizenship; indeed, the UNESCO Working Group on Global Citizenship Education includes empathy among global citizenship competences (UNESCO/UN YAG & CUEB, 2017).

- S2 communication - use of relevant communication strategies, domain-specific codes and tools depending on the context and the content.

Communication can be defined as a process during which people interact with each other and exchange verbal and non-verbal messages (Brooks & Heath, 1985; Groogan 1999). Communication can be considered a social action because it involves a process of sharing between those who communicate; communication is also a cognitive activity because it relates to thinking; finally, communication is closely related to action, because every act of communication influences the behaviour of the communication participants (Anolli, 2006). The importance of communication skills is recognised in many fields: effective communication helps vulnerable people to make decisions about their health (Donnelly & Neville, 2008), support students in their education and career preparation (Riemer, 2007) and is an important requirement for psychological work (European Federation of Psychology Associations, 2011) to help clients interpret their story and gain new insights into their situation (Kuntze et al., 2009).

- S3 collaboration - engagement in group activity and teamwork acknowledging and respecting others.

Teamwork can be defined ‘as a set of skills that individuals use to foster the success of groups or teams’ (Hughes & Jones, 2011, p. 5). Within the world of work, the ability to collaborate is a skill that is considered crucial for success (Dede 2010; Trilling & Fadel, 2009), even when, due to technological progress, individuals work in online professions (Levy & Murnane 2012). The development of this ability is the result of a learning process that should be stimulated from the school and university context (Hart Research Associates 2010) and for this reason, it is an area of investigation in developmental and educational psychology (Hughes & Jones, 2011). Teamwork skills have positive effects on job satisfaction (Batt, 2004), on individuals' job performance (Benderset al., 2001) and general personal development (Kuh, 2008; Hughes & Jones, 2011).

## Learning-to-learn area

- L1 growth mindset - belief in one's and others' potential to continuously learn and progress.

The growth mindset refers to the belief that one's mental capabilities can be developed; it contrasts with a fixed mindset, which is typical of those people who think that their intellectual capabilities can be immutable (Dweck, 2013). People who possess a growth mindset are able to set goals and commit themselves because they believe that their intelligence can be improved and developed (Dweck & Yeager, 2019). Consequently, having a growth mindset is correlated with academic success (Aronson et al., 2002) and with the perception of challenges as opportunities to enhance one's intelligence (Blackwell et al., 2007).

- L2 critical thinking - assessment of information and arguments to support reasoned conclusions and develop innovative solutions.

Critical thinking can be defined as the ability to use strategies that increase the possibility of achieving a desirable outcome (Halpern, 2013). It is a process of reflection that requires logic (Paul, 1992). Most definitions of critical thinking include concepts such as logic, judgement, reflection and mental processes (Fischer & Spiker, 2000). Research in education should focus on 'how' to think rather than 'what' to think (Daud & Husin, 2004); this belief is supported in education because thinking critically can support a person's functioning and development (Tsui, 2002). Indeed, critical thinking helps to reason and evaluate the arguments of others and try to solve complex problems (Allegretti & Frederick, 1995).

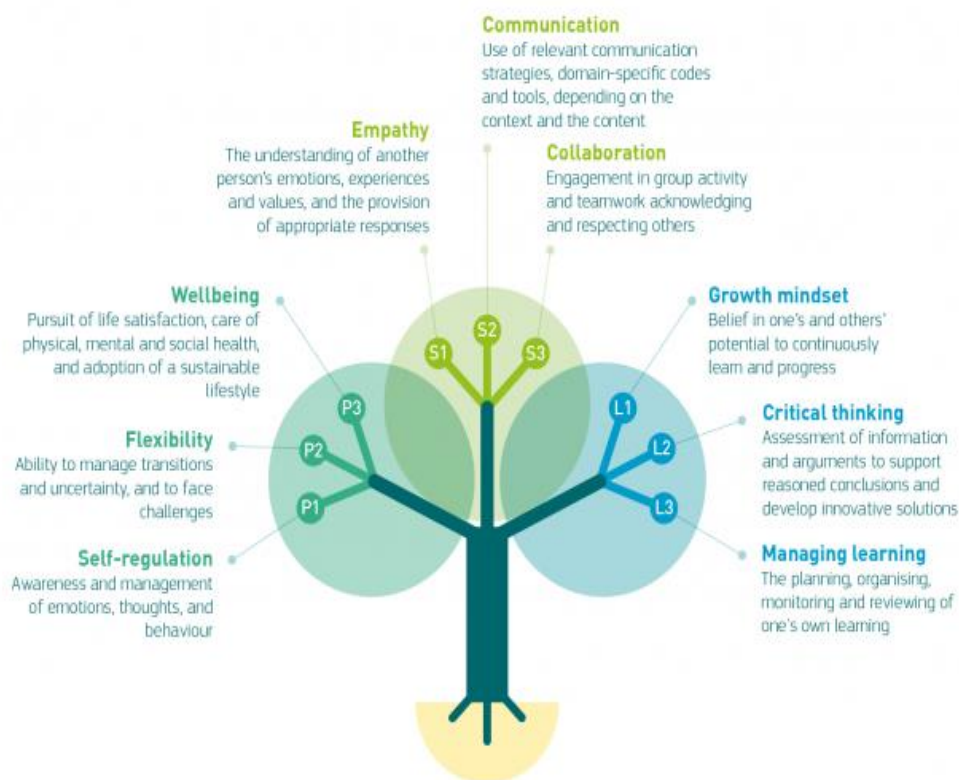
- L3 managing learning - the planning, organising, monitoring and reviewing of one's learning.

Skills at managing learning concern the scheduling of time for learning and the management of the learning process itself (Del Valle & Duffy, 2009). From the perspective of educational psychology, the correct use of these functions requires knowledge of the conditions of learning (Gagné, 1990). The capacity for goal-setting, self-monitoring, self-instruction, and self-reinforcement is referred to as



self-regulated learning (Schraw et al., 2006). It is a self-directed process that enables the transformation of mental abilities into skills (Zimmerman, 2002). People who possess this ability are able to understand their learning strengths and weaknesses (Isaacson & Fujita, 2006).

**Figure 1.5. LifeComp at a Glance.**



**Source: LifeComp**

LifeComp Tree of competences describes nine competences, organised into three areas: The "personal" area (P1, P2, P3), the "social" area (S1, S2, S3) and the "learning to learn" area (L1, L2, L3) © EU 2020, creative commons (CC BY 4.0)

**Figure 1.6. LifeComp key competence components and descriptors (Sala et al. 2020).**

AREA	COMPETENCES	DESCRIPTORS
PERSONAL	<b>P1 Self-regulation</b> Awareness and management of emotions, thoughts and behaviour	P1.1 Awareness and expression of personal emotions, thoughts, values, and behaviour
		P1.2 Understanding and regulating personal emotions, thoughts, and behaviour, including stress responses
		P1.3 Nurturing optimism, hope, resilience, self-efficacy and a sense of purpose to support learning and action
	<b>P2 Flexibility</b> Ability to manage transitions and uncertainty, and to face challenges	P2.1 Readiness to review opinions and courses of action in the face of new evidence
		P2.2 Understanding and adopting new ideas, approaches, tools, and actions in response to changing contexts
		P2.3 Managing transitions in personal life, social participation, work and learning pathways, while making conscious choices and setting goals
	<b>P3 Wellbeing</b> Pursuit of life satisfaction, care of physical, mental and social health; and adoption of a sustainable lifestyle	P3.1 Awareness that individual behaviour, personal characteristics and social and environmental factors influence health and wellbeing
		P3.2 Understanding potential risks for wellbeing, and using reliable information and services for health and social protection
		P3.3 Adoption of a sustainable lifestyle that respects the environment, and the physical and mental wellbeing of self and others, while seeking and offering social support
SOCIAL	<b>S1 Empathy</b> The understanding of another person's emotions, experiences and values, and the provision of appropriate responses	S1.1 Awareness of another person's emotions, experiences and values
		S1.2 Understanding another person's emotions and experiences, and the ability to proactively take their perspective
		S1.3 Responsiveness to another person's emotions and experiences, being conscious that group belonging influences one's attitude
	<b>S2 Communication</b> Use of relevant communication strategies, domain-specific codes and tools, depending on the context and content	S2.1 Awareness of the need for a variety of communication strategies, language registers, and tools that are adapted to context and content
		S2.2 Understanding and managing interactions and conversations in different socio-cultural contexts and domain-specific situations
		S2.3 Listening to others and engaging in conversations with confidence, assertiveness, clarity and reciprocity, both in personal and social contexts
	<b>S3 Collaboration</b> Engagement in group activity and teamwork acknowledging and respecting others	S3.1 Intention to contribute to the common good and awareness that others may have different cultural affiliations, backgrounds, beliefs, values, opinions or personal circumstances
		S3.2 Understanding the importance of trust, respect for human dignity and equality, coping with conflicts and negotiating disagreements to build and sustain fair and respectful relationships
		S3.3 Fair sharing of tasks, resources and responsibility within a group taking into account its specific aim; eliciting the expression of different views and adopting a systemic approach
LEARNING TO LEARN	<b>L1 Growth mindset</b> Belief in one's and others' potential to continuously learn and progress	L1.1 Awareness of and confidence in one's own and others' abilities to learn, improve and achieve with work and dedication
		L1.2 Understanding that learning is a lifelong process that requires openness, curiosity and determination
		L1.3 Reflecting on other people's feedback as well as on successful and unsuccessful experiences to continue developing one's potential
	<b>L2 Critical thinking</b> Assessment of information and arguments to support reasoned conclusions and develop innovative solutions	L2.1 Awareness of potential biases in the data and one's personal limitations, while collecting valid and reliable information and ideas from diverse and reputable sources
		L2.2 Comparing, analysing, assessing, and synthesising data, information, ideas, and media messages in order to draw logical conclusions
		L2.3 Developing creative ideas, synthesising and combining concepts and information from different sources in view of solving problems
	<b>L3 Managing learning</b> The planning, organising, monitoring and reviewing of one's own learning	L3.1 Awareness of one's own learning interests, processes and preferred strategies, including learning needs and required support
		L3.2 Planning and implementing learning goals, strategies, resources and processes
		L3.3 Reflecting on and assessing purposes, processes and outcomes of learning and knowledge construction, establishing relationships across domains

**Source: LifeComp.**

## **1.7. COMPETENCES EVALUATION TOOL: SELF-INCA TOOL.**

The starting point for constructing the SELF-INCA TOOL (Annex 1) was to verify the presence of existing scales assessing Lifecomp. We used a bibliographic search conducted in the scientific databases (SCOPUS and PsycINFO) to do this. The keywords chosen for this search were "Lifecomp Scale" and "Lifecomp Measure". The research was conducted in English by two research team members separately. A time range between 2020 and 2023 was used for the selection of the articles. This allowed us to exclude all publications that preceded the Lifecomp framework proposed by the European Union (2020). Unfortunately, probably due to the recent publication of the Lifecomp framework, the search did not produce satisfactory results.

Therefore, we repeated the search using the same scientific databases, but each competency considered the outcome of the self-management training: critical thinking, empathy, assertive communication, efficient communication, self-regulation, flexibility, collaboration, growth mindset, and learning management. The keywords considered were the names of the competencies followed by "scale" or "measure". This allowed us to identify several articles which we analysed.

The analysis of the articles made it possible to identify several valuable measures to evaluate the constructs. As a result, 95 items emerged from this examination to form an initial version of the SELF-INCA TOOL. The items were identified by analysing the scale's psychometric properties and referring to Cronbach's alpha reliability index, considering a minimum value of 0.70. Some items were adapted to the target. All subsequent steps were carried out directly in English, avoiding the need for back-translation that could have further altered the meaning of the chosen items. To assess

whether the items adequately represented the investigated constructs, four experts dealing with competence development and knowledge in the field of psychometrics were contacted. They were asked to assess the clarity and redundancy of the items separately. The experts were asked to give a rating on a scale from 0 to 10, and the average for each item was calculated with respect to clarity and redundancy. Items that were within a threshold of 7.5 were considered unclear or redundant. Following this analysis, 26 items were eliminated because they were considered unclear or redundant.

In a second step, we asked four other experts to assess the correspondence with the assessed construct for each of the remaining 69 items. Each Expert was asked to match the item with a construct that he or she thought was assessed by that item. The item was eliminated when the match was less than 75% (less than three experts). This second phase allowed us to eliminate an additional 13 items, resulting in an instrument of 56 items (between 5 and 8 items per scale).

Finally, to make the instrument homogeneous and not too long, we decided to keep only five items for each construct, choosing the items that were the best compared to the experts.

The final instrument consists of 45 items. First, the subject must read statements and indicate how well the participant in the self-management training can master them. The answers must be given on a 7-level Likert scale (from 0 = Not yet competent, not yet demonstrated appropriately, to 6 = Expert, demonstrated proficiency as expected of a highly experienced. Demonstrates outstanding knowledge, skill, and delivery of this competence).

Self-Inca tool can be found in annex 1 of this document.

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## DIDACTIC UNIT 2

### Implementation of self-management learning programs (SLP): a practical approach

Instituto Valenciano de Servicios Sociales - IVASS

## **2.1. UNIT OBJECTIVES**

- To understand why PwID need to participate in self-management groups.
- To know how to implement self-management learning programs step by step.
- To know effective methodologies to work in self-management programs.
- To understand the importance of developing metacognitive skills to improve self-advocacy skills.

## 2.2. INTRODUCTION.

The new definition of Intellectual Disability of the AAIDD and the Quality of Life model of R. Schalock and M.A. Verdugo are two theoretical models that organizations adopt to plan care services.

These models mean a new philosophy to change and reorientation of care services direct.

In 1992 the then American Association on Mental Retardation (AAMR) promoted a paradigm shift in the definition of mental retardation that incorporated self-determination, inclusion, equity and community supports as aspects on which to determine the supports that people need to improve their functioning (Schalock & Verdugo 2003).

From that time to the present, the definition of mental retardation has undergone continuous revisions in successive editions of published manuals until the term mental retardation has been replaced by intellectual disability.

The AAIDD presented its first definition of the term intellectual disability in the 11th edition of its Manual "Intellectual Disability: Definition, diagnosis, Classification and Systems of support", (2010). The change of term was motivated by the very evolution of the general construct of disability which in the previous two decades had evolved from being "a person-centered characteristic or trait (often designated as a deficit) to constituting a human phenomenon with its genesis in social and/or organic factors..... that result in functional limitations that reflect an inability or limitation both in personal functioning and in the performance of roles and tasks expected of a person in a social context." The use of the term intellectual disability implicitly points to the importance of context by adopting an "ecological perspective focused on the interaction of the person with his or her environment, while highlighting how the systematic application of individualized supports can enhance human functioning." (AAIDD,2010).

Currently, "the 12th edition of the AAIDD manual (2021) incorporates the significant advances that have occurred in the field of ID over the past two decades. These advances relate to better understanding of I.D. with an emphasis on the human and legal rights of people with disabilities, including self-advocacy or self-management and empowerment" (AAIDD, 2021).

Self-determination is a key construct in understanding intellectual disability. Whemeyer and Schalock (2001) define it as: "acting as the primary causal agent in one's own life and

making choices and decisions about one's own quality of life, free from unnecessary external influence or interference." The definition implicitly refers to the relevance of quality of life for the well-being of people with ID.

There is a clear relationship between quality of life and self-determination. The concept of self-determination in relation to the concept of QOL has been the subject of numerous investigations that conclude that individuals with disabilities who exhibit higher quality of life also show higher levels of self-determination (Wehmeyer and Schalock, 2002, Wehmeyer and Schwartz, 1998).

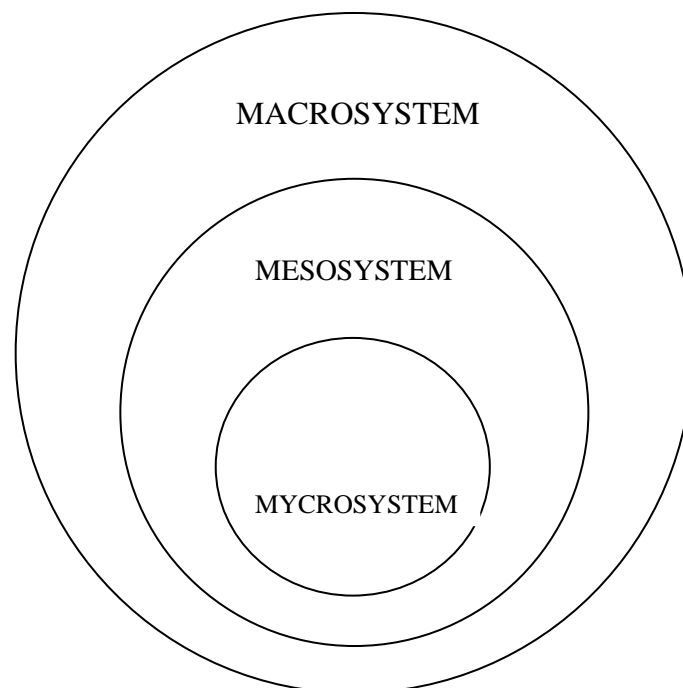
The Special Interest Research Group on Quality of Life of the International Association for the Scientific Study of Intellectual Disabilities highlighted as one of the principles for the application of quality of life: "Increase the degree of personal control and individual opportunities exercised by the individual in relation to his or her activities, interventions, and contexts" (Schalock and Verdugo 2003).

Schalock and Verdugo (2003) propose a multidimensional model of QoL that has become the benchmark for organizations and service providers. From their research findings self-determination emerges as one of the eight basic dimensions of quality of life along with: emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, social inclusion and rights.

Schalock and Verdugo's QoL model adopts an ecological approach by understanding that the concept of quality of life cannot be separated from the context where people with special needs live and interact. From this perspective, they analyze the microsystem, mesosystem and macrosystem to ascertain the needs of the person in the environments in which he/she lives.

**Figure 2.1. Ecological approach.**

<b>MICROSYSTEM</b> <i>The immediate social context, such as the family, home, peer group and workplace, which directly affects the person's life.</i>
<b>MESOSYSTEM</b> <i>The neighborhood, community, service agencies, and organizations, which directly affect the functioning of the microsystem.</i>
<b>MACROSYSTEM</b> <i>The broader cultural patterns of culture, socio-political trends, and economic systems, as well as factors relating to society, which directly affect values and beliefs, as well as the meaning of words and concepts</i>



**Source: adapted from Bronfenbrenner, U. (1979).**

Regarding the Self-Determination dimension, at the microsystem level, there is a strong call for greater opportunities for participation in life, related to a growing advocacy for inclusion, equity, choices, and self-determination.

At the mesosystem level, service and support providers are implementing quality improvement techniques focused on designing environments and support programs that provide opportunities for choice and control (e.g., lights, temperature, privacy, and personal space), and encourage choices, personal control, and personal decisions and goals.

At the macro system level, numerous legal standards uphold the rights of people with disabilities with respect to the self-determination dimension. As a result, we are seeing how some self-advocacy organizations have emerged (Schalock and Verdugo 2003).

This ecological approach clearly advocates the need to include key dimensions and indicators of CSD that reflect the multiple systems in which all people live: micro, meso and macro.

In self-determination, indicators of autonomy stand out, understood mainly as independence of the person, choices, and environmental control.

**Table 2.1. Ecological approach: prototypical indicators of Quality of Life.**

LEVELS	SELF-DETERMINATION
MICROSYSTEM (personal assessment)	Autonomy - Self-direction - Personal control Preferences - Choices
MESOSYSTEM (personal evaluation)	Choice opportunities / Decision making Opportunities for choice / Personal control Person-centered planning
MACROSYSTEM (Social indicators)	Social policies Legislation National or international treaties and conventions Self-advocacy organizations

**Source: adapted from Schalock and Verdugo (2003).**

Everyone with ID has the right to self-determination, but their level of intellectual and adaptive functioning will determine the degree of difficulty of the skills they are able to learn.

People with severe ID may make choices in the micro-system: what do I want for breakfast; what clothes do I like; what activities do I want to do; who do I want to keep me company. These are choices that entail concrete contents in simple social situations, but that are of great value because they respect people's rights to have control over their lives.

People with moderate ID can participate in groups in which decisions are made that affect the organisation of services provided they don't have to handle complex ideas or abstract concepts. They can make decisions about which activities they can organise or understand; for example, the reasons why it is not possible to organise them and the aim needs to be changed.

People with slight ID can understand concepts involving abstract thinking when they are not excessively complex. For example, they can understand what it means to have rights, or they can understand how voting works. Their level of intellectual and adaptive functioning makes them able to form part of self-management groups in which they act as representatives of others to defend the rights of the group.

In this context, the groups of self-advocates are a promoter instrument of this change in philosophy, they are one of the actions in favor of the self-determination of people with intellectual disabilities. People with intellectual disabilities must have the opportunity, through their life experience, to develop the skills and components that make up self-determination.

The groups of self-advocates are undoubtedly an important way of developing self-determination and an opportunity to promote the paradigm of support and quality of life in associations.

The self-management groups are those places where they "train" and learn to participate, choose and produce actions aimed at being the protagonists of their own lives.

Self-defense, self-management..., related to "self-advocacy", which means that people with intellectual disabilities speak for themselves, represent themselves, are their own spokespersons, are protagonists of their lives.



### **2.3. HISTORY OF THE SELF-MANAGEMENT PROGRAMS AND ITS LINK WITH OTHER TRANSNATIONAL INSTRUMENTS.**

The history of Self-management begins at the 8<sup>th</sup> World Congress of the ILSMH (International League of Associations for Persons with Mental Deficiency, today called Inclusion International) in Nairobi in 1982. Already then, a group of people with intellectual disabilities presented a series of recommendations, among which was:

"A higher number of mentally handicapped people should be invited to take part in the committees and act in the commissions".

In 1985, the ILSMH issued a position statement entitled "Participation in family and community life", which is one of the most important documents of the history of self-management.

At the General Assembly of "International Inclusion" held in Cork, Ireland in 2001, this organization urged all its member organizations to "encourage self-advocates to participate in its affairs and decision-making. People with intellectual disabilities have chosen the term "self-advocates" to clearly show their determination to take control of their own lives as much as possible, and to live alongside the rest of the community."

In addition, it is necessary to highlight, above all, the Convention on the Rights of Persons with Disabilities approved by the United Nations General Assembly on December 13, 2006. Article 3. General principles, explicitly refers to the freedom to make one's own decisions and to full and effective participation and inclusion in society.

Currently, there are numerous groups of self-advocates supported and reinforced by institutions and associations around the world.

## **2.4. METACOGNITIVE METHODOLOGIES AND OTHER STRATEGIES TO DEVELOP THE SKILLS RELATED TO SELF-MANAGEMENT PROGRAMS.**

People with intellectual disabilities have the right to participate in the life of their community and make decisions, just like other citizens. To exercise these rights, they need to learn some skills quite related to metacognitive strategies such as:

- Make decisions and choose in everything that concerns them in their lives.
- Decide for themselves (with the necessary support in each situation).
- Interact and relate to people inside and outside the family.
- Experience mistakes and disappointments and be helped to understand and manage feelings related to them (for example, tolerance of frustration).
- Have the experience of successes that promote the feeling of self-efficacy.
- Be representatives of themselves.

We often observe that these skills are at the basis of decision-making, making choices, learning from one's own experience and being a representative of other people.

In our project, it might be stated that metacognitive skills are considered relevant for the PwID to develop the skills to decide, choose and represent, as well as to increase the effectiveness of self-management groups.

## 2.5. PHASES OF A SELF-MANAGEMENT PROGRAM

- Preparation/design.
- Roles of organizations, professionals, and families/legal tutors.
- Profile and selection process of PwID to take part in the program.
- Objectives of self-management programs.
- Benefits: participants, educators, and organizations.<sup>1</sup>
- Implementation: activities included and methodologies to be used in a SLP.
- Monitor, evaluation, analysis, and final report.
- Dissemination of self-management programs.
- Integration of SLP in the educative plan of the center.

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<sup>1</sup> (Based on Feaps, 2013)

### **2.5.1. Preparation/design**

Previously to start the self-management program, several steps must be done. In this section, we talk about how to engage the organization to support the program, what are the profiles of educators and PwID to participate in it, which objectives a self-management program must pursue and the benefits organizations and PwID may get.

## **2.5.2. Roles of organizations, professionals and families/ legal tutors.**

### **a) Roles of the organization.**

The support model and the Quality of Life model give full meaning to self-determination and from them arises the philosophy that organizations must assume when self-management groups are created within this context.

In practice, the organization must incorporate the philosophy of self-management into its objectives, mission, and vision. All the components of the organization, from the management positions that supervise the actions to the front-line professionals that execute the plans and develop the objectives, must be aligned and committed to defending the right to self-determination and involved in developing actions so that self-determination is effective. Considering that the groups of self-advocates are a way to develop self-determined life skills, the organization must see them as the instrument through which the PwID exercise the right to self-determination.

The role of the organizations, among others, entails the commitment to support the creation of the groups, assuming that giving voice to the PwID means listening to proposals and adopting changes that affect the organizations itself. It is therefore necessary that organizations are ready to assume this change of mentality.

We take as a reference the FEAPS document, "Creation of self-management groups" to comment on the actions that organizations might develop within a self-management program:

- Incorporate the self-determination of the PwID as an objective of the organization.
- Develop group programs for self-advocates making their objectives, actions and methodologies explicit.
- Include self-advocate programs in the organization's annual plans.
- Describe indicators to evaluate the development of programs.
- Designate those responsible professionals for the groups of self-advocates who will be in charge of developing the programs.

**b) Roles of the professional who coordinates the self-management program.**

In order to coordinate the work of the different self-management groups, it will be necessary to have a professional who coordinates, stimulates, gives support and monitors the groups that are part of this network.

**c) Roles of the support professional.**

The PwID have limitations in their cognitive, practical and social skills that make the figure of the support professional necessary to guide them to understand and express themselves.

Each self-management program must have a support person, so called because their role is to offer the necessary support to each self-advocate person to make decisions, speak for themselves and participate in the organization or in their closest environment.

The support person plays a role determined by their mentality and skills. The ideal profile of this professional is explained following (FEAPS, 2013):

Attitudes:

- Must be trained in the support model and the quality of life model (QoL).
- Committed to promoting the right to self-determination.
- Respects the right of people with intellectual disabilities to make their own decisions.
- Must have an open attitude to equal treatment, support, and cooperation.
- Be able of not adopting a paternalistic attitude.
- Be aware that she is not the protagonist of the program, but a facilitator of the group demands.
- Be aware that their role is support, not control or direction.

Skills:

- Facilitate opportunities for effective decision making.
- Help self-advocates make informed choices.
- Help express different opinions.

- Facilitate a relationship based on trust, mutual respect and understanding.
- Listen carefully.
- Get to know people with intellectual disabilities well.
- Consult before speaking for the interested parties themselves.
- Encourage self-stakeholders to speak up, whenever possible.
- Respect the right to privacy of people with intellectual disabilities.
- Empathize with group members.

**d) Roles of the families and/or legal tutors.**

The family (or legal tutors) is the main provider of support for PwID. They are their reference for socialization and their security base. The family is the natural context where the needed self-determined behavior skills are acquired. There can be no effective self-determination if the PwID does not find support for it in their family environment. If the supports for self-determined behavior are only given in the context of the organization, self-determination will not be effective because it is not part of the life of the PwID, being only a mere activity that takes place within the organization where the self-management groups are developed.

In addition, family members are usually the legal representatives of the PwID, so they must be informed of the activities in which they participate.

For these reasons, it is necessary for the family to be committed to promoting the right to self-determination. From this approach, the role of the family with respect to the self-management group program is to understand that the group is an instrument for developing self-determined behavioral skills and, therefore, to support the implementation of the program within the organization.

One way for families to be aware of the need for this commitment is to be trained on the support model, the quality of life model, the right to self-determination and the philosophy of self-management. This means that the organization can expand the objectives and activities of the self-management program to include those that involve families.

### 2.5.3. Profile and selection process of PwID taking part in the program.

#### A) ACADEMIC APPROACH

The work of Sandjojo et al., (2018) might help us to concrete the profile of participants taking part in self-management training activities. According to these authors, the participant profile is “adults (<18 years) diagnosed with intellectual disabilities, and they at least had to be able to focus on instructions and exercises during the training...no minimal level of cognitive function required (e.g. regarding language skills or intelligence level).

#### B) DSM5 APPROACH

In order to assess the capabilities of people with intellectual disabilities related to their participation in self-management programs, the diagnostic criteria of DSM5, Diagnostic and Statistical Manual of Mental Disorders of the APA (American Psychiatric Association) might be useful (See table 2.2).

**Table 2.2. DSM5: concept of disability and diagnosis criteria.**

<b>Concept of disability</b>		
DSM-5 defines intellectual disabilities as neuro developmental disorders that begin in childhood and are characterized by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living. The DSM-5 diagnosis of ID requires the satisfaction of following three criteria:		
Deficits in intellectual functioning “reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience”— confirmed by clinical evaluation and individualized standard IQ testing.	Deficits in adaptive functioning that significantly hamper conforming to developmental and socio-cultural standards for the individual's independence and ability to meet their social responsibility.	The onset of these deficits during childhood.

**Source: DSM-5.**



This fifth edition of the manual adopts the philosophy of the supports model of the American Association on Intellectual and Developmental Disabilities (AAIDD, 2021). As we can see, DSM5 points out the need to offer support to improve adaptive behavior and defines the severity levels of intellectual disability (mild, moderate, severe, and profound) according to adaptive functioning and not according to intelligence quotient (IQ) scores because it is adaptive functioning that determines the level of support required.

Following the DSM5 criteria, people with sufficient capacity to form part of self-management groups are people with a low level of intellectual disability in the three domains or people with a significantly lower level in the conceptual domain than in the social and practical domains which are slightly above of the low level.

Regarding the type of support needed to improve functioning, people who need intermittent support in conceptual, social and practical skills meet the appropriate profile to participate in self-management groups.

In addition to these diagnostic criteria that we have just mentioned, others should also be considered that include personal and pragmatic aspects, such as the following:

- Link of the PwID with the organization that promotes the program.
- Motivation and interest showed in the program. It is the person who must decide if they are interested in this activity and not leave this decision in the hands of professionals who recommend their participation or relatives who want them to be included in the program.
- As a guide, the program is aimed at adults over 18 years of age, since probably the contents related to self-defense and representation make more sense after that age.
- As in other activities, it is convenient that there be gender parity in the group, this being a recommendation, since in some cases it may not be possible to achieve this parity.

### C) SELF-ADVOCATE GROUPS: WIDER PARTICIPATION

Some groups of self-advocates have also been formed with people with intellectual disabilities with extensive support needs (people with autism, people with cerebral palsy, etc.), in these cases the groups usually have a smaller number of members (six people, for example), we must pay more attention to the "rhythm" of the group, which is usually slower, and use support tools (for example, augmentative communication).

In the case of people with greater support needs, it will be necessary to make adaptations of the environment (accessibility), of the communication systems or others.

This is an added learning situation both for the members of the group (with fewer support needs, with older ones...), and for the support person who, if well managed will, undoubtedly, get a positive and beneficial experience for everyone.

Can any person with an intellectual disability belong to a self-management program?

In principle, yes, if it is clearly stated the desire to participate and belong to the group. From the theoretical foundation of the program, it is proposed that the group be started with people with disabilities with a higher level of autonomy and less need for support to guarantee a certain level of 'initial success', to show that the experience works and everyone can learn from it. Thus, the model might be generalized and extended to other groups of people with greater support needs. You learn from mistakes, but it is also very positive to have successful experiences. People with disabilities are full of experiences of failure in their lives. Therefore, it is very good and stimulating for them to have positive experiences of success.

At this point it is necessary to reflect if limiting the participation of certain people with intellectual disabilities at the beginning of the experience. This does not mean excluding these people, but rather postponing their participation in this experience until a next phase. In some cases, when working with a historically 'excluded' group, everything related to 'exclusion' is taken badly, and wrong conclusions can be drawn (prejudice).

**Table 2.3. IVASS example of participants in self-management groups.**

According to IVASS experience in self-management programs and self-determination, this type of activities should be centered on the participants, their interests, their demands and their reflections.

Therefore, those who are part of the group must show sufficient cognitive skills to understand the meaning of the program, the contents and the reflections that arise in the meetings, as well as a minimum of capacity of abstract thinking that allows the understanding of what is discussed in the group.

In this way, the selection is a key process that must be based on the evaluation of the cognitive and social skills of the candidates. Sensory or physical functional limitations do not prevent participation in the program since it is possible to overcome them by offering the appropriate support.

**Source: IVASS internal reports.**

## D) SELECTION PROCESS

### D.1. Interview of the candidates

The support person will be responsible for conducting individual interviews with people with disabilities who have expressed their interest in participating in the group of self-advocates.

The interview has three main objectives:

- Assess whether the candidate has well understood the objectives of the program or if her expectations are going in a different direction (do something fun, do a new activity...)
- Assess whether the motivation is authentic or mediated by professionals or relatives who want to enroll them.

- In addition, the interview serves to explain well what the groups of self-advocates are.

#### D.2. Selection of participants

Related to the selection of the participants, the support educator should take into account several considerations. It is important to have complete information about each candidate, which can be obtained through interviews both with the families and with professionals who have some connection and know the person with ID well (professionals in psychology, social work, social education, personnel from the area of employment, housing, leisure area, etc.). In these interviews, it is convenient to talk not only about the skills but also about the motivation and interest of the person with ID perceived by relatives and staff. With this information, the person assesses those who are close to the recommended profile that has been described earlier in this text.

#### **2.5.4. Objectives of self-management programs.**

##### **Objective linked to the organization mission:**

- To promote the self-management and self-determination of people with intellectual disabilities who regularly attend the center.

##### **Self-management program specific objectives**

###### **General:**

- To give the opportunity to the participants to know, give their opinion, participate, decide and choose on issues related to their own lives.

###### **Specifics:**

- To acquire knowledge about the issues and topics proposed by the group.
- To acquire personal and social autonomy skills.
- To acquire communication skills and skills to participate in meetings.
- To acquire skills to reflect and assess critically.
- To acquire decision-making skills.
- To acquire skills to deal with mistakes and frustration.
- To develop the feeling of self-efficacy through successful experiences.
- To acquire skills to represent oneself and others. (Participation in associative life).

## 2.5.5. Benefits: participants, educators and organizations<sup>2</sup>

### Benefits for the participants:

To have the opportunity, through their life experience, to develop the skills and components that form the self-determination. They must be able to participate in a real and active way in the contexts in which they operate, and this inclusion, this "empowerment" makes them feel valued as people: the power of what they think, do and feel is important for others.

Self-management programs are places where everyone feels accepted, included and valued: "in the SLP, I am accepted, I am one more". They are spaces for participation and listening; to meet with others and with oneself; to, little by little, discover and accept their limitations; and, at the same time, discover their abilities and learn to be responsible for their own choices and decisions.

Self-management groups ARE NOT leisure activities, nor spaces to develop social skills.

"Defending and protecting yourself means taking charge of your own life. Defending and protecting yourself means telling other people what you think, how you feel and what matters, so they can count on you. Your family, your friends, the people you work with, and the rest of the community won't know your point of view unless you tell them what you think."

(Definition stated by a self-management Canarian group).

"This self-management thing makes us realize that we have some rights, but also some obligations or duties to fulfill. It makes us more responsible, and we also have to accept that, like everyone else, we can make mistakes. We would not have this great opportunity to learn if our parents or siblings were on top of us all day, doing things for us, deciding what is best for us. That is why we increasingly

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<sup>2</sup> (Based on the Feaps, 2013)

make decisions for ourselves, since we are the protagonists of our lives".

(Eva Gómez, Congress of Families - FEAPS, Extremadura, May 2003)

### Benefits for the organizations.

The groups of self-advocates are undoubtedly an important way of developing self-determination and an opportunity to promote the paradigm of support and quality of life in associations, therefore, they are also another opportunity for change and reorientation of the care services.

## **2.5.6. Implementation: activities included and methodologies to be used in a SLP.**

### Activities to involve the organization.

As it has previously mentioned, the organization must be committed to promoting the right to self-determination and promoting self-management groups as the instrument to develop self-determined life skills.

### Presentation of the project.

The first step in implementing the program will be for the organization to learn about the project in order to get its involvement in the formation of groups of self-advocates. The project will be presented to the management team by those who defend it, who may be staff from the organization or people with management positions interested in the project moving forward.

### Approval of the project and selection of support persons.

Once the project has been approved and the commitment of the organization has been obtained, the support professional and those responsible for coordinating the program are selected. The profile of the support person and the person in charge of coordination have been already described.

### Project communication

The organization must promote strategies so that information about the project reaches all levels of the organization. Self-management groups cannot be limited to being just another activity in which to learn skills, but must be considered as active elements of the organization since they are the way in which people with intellectual disability will be represented and will make demands that compromise the organization itself.



### Constitution of the groups of self-management.

Before constituting the groups, it is necessary to decide which will be the number of the components.

It is recommended a maximum of 8 participants per self-management group. The reason for this decision is that the support educator must supervise the process of each participant. A number greater than ten people does not allow effective supervision of individual processes by the support person.

It might happen that the number of applicants is higher than ten. In that case, it will be necessary to consider how this will interfere with the monitoring and evaluation process. Therefore, it might be convenient to create a new group in charge of the same support person or to require to the organizations another professional to join the project. If for organizational reasons this is not possible, the alternative is to maintain a waiting list in case there are cancellations or finally a new group is formed.

### The meetings.

#### a) Kick-off meeting.

The selected participants are invited to the group constitution meeting.

The content of this meeting is<sup>3</sup>:

- To inform learners of the start of the self-management program.
- To explain what self-management is.
- To explain what the group goals are.
- Explain the group working dynamics.

The support person is responsible for convening the meeting by announcing the date, time, and place.

This meeting is important because it is the moment when the participants make contact with each other and with the support person.

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<sup>3</sup> Note: it is proposed within SELF-IN project to start also explaining what Erasmus is and its horizontal principles.

The structure of the first meeting is as follows:

- Presentation of the group: the support educator invigorates the group with dynamic introductions to start getting to know each other.
- Presentation of the program: the support educator presents the SELF-IN project and training course and subsequent self-advocacy program.
- Analysis of expectations: the support educator proposes group dynamics techniques for them to express what they expect from the self-management program and what they would like to find in the group. This activity is important because it helps the support professional to observe how the group relates to each other and what role each participant plays in the group. In addition, he/she can learn what skills or difficulties people have in expressing their ideas in order to provide appropriate support.
- Schedule and frequency of meetings: the group should establish the periodicity of meetings and the calendar. If the schedule is already established by the organization, the support person will inform the group.
- Standards of behavior: the first meeting is also the time to establish the norms of behavior:
  - The main rule for relating to the group is mutual respect.
  - In addition, to work in a group it will be necessary: a) ask for a turn to speak and respect it; b) pay attention to the group. Not to whisper, not to talk in small groups; c) accept the decisions of the majority; and d) attend meetings regularly.
  - Misbehavior can be penalized. If misbehavior is serious, the person may be asked to leave the program.
  - It should be highlighted that, during the kick-off meeting, a commitment to respect the rules of the group is highly recommended to be signed.
- Election of the group spokesperson. The spokesperson of the group will be elected by voting among those who express their desire to be the spokesperson.
- Inform about the content of the program: a) explanation of what self-management is; explanation of what the group goals are; b) explanation the working group

methodology; b) to inform about the activities foreseen to be carried out during the rest of the meetings (theoretical presentations to be developed; visualization of documentaries; development of educational resources; discussion groups; evaluation; visits to centers of interest; meetings with social agents...)

**Note:** within the SELF-IN project, the last part of the meeting should be devoted to inform that the first step of the program will consist in continues with a 20-hour course to acquire self-management skills (Project result 2 of SELF-IN project)

b) The rest of the meetings.

The rest of the meetings will be devoted to implement the activities explained during the kick-off meeting in order to achieve the program objectives.

### 2.5.7. Monitor and evaluation of self-management programs

The evaluation methodology proposed in this self-management program follows a double approach.

On the one hand, it is aligned with the evaluation methodology proposed by the Quality of life Model (Schalock, 2004; Schalock et al., 2008 and Claes et al., 2009) by which the evaluation of the quality of life of people with intellectual disabilities should be oriented: a) to assess the value and the quality of the self-management program based of consumer satisfaction and personal outcomes; and b) the use of the quality indicators (behaviors, perceptions and conditions that might give an indication of a person's well-being). According to this, Self-In project has focused, overall, on the implementation of those indicators related to 3 domains of the model of QoL: a) personal development (education status, personal skills, and adaptive behavior); b) Self-determination (choices/decisions, autonomy, personal control, and personal goals); and c) social inclusion (community integration, community roles and support).

On the other hand, it has been considered the educational nature of this project (Erasmus+), proposing an evaluation methodology in which the key competences to take part in self-management programs are assessed. For it, the SELF-IN project has produced and implemented a competence evaluation tool (**Self-Inca tool**) based on the LifeComp (European Framework for Personal, social and learning to learn key Competences) (Joint Research Center for Policy Report, 2020).

The proposed evaluation methodology of the self-management programs (table 2.4 and 2.5.) is a substantial part of the whole project impact evaluation which is fully explained in the "SELF-IN dissemination and impact plan" (pages 30-33).

**Table 2.4. Self-management program evaluation: activities and tools.**

Activities	Tools	Target group
2 <b>Group discussions</b> with PwID at the end of the self-management programs to assess elements related to facilitators, barriers, supports and changes of PwID participants.	Discussion guide for the final group discussions (objectives, key topics to discuss)	PwID
2 passes of an <b>accessible questionnaire of satisfaction</b> for PwID taking part in self-management programs	Accessible satisfaction questionnaire for PwID.	PwID
3 passes of the <b>SELF-INCA tool</b> (Before start training period, once finished training period; and at the end of the Self-management programs.	PR1 SELF-INCA tool.	PwID
<b>Satisfaction questionnaire</b> and expectative of use of SELF-IN resources and methodologies of participants disability educators.	SELF-IN impact questionnaire for educators taking part in SLP.	Educators
2 <b>Group discussions</b> with educators to assess the quality and usefulness of the Self-management programs.	Discussion guide for the final group discussions (objectives, key topics to discuss)	Educators

**Source: SELF-IN project**

**Table 2.5. SELF-IN Self-management programs impact activities schedule**

IMPACT ACTIVITIES SCHEDULE	2023							2024												
	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11	12	
Training activity in Padua (15 hours) for educators before starting the self-management programs	1																			
20h training course for people with intellectual disability before starting the self-management programs (implementation of PR3: 15 exercises)					1	1	1													
1 Group discussion with PwID to assess the quality and usefulness of the Self-management programs.													1							
1 Group discussion with educators to assess the quality and usefulness of the Self-management programs.													1							
2 passes of an accessible questionnaire of satisfaction for PwID taking part in the training sessions and self-management programs.								1					2							
Pass of the SELF-INCA tool 3 times. (Before start NT, once finished NT; and at the end of the SLP)					1			2					3							
Satisfaction questionnaire and expectative of use of PRs of participant disability educators.													1							

Source: SELF-IN project

Finally, the table 2.6 presents the indicator used to assess the quality of life of people with intellectual disability taking part in SELF-IN project.

**Table 2.6. Quality of life of people with intellectual disability: key performance indicator.**

Name of the indicator	<b>(KPI 1) IMPROVEMENT QUALITY OF LIFE OF PWID</b>
<b>Objective</b>	To improve the quality of life of people with intellectual disability taking part in the self-management programs.
<b>Definition of the indicator</b>	
<ul style="list-style-type: none"> <li>• This is considered the key impact of the project.</li> <li>• PwID from Ubuntu and IVASS will take part in the national training activity (NT1 and NT2) and in the self-management programs.</li> <li>• As a result, it is expected that PwID will:               <ol style="list-style-type: none"> <li>a) Acquire those key competences needed to take more advantage of self-management programs as defined in PR2 and SELF-INCA tool.</li> <li>b) Improve their self-determination and social inclusion, therefore their quality of life.</li> </ol> </li> </ul>	
<b>Goal</b>	<p>Quantitative:</p> <ul style="list-style-type: none"> <li>• Improvement of the 60% of the PwID competences linked to self-determination and social inclusion in Spanish PwID participants.</li> <li>• Improvement of the 60% of the PwID competences linked to self-determination and social inclusion in Belgium PwID participants.</li> </ul> <p>Qualitative:</p> <ul style="list-style-type: none"> <li>• Improvement of the self-determination and social inclusion of Spanish PwID participants.</li> <li>• Improvement of the self-determination and social inclusion of Belgium PwID participants.</li> </ul>
<b>Acceptance criteria</b>	<p>Quantitative: positive statistical general score mean difference of the whole sample studied.</p> <p>Qualitative: General (NOT BY COUNTRY) improvement of only one dimension: or self-determination or the social inclusion of PwID.</p>
<b>Measuring tools</b>	<ul style="list-style-type: none"> <li>• SELF-INCA TOOL (Competences)</li> <li>• 4 discussion groups (self-determination and social inclusion). 2 discussion groups in Belgium (Educators + PwID) and 2 discussion groups in Spain (Educators + PwID)</li> <li>• Satisfaction questionnaire for PwID.</li> </ul>
<b>Frequency of the measurement</b>	<ul style="list-style-type: none"> <li>• 3 SELF-INCA tool passes: 1) At the beginning of NT1 and NT2; at the end of NT1 and NT2; at the end of the self-management programs.</li> <li>• 1 pass of a satisfaction questionnaire for PwID taking part in the project at the end of the self-management groups.</li> <li>• 4 discussion groups at the end of the self-management programs.</li> </ul>
<b>Facilitator</b>	IMPACT PLAN
<b>Person responsible</b>	M.S.

**Source: SELF-IN project**

Additionally, SELF-IN project design and the evaluation methodology have been based on the following papers:

Self-management programs:

- Sandjojo, Janice & Gebhardt, Winifred & Zedlitz, Aglaia & Hoekman, Joop & Haan, Jeanet & Evers, Andrea. (2018). **Promoting Independence of People with Intellectual Disabilities: A Focus Group Study Perspectives from People with Intellectual Disabilities, Legal Representatives, and Support Staff:** Promoting Independence of People with ID. *Journal of Policy and Practice in Intellectual Disabilities*. 16. 10.1111/jppi.12265.
- Sandjojo, Janice & Zedlitz, Aglaia & Gebhardt, Winifred & Hoekman, Joop & Dusseldorp, Elise & Haan, Jeanet & Evers, Andrea. (2018). **Training staff to promote self-management in people with intellectual disabilities.** *Journal of Applied Research in Intellectual Disabilities*. 31. 10.1111/jar.12440.
- Sandjojo, Janice & Eltringham, Emma & Gebhardt, Winifred & Zedlitz, Aglaia & Embregts, P. & Evers, Andrea. (2020). **Self-management interventions for people with intellectual disabilities: A systematic review.** *Patient Education and Counseling*. 103. 10.1016/j.pec.2020.06.009.
- Sandjojo, J. & Gebhardt, Winifred & Zedlitz, Aglaia & Hoekman, J. & Dusseldorp, Elise & Haan, J. & Evers, A.. (2018). **Development of the Leiden Independence Questionnaire for Support Staff: a measure of staff behaviour regarding promoting independence of people with intellectual disabilities: Leiden Independence Questionnaire for Support Staff.** *Journal of Intellectual Disability Research*. 63. 10.1111/jir.12574.
- Sandjojo, Janice & Zedlitz, Aglaia & Gebhardt, Winifred & Hoekman, Joop & Haan, Jeanet & Evers, Andrea. (2018). **Effects of a self-management training for people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities.** 32. 10.1111/jar.12536.



## Quality of Life:

- Schalock, Robert & Bonham, Gordon & Verdugo, Miguel. (2008). **The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities.** *Evaluation and program planning*. 31. 181-90. 10.1016/j.evalprogplan.2008.02.001.
- Claes, Claudia & Van Hove, Geert & Loon, Jos & Vandeveldde, Stijn & Schalock, Robert. (2010). **Quality of Life Measurement in the Field of Intellectual Disabilities: Eight Principles for Assessing Quality of Life-Related Personal Outcomes.** *Social Indicators Research*. 98. 61-72. 10.1007/s11205-009-9517-7.

### **2.5.8. Dissemination of self-management programs.**

Objectives:

- To publicize the program.
- To make visible the capacities of the PwID.
- To show the capacity to be representatives as a valued social role.

Participation of self-advocates in dissemination: self-advocates themselves present and explain what self-management is and what is done in a self-management group.

Dissemination of self-management programs should be spread over several levels:

- a) Board of directors: formal presentation of the program to the board of directors.
- b) Professionals/educators: program presentations.
- c) Families: talks, information sessions and presentations in the association.
- d) People with intellectual disabilities: informative talks and presentations.
- e) Community / key stakeholders: take advantage of any act or event of the association to present and explain the program.
- f) Social media (Facebook, Instagram, Twitter...)

### **2.5.9. Integration of SLP in the educative plan of the center.**

To obtain board approval for the self-management program to be part of the organizational plan of each service. This is the way to demonstrate the organization's commitment to promoting self-determination.

## 2.6. BIBLIOGRAPHY

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DIDACTIC UNIT 3.  
METACOGNITION AND MOTIVATION FOR SUCCESSFUL AND SUSTAINABLE  
SELF-MANAGEMENT.

GROEP UBUNTU

### 3.1. UNIT OBJECTIVES

- The adult educator understands the concepts of metacognition, intrinsic motivation and growth mindset, and can define them.
- The adult educator is able to explain how metacognitive skills are part of the problem solving cycle, transfer and decision making.
- The adult educator is able to define the differences between a fixed and a growth mindset.
- The adult educator is able to explain why metacognitive skills and growth mindset are a challenge for PwID.
- The adult educator knows how successful self-management is depending on metacognitive skills and a growth mindset.
- The adult educator knows the characteristics of mediational interventions and understands what process metacognitive reflection means and is able to generate examples.
- The adult educator knows what environmental conditions may have a negative impact on the self-management of and knows how to overcome these conditions by creating a Laboratory for Learning.

## 3.2. INTRODUCTION

### Self-management, metacognition and intrinsic motivation: why, what, how?

**3.2.1.** Real and successful participation to society contributes to the Quality of Life of all people. The political and social environment has a very decisive responsibility in this, as they have to create conditions that enable all people to participate by open up and adapt the environment, so everyone can exercise his rights. At the same time, all individuals themselves have to adapt to this same environment and to the society, by taking into account regulations, respecting the integrity of other people, by dealing appropriately with what society expects and with simple and complex situations, challenges and problems. Education plays a significant role in this by preparing all people to become an active and successful participant and contributor to society. The complexity and the ever faster changing society set high demands on the learning ability of individuals. In this, people with a learning or intellectual disability are particularly challenged, due to unfavorable conditions inherent to the individual and the disability or due to social, environmental factors. Intelligence typically is defined as consisting of *adaptation to the environment* (R. Sternberg, 2019), and consequently, the definition of intellectual disability includes a *lack of adaptive skills* (R. Luckasson et al, 2002).

**3.2.2.** Many of the adaptive skills -as found in literature- are partially referring to but also relying on cognitive skills, necessary to function actively, independently at home, at school and in the community (Lombardi, 2019) and be successful in one's daily life. Ditterline et al. (2008) noted that these skills involve being able to independently care for one's personal health and safety, dress and bathe, communicate, behave in a socially acceptable manner, effectively engage in academic skills, recreation and work, and to engage in a community lifestyle. These skills are seen in simple planning for preparing a breakfast but also on planning of life goals (and work towards them); it is on making simple (yellow or red shirt) but also more complex choices (traveling to with who); it is on exercising rights; it is on dealing with unforeseen situations as on learning from past experiences; it is on what you can do at your home privately and on how to live together with others... In many commonly used scales and checklists based on models of the construct of adaptive behavior (see overview Lombardi, 2019), the cognitive topic is significantly present in skills referring to: problem solving, learning to learn, self-management, self-regulation or learning to learn. These skills may be seen as relying on

a (limited) set of *metacognitive skills* (see 3.3. - 3.5) that are rarely addressed in curricula or support plans, that too often only focus on contents.

Besides knowledge and practical skills (referring to “*content*”, such as what are opportunities for doing sports in the neighborhood, cooking, what to do when being sick, what are rules for living with others, what are my rights,..) it is important to be able to use these *concrete substantive skills* for making choices, for solving problems or for using in a new situation what has been learned in the past (transfer). In this learning from mistakes, taking initiative, avoiding impulsive decisions, planning, define strategy, reflecting... are all supporting the mentioned learning, problem solving, decision making processes. They are not “content” but refer to the other side of the coin: learning, problems solving, thinking “*processes*”. These *abstract general skills* (for didactic reasons we will use metacognition), contribute to the probability that a goal will be attained, a problem will be solved, a choice will be made in a well-considered way or transfer will happen.

**3.2.3.** PwID - too often - are not expected to be able to apply these processes or to acquire these processes. It is true that the acquisition and the spontaneous performance of these metacognitive skills are a challenge for PwID and their educators. But process oriented, cognitive educational approaches - e.g. Instrumental Enrichment (e.g. Feuerstein& Jensen, 1980), Bright Start (Haywood et al., 2022) or Reflecto (Gagné, 2004) - show that PwID are able to learn and to use these cognitive skills. A specific process oriented educational methodology and a modifying environment are necessary conditions (3.6. - 3.7.). At the same time, the PwID acquires (and needs) a growth mindset (3.4. - 3.5.), important as the source for intrinsic motivation to do efforts to learn, think or take initiative.

When self-management is a goal of educational efforts, to promote autonomy, independent living and Quality of Life, it is important if not necessary, to address these metacognitive skills and to work towards a growth mindset. Clearly, addressing these skills will only be successful when the PwID has already acquired these skills. Generally, PwID have little awareness of their cognitive processes. For metacognition needs to be fostered through explicit instruction (Wong & Wong, 1986; Wong et al, 1996). If not, autonomy, self-management or independence will not be found; on the contrary, helplessness will be seen.



**3.2.4.** This process oriented approach is as well applicable in a face to face support situation as in a group context such as a SLP, to create awareness on rights or to promote (self-) advocacy. An adult educator may have in mind to individually support a PwID on decision making in the context of ‘what to prepare for dinner’ and ‘how to prepare the dinner’, or when choices need to be made regarding ‘how to spend free time’, ‘how to use the public transport to go to work’. The adult educator may also be in charge to support a SLP program on sexuality or on voting, and will not only give input on the content, but will also support the process of making choices, set up a plan to realize a common goal, look and choose the resources, etc. Anyhow, in both modalities, the adult educator will create a context that is a *laboratory* for learning, thinking, making choices useful in many other situations where they can rely on these skills to show independence or self-determination.

### **3.3. METACOGNITIVE SKILLS: ORIENTATION, MONITORING AND REFLECTION IN PROBLEM SOLVING, TRANSFER, DECISION MAKING AND SELF-MANAGEMENT.**

#### **Metacognitive skills and applications.**

##### **3.3.1. Self-management**

Self-management (Sandjojo, 2019) is an overarching term involving all cognitions and actions of a person that deliberately influence his or her behavior in order to realize self-selected outcomes. Lombardi (2019) makes it more concrete, referring to the skills related to plan and organize tasks and activities, to work independently, and to self-correct behavior as needed.

*Successful self-management* relies on the *conscious* direction of mental, cognitive processes to find thoughtful *solutions to problems* or to make *well-considered choices* and decisions. In *problem solving*, the goal is to move from a problem situation (e.g. not having enough money to pay for the bus ticket) to a solution, overcoming obstacles along the way. In *decision making*, the goal is to select from choices or to evaluate opportunities (e.g. what kind of public transport helps me best to reach the sports club?). (Sternberg & Grigorenko, 2000). Also *transfer* relies on this kind of conscious direction of mental processes, when defining how to overcome a need and making choices between alternative approaches for action, experienced and acquired in the past. Those processes of problem solving, making choices and transfer, although not completely the same, share many of the same *metacognitive skills*. These processes or skills are often presented as ‘the problem solving cycle’, but –as will be explained– also refers to and includes the steps and the skills for appropriately making choices. This cycle is a heuristic and so transversally, very generally applicable: it is a general strategy and practical method for problem solving and decision making, although not guaranteeing a solution or best choice. It is, nevertheless, a sufficient and supporting approach to deal with new, complex, abstract, difficult situations. It is a strong tool, especially for contributing to self-regulation, taking initiative, and dealing with challenges and problems -often not well developed in-. For didactic reasons, we present the cycle in general (see 3.3.2.) and the associated skills as a three phases structure (Warnez, 2002;

Warnez & Kopacsi, 2011), including the potential to expand and refine the phases up to 7 steps (see 3.3.3.; Warnez et al., 2015), and so to find a match with the zone of proximal development<sup>4</sup> of the PwID.

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<sup>4</sup>The Zone of Proximal Development is defined as the space between what a learner can do without assistance and what a learner can do with adult guidance or in collaboration with more capable peers

### 3.3.2. Metacognition and problem solving cycle in general

Besides content or knowledge and practical skills, metacognitive skills are responsible for the adequacy with which people perform actions or deal with complex (cognitive) tasks, such as solving problems, making choices... Metacognition is the ability to use prior knowledge to plan a strategy for approaching a task, to take the necessary steps to solve the problem, to reflect on and to evaluate results, and to modify one's approach as needed (Flavell, 1976). Metacognitive skills have an impact on many, if not, all domains of life, as they are transversal in nature and are prerequisites for independent living, successful societal participation and *adaptation* to the environment.

With Fogerty (1994) and Sternberg (2000, 2019) we frame metacognition as a process that spans three<sup>5</sup> distinct phases, all important to be successful; this *cognitive structure* covers a general problem solving strategy, with a *mental orientation* (actions and considerations done before approaching a task or problem, including a step by step plan), a *monitored performance* (check the correct application of the plan and the progress toward the desired outcome and adapt the plan if necessary) and a moment of *evaluation/reflection* on the outcome and the process. The goal is to spontaneously make use of this cognitive structure and related skills in a conscious, *self-regulated* way, every time things are *new, difficult, challenging, complex...* Anyhow, this structure and skills contribute to autonomy and independence. They enable clients to take initiative to deal with tasks and challenges/problems, and to deal with them in a systematic and well-considered way, i.e. in a self-regulated, mentally prepared, planned, monitored and reflective way. In addition, it is at the same time a good basis for learning.

More concrete, these skills help to inhibit impulsivity (often seen in PwID) and to avoid behaviour that is not task relevant or reflect non-efficient solution strategies, such as trial and error.

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<sup>5</sup>Three phases with several subphases, to be taught and presented in an individualized and tailored way to the client; the three basic phases, however, always need to be presented as an indivisible whole (prepare, act, evaluate).

### 3.3.3. Problems solving cycle in detail – 3 phases & 7 sub-phases

#### 3.3.3.1. MENTAL ORIENTATION – be ready and prepared

##### *a. Being alert*

Alertness refers to giving attention to what actually is happening, to find if things are ok or are not. In particular, this skill refers *problem sensitivity*, intuitively feeling that something new, difficult, different, strange, wrong, etc. is happening. Alertness may lead to targeted actions, which starts with slowing down, avoid impulsivity.

##### *b. Exploring*

This is an exploration of the situation, of the feeling that something is going wrong, or, that a choice has to be made. This results in a *problem definition*. The strange feeling, the ongoing situation, the task, the problem is examined more closely, and this in a rational way, if possible with definition of the conditions and reasons that created the mistake, the bad feeling or the problem. After the exploration, it is clear what the task *requirements* are, and what good *outcome* has to be found.

##### *c. Identifying and choosing a solution/solutions or 'good' approaches*

This skill is making a choice for the *most efficient and available strategy* to deal with the situation. There are -often!- several ways of solving a particular problem.

You make a choice depending on the desired result and the task requirements, and based on previous experiences and availability.

##### *d. Planning*

After selecting a strategy, a concrete *step by step plan* is made; at the same time one may look forward and reflect on the expected outcome.

#### 3.3.3.2. MONITORING – act and check progress

##### *e. Applying the plan*

During this phase the step by step plan is performed, but - this is essential - the activity is combined with a *simultaneous and continuous monitoring* to see whether the plan is being followed as previously defined, and in particular to see whether the effort is leading to the desired outcome. If this is not the case, adjustments have to be made, by going back to previous phase.

### 3.3.3.3. REFLECTION – evaluate and look back

#### *f. Check and review*

At this point, after the step by step plan has been implemented, it is checked whether the goal and desired outcome has been achieved. Besides an evaluation of the *outcome* (right/wrong, ok/not ok, feels well/not), this skill also includes a reflection on the *way* the outcome has been achieved. A product and a process evaluation are both part of this check and review phase.

#### *g. Transfer*

This skill refers to the *link* someone makes between the actual experience, and ‘other’, past and future situations.

### 3.3.4. The role of self-regulation in the problem solving cycle

In addition to the metacognitive skills as presented in the previous section, self-regulation is a supporting metacognitive skill and at the same time an important tool for ‘full’ independence. Self-regulation refers to *self-questioning* and *self-answering* (*self-talk*) and to give yourself direction (*self-instructions*). It is what replaces the directions, instructions, guidelines of external sources, such as parents, educators.... Self-instructions are internalized instructions from external sources. Self-regulation is a critical skill for whatever is “*self*” (self-control, self-management, self-determination, self-regulation...). This metacognitive activity may be seen as *talking to yourself*. The previous chapter 3.3.3. helps us to define the content of the self-talk or *what* someone can say to themselves during the problem solving cycle.

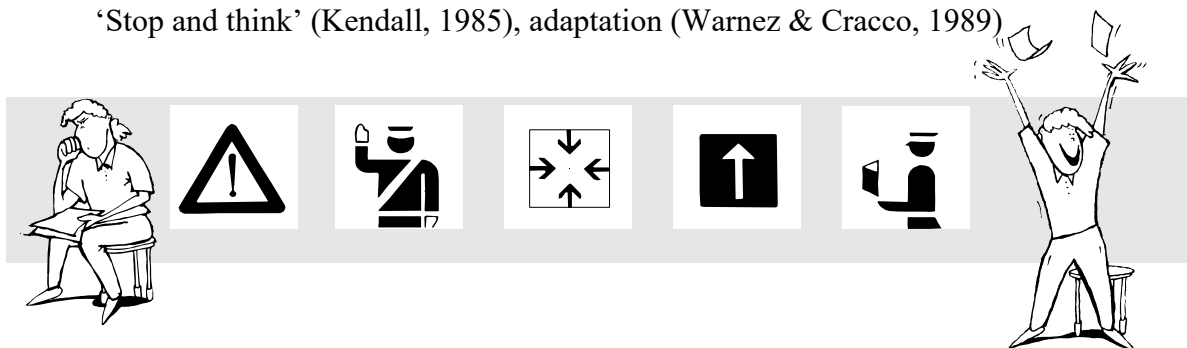
Some *examples*:

- *Being alert*: e.g. "Oops, something doesn't feel well. Stop! Something is not right here, let me have a look at it."
- *Exploring*: e.g. "What's going on here? What's wrong? Why do I feel uncomfortable?"
- *Identifying and choosing good solution(s) or approaches*: e.g. "What's the reason for this mistake? What may help here? May something that I did in the past help me here? Is there another way to approach this? What may be the best way to deal with this problem?"
- *Planning*: e.g. "What to do first? And next step? And will this work?"
- *Applying the plan*: e.g. "How am I doing? I did the first step, now I'm going to do the second. Am I still working according to my plan? Does it still feel good? Maybe I have to review my plan."
- *Check and review*: e.g. "Is the outcome ok? Did I reach my goal? Is this what I expected? Let me look at the way I did it. Was this the best approach? What did I learn?"
- *Transfer*: e.g. "How can what I have done or learned now be useful later on? How can I use this in similar contexts and in other contexts? What principle or rule can I abstract from this experience?"

### 3.3.5. Visual tools

Many educational approaches implemented with young children and low functioning people, take advantage of visual cues instead of language to guide someone through the cycle. According to Bandura (1969), a cognitive process may ‘involve two representational systems -an imaginal and a verbal one’ (p. 133). Images are alternatives for words in represent concepts or whatever content. They may be useful as guiding principles and so as instructions, not by talking but by visualizing. Some examples:

‘Stop and think’ (Kendall, 1985), adaptation (Warnez & Cracco, 1989)



‘Self-Control training’- Meichenbaum (1981); ‘Beertjesmethode’ -Timmermans (o.a.







‘Algemene vaardigheidstraining’- (vzw den achtkanter, Warnez et al., 2015)



### **3.3.6. Content and process**

It's important to understand that you cannot work on metacognitive skills in a vacuum. Metacognitive skills are always applied to a concrete context with content, to real life situations or to real problems and challenges. The content is the problem (missing the bus or wake up to late), the assignment (preparing a meal or planning a day) or a global challenge (how to make well considered choices for voting during the actual elections). The practical skills refer to what you have to do to use public transport or to prepare soup or an appetizer. The metacognitive skills and the problem solving cycle will not be helpful, when there is not sufficient knowledge or skills that you need to find a specific outcome. In this, it is important to establish this content related condition before you can expect someone to implement the problem solving cycle. To reach the railway station by bus, you need a lot of thinking (planning etc.), but you also need to know what 'taking a bus' exactly means in terms of knowledge and practical skills. You can not expect that someone will be successful in taking the bus to the railway station, the persons have not been taught what it means to take the bus and has not yet acquired the practical skill of taking a bus.

Also, the problem solving cycle *-metacognitive in nature-* needs underlying cognitive functions that supports the practical skills such as: comparing, accurate perception, time concepts, memory, classification, transformation...

### **3.4. MOTIVATIONAL ORIENTATION: GROWTH MINDSET AND INTRINSIC MOTIVATION.**

#### **Beliefs on potential and learning.**

##### **3.4.1. Intelligence, cognition and motivation.**

Many conditions, related as well to the environment as to the individual, influence one's cognitive development and functioning. One of the conditions is motivation, in particular intrinsic motivation.

A widely accepted model to understand the relationship between cognition and motivation, is the "transactional perspective on human ability" as proposed by Haywood (2010, 2020). The transactional perspective rests on the three constructs: intelligence, cognitive processes, and motivation as the foundation of human ability: (a) intelligence, which is essentially biological, largely genetic in origin and relatively resistant to change; (b) cognitive processes, defined as modes of thinking, which are acquired through experience, thus modifiable also by experience; and (c) intrinsic motivation, defined as a trait reflecting the tendency to derive personal satisfaction from information processing and action, whose development depends substantially on experience. The various ways in which these three essential variables combine form a very broad range of individual differences in learning and thinking efficiency and effectiveness.

Haywood (2010) states that the potential ('intelligence') of each individual needs cognitive skills to 'make' available the potential; at the same time, as well for the development of the cognitive skills as for using these skills, intrinsic motivation is a *necessary* condition. So, to be successful, approaches that focus on (meta-)cognitive skills, as is the case when a PwID needs to acquire skills for self-management and independent decision making, need not only to include goals related to modes of logical thinking such as problem solving and self-regulation; they also need to include goals aiming to develop personality traits that emphasize learning and thinking for its own sake and as its own reward, i.e. intrinsic motivation. Intrinsic motivation is seen in higher level of autonomy, more efficient and effective learning and problem solving and in a preference for performing self-regulated tasks without extrinsic incentives or rewards. This motivational orientation is a fundamental issue for whatever kind of autonomy, just as meta-cognitive competency, self-efficacy and attributions are

fundamental. (Graham & Berman, 2012). Also, in intrinsically motivated people, specific beliefs on their cognitive potential are found: they show evidence of a set of optimistic beliefs regarding their intelligence and learning.

### **3.4.2. Extrinsic versus intrinsic motivation - fixed versus growth mindset**

Two models may be helpful to understand the preferred motivational orientation for independence and self-determination.

One model of motivation is presented as a continuum from extrinsic at the one end to intrinsic motivation at the other: this model is mainly linked to tools used by social environment to praise or disapprove and discourage efforts and outcomes of efforts. In general, process oriented feedback on efforts supports the development of intrinsic motivation - efforts are done for its own sake and as its own reward; feedback on outcomes of the efforts will rather create extrinsic motivation - extrinsic reward is sought for desired outcomes. This model is helpful to find educational strategies for promoting intrinsic motivation.

The second model is related to implicit philosophies or beliefs that someone has about his or her personal intelligence, adaptability, learning potential, coping style, locus of control, etc. Also, these beliefs have an impact on the quantity and quality of the learning or thinking efforts done by the person. These beliefs may be seen as the 'content' of intrinsic motivation from the viewpoint of the person.

For an adequate development of self-management competence, intrinsic motivational orientation and a growth mindset show to be more powerful than the pure extrinsic reinforcement approaches. Outcomes reinforced by rewards are not long lasting (they disappear as soon as the reinforcement disappears or when a reward is not attractive anymore), and extrinsic motivation driven support is not a good basis for transfer. This is the process that refers to spontaneous, well considered performance in the future of what has been learned in the past.

### 3.4.3. A growth mindset

A growth mindset is an interesting concept as it may be seen as including an intrinsic motivational orientation and other motivational and some dynamic affective issues, as e.g. the need for a safe environment, a positive self-image, a high level of self-efficacy, etc. In line with Haywood's 'transactional perspective', and besides the metacognitive competence, a sustainable growth mindset may be seen as the other necessary condition for successful self-management. For successful self-management, one takes profit from a growth mindset, because this mindset is related to attitudes, beliefs and consequent actions that support taking initiative, adaptation, flexibility, learn from previous experiences...

Carol Dweck (2015) finds two mindset profiles -fixed and growth- to be seen as the ends of a continuum. Everyone is somewhere between the two ends, and has a mindset that is more a fixed mindset or a more growth mindset<sup>6</sup>.

In general, people with a *fixed mindset* believe that they are either born with talent or they are not, they are either naturally good at something, or they are not. They consider intelligence as a fixed trait and believe that inborn talent determines success. People with a *growth mindset* believe that talent comes through effort. They are convinced that anyone can be good at anything, and that their abilities can be developed through dedication, perseverance, and the right strategy.

Individuals with a fixed mindset seek to *validate* themselves. Individuals with a growth mindset focus on *developing* themselves.

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<sup>6</sup><https://www.youtube.com/watch?v=M1CHPnZfFmU>



A growth mindset is characterized by *openness for challenges* (novelty, complexity, difficulty is challenging and fine, while a fixed mindset looks for familiarity, ease, simplicity). With a growth mindset, people attribute successes to their efforts, responsibility and abilities (internal locus of control), while a fixed mindset tends to attribute successes to external factors. Enjoying the process of doing efforts is not a feature of a fixed mindset, as efforts are done for the reward. With a growth mindset, you believe that you are able to learn and deal with challenges, taking responsibility and initiative and... accepting risk and a feeling of not being sure... A passive attitude, waiting for instructions or help is more often found in people with a fixed mindset. Mistakes are considered as learning opportunities and invite for perseverance; with a fixed mindset, people give up and avoid mistakes.

Although this distinction may seem simple, the implications are enormous on independence, on development or on self-determination and so self-management. With a growth mindset, people believe they can develop any ability through dedication and hard work. Because of this belief, they have a desire to learn. This enables them to embrace challenges and persevere when setbacks invariably arise during the learning process.

With a growth mindset, efforts are seen as an essential ingredient on the path to mastery. They don't shy away from effort; they embrace it. And when they see others succeeding

on their path to mastery, they find inspiration and lessons to learn for their own development. A growth mindset leads people into an upward spiral of continuing developing, reaching ever-higher levels of personal mastery and achievement. As a self-actualizing person, they have more peak experiences, improved relationships, and greater productivity in their fields of endeavor. Quality of Life is the outcome...



## 3.5. METACOGNITION AND MOTIVATIONAL ORIENTATION IN PWID

### Challenges and opportunities

**3.5.1.** The need for continuous adaptation to and dealing with expectations from the environment is not obvious for people with intellectual disabilities (see 3.2.). At the same time, active citizenship and full participation requires many skills; it is a universal right for all, while every individual has the right to define this according to their own preferences and wishes. This is fundamental for one's quality of life, always referring to a very individual perception.

In general, the lack of adaptive skills, the learning problem, the complexity of the environment and the negative beliefs that social environment may have on disability are some of the conditions that challenge the PwID in the enjoyment of their (universal) rights - if one already is aware of these rights.

**3.5.2.** Beside other skills and attitudes, metacognition and an intrinsic oriented motivation play a major role when autonomy, self-management and self-determination matters. Self-management is especially related to taking *initiative* and to doing *efforts* to adapt, to be flexible, to solve problems and make *well considered* choices independently. Without claiming that everything is possible, it is known that what social environment beliefs regarding what PwID are able to learn, has as significant impact on their development and level of functioning. General beliefs on the learning potential of PwID, include - between other - a dependency on others to solve problems and make choices, not being able to acquire cognitive strategies and so not to be able to implement them... It is true that the learning process of PwID is different from people without an intellectual disability. Learning happens slower, cognitive tools are missing or not used, etc. Therefore, specific teaching strategies are required. But, when the general beliefs are not including presuming competence<sup>7</sup>, there is no reason to do efforts to teach (e.g.) metacognitive strategies to solve problems or making choices - as the

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<sup>7</sup>Presuming competence means to **assume that everyone has the capacity to think, learn, understand, participate** —even if you don't see any tangible evidence that such is the case. It's assuming no one is inherently incapable; they just need the right supports and systems to help them succeed. **Presuming competence is about giving someone a chance—and helping them take that chance in any way you can.** (b.o. : Biklen & Burke, 2006)

learner is not able to acquire these skills. For this reason, cognitive goals are very often not part of a curriculum or supports plan of our target group.

Curricula are mainly content and practical skills oriented. And so, due to this observation, they have significant difficulties with strategic processing and metacognition. (Gersten, Fuchs, Williams & Baker, 2001).

In case PwID do use strategies, often they are used in an inefficient way, or they rely on trial and error. Also, it is a challenge for PwID to generalize as transfer of a procedure learned in a specific situation, is for them not evident to be applied in a new context. They have never learnt to make abstraction of the procedure.

This perspective supports the usefulness of instruction that focuses on teaching cognitive and metacognitive strategies. However, whatever cognitive development of a person is linked to the beliefs one has about his or her ability to learn, to think, to solve problems... And so, cognitive development needs a motivational orientation that is focusing on growth and willingness to do efforts, although the outcome may be unclear or unpredictable. This intrinsic motivation supports cognitive development.

**3.5.3.** Despite the challenges mentioned in 3.5.2., it is possible to teach metacognitive strategies in PwID (Sager, 2017; Stipanovic, 2015). There is extensive evidence that increased metacognitive skills can positively influence learning outcomes in addition to learning ability (i.e., intelligence) and therefore allows the compensation of cognitive disabilities (Veenman et al., 2006) given one knows about the different strategies and how to apply them (Pintrich, 2002). This means, that these skills first need to be acquired step by step before applying and generalizing them to complex situations. (Demely et al, 2016)

In addition, for the educator working with PwID, it is a challenge to deal with and often found deficit in language, verbal tools and concepts, reducing the ability to engage in metacognition and metacognitive reflection consciously. (Farah & Badrie, 2016) This is significant, as the main approaches for cognitive development and transfer, are based on interactions, characterized by questioning, labeling and reflections, not only initiated by the educator but also expected to be initiated by the PwID.

3.5.4. Whenever *self* is at stake, as is the case in self-management or self-regulation, one needs to take initiative for thinking and doing something. Taking initiative and doing efforts not always is seen in PwID, especially when challenging situations appear or - more generally - when someone has experienced over and over again that someone else takes the lead, gives instructions, solves problems, decides or makes choices on their behalf. Also, it is much “easier” when you rely completely on someone else, who solves problems for you, who does your housekeeping... and so, waiting, not taking initiative and a passive attitude is rewarded. At the same time, this same someone else gives you the feeling not to be able to solve problems; he avoids challenges and failure with the intention to help, and so keeps you away from opportunities to learn to take initiative, to be become sensitive for problems, to learn to deal with failures... *Learned helplessness* is the outcome. Characteristics of learned helplessness are often found in: low self-esteem, lack or no intrinsic motivation, low expectations of success, less persistence, not asking for help, ascribing a lack of success to a lack of ability, attributing success to factors beyond their control, such as luck. They often believe that they are unable to control or change the situation, so they do not try — even when opportunities for change become available. Learned helplessness is often seen, and is a barrier for managing everyday duties or responsibilities. (Zimmerman, in Nickerson, 2022)

Their motivational orientation is mainly extrinsic: actions are done for rewards that are expected. The social environment helps them to avoid failure, but exactly by doing this, a low self-esteem or negative estimation of their potential is set. Not the failure or mistake itself is the reason for a negative self-esteem, but the way the social environment deals with the mistake: instead of approaching a mistake as an opportunity for learning, the educator solves the problem or corrects the error. When this happens frequently, the PwID learns that when things are new, complex or difficult or when a mistake occurs, someone else - always - comes and solves the problem. As a consequence, he learns that he is not able to deal with challenging situations. He learned to be passive. It is not the mistake or failure itself that is responsible for a low self-esteem, but the way the social environment deals with the mistake. Mistakes - except if dangerous... - don't need to be avoided but need to be seen as opportunities for learning.

And so, learned helplessness goes hand in hand with a fixed mindset, being a ‘copy paste’ of the beliefs of the social environment or educator regarding the potential and learning ability of PwID. A lot of potential is not used...

Working toward a growth mindset and intrinsically motivated PwID, believing that they are able to learn and to adapt, and accepting that they need to do efforts for this and also enjoying doing this, without fearing mistakes, is the antidote for the passive attitude and for not using their potential. As long as the hindering helplessness condition or the fixed mindset is present, whatever *self* will not be possible.

### 3.6. THE ROLE OF METACOGNITION AND MOTIVATIONAL ORIENTATION IN SELF-MANAGEMENT APPROACHES

As explained in the first unit, self-determination, self-advocacy, self-management is closely related to making choices, decision making, be independent.... These competences are basically applications of the problem solving cycle, directed by the self-regulating speech. (3.2.)

Whatever challenge on the continuum of independent living to (group) self-advocacy will be approached by goal setting, defining options and select one, producing a plan, take responsibility to work towards the goal according to the selected option and plan, and checking the outcome – all in a well-considered way. In this, the metacognitive nature of self-management is clear. Besides, taking the responsibility to work toward the goal and take initiative, will rely on the motivation to realize the goal and the client's self-confidence and self-efficacy. In this, a client showing evidence of a growth mindset, embracing challenges and realizing that positive outcomes are not guaranteed, will find the resources to produce the energy.

Whatever support a professional provides regarding independent living or self-advocacy (individual or in group), this support has several goals. It is focusing on the situation or challenge that is going on: how can the professional help the client to make well-considered choices and decide what he has in mind to realize Quality of Life. This focus on metacognitive skills, at the same time is complemented with the goal to raise awareness and enjoy rights. It means, that the support has a goal *beyond* the specific training of skills to empower the client. In addition, as a second goal *beyond*, the metacognitive competences at stake are useful in whatever situation when the client wants to realize a goal, is eager to be successful at work, to solve whatever problem, etc. This is because the metacognitive skills are transversal, and can applied in all domains of life.

Therefore, support toward independent living or self-management learning programs are referring to contexts that are created with a specific goal (unit 2), but that has a significant potential to be a Laboratory of Learning, where skills are addressed that are important for PwID to be and become independent and being the director of one's life.

### **3.7. INSTRUCTIONAL STRATEGIES AND ECOLOGICAL CONDITIONS TO IMPROVE METACOGNITIVE AND MOTIVATIONAL PROCESSES FOR SELF-MANAGEMENT.**

#### **From theory to practice: methodology**

##### **3.7.1. Introduction - conditions**

Supporting towards autonomy, independent living, self-determination... needs strategies that deal as well with the content - knowledge and practical skills regarding mainstream services, housekeeping or *rights* - as with the tools someone needs to profit from this knowledge and skills. Self-management or making choices always include a content (what) and a process (how). This chapter doesn't deal with content, but with specific support strategies that help PwID to manage successfully their lives - to be understood as a huge set of all day small and big aspirations, wishes, goals and challenges. Combining the aforementioned knowledge and practical skills with specific process focused support strategies to empower PwID by creating opportunities to acquire, try out and perform prerequisite metacognitive skills, is innovative. Independent the focus or content of the group or individual support aiming to foster self-management and Quality of Life in PwID, the motivational and cognitive competences - as explained in previous sections - will be and need to be addressed.

To be successful, specific conditions need to be created. In this section, we will point to those conditions that have a strong link with the cognitive and motivational focus of the Self-In - project.

A critical prerequisite for success is linked to the *beliefs* of the educator and the social environment on the learning potential and the social rights of PwID<sup>8</sup>. According to Sandjojo (Website HandicapNL, 2022) PWID are often prevented from becoming more independent, due to educators not having enough time for family members often take over.

With a presuming competence-belief system, the educator needs to acquire competences to support the PwID in the acquisition and in the performance (transfer) of the critical

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<sup>8</sup>The content of the promoting beliefs and tools to assess and explore these beliefs of the educator, are available in several languages on <https://cognitioninclusion.ensa-network.eu/project-results/> (Cognition & Inclusion, 2019, 2017–1–BE02–KA202-034722).

metacognitive skills (problem solving cycle), and to support a growth mindset. This not only refers to educational materials to teach the necessary metacognitive skills, but also cognitive educational methodologies, taking into account the intellectual challenges of PwID. The Self-In-project mainly relies on the Feuerstein based Mediation Interventions approach (see 3.7.3) as this model focuses on metacognitive reflections, useful during individual independent living support or SLP's<sup>9</sup>.

We have to recognize that metacognitive reflections will be successful, only when the participant of a SLP or whatever support focusing on independent living or self-determination, has a sufficient understanding of the metacognitive processes that are needed for successful self-management. A preceding training course may be necessary to prepare the client, for him to understand at least the basic metacognitive skills and concepts, being key for sharing reflections. This preceding training is focusing on the acquisition of the metacognitive skills<sup>10</sup>, while the SLP's and the individual or group sessions focusing on independent living, are powerful tools to learn how to apply these skills in contexts that really contribute to autonomy (including active participation or self-determination) and Quality of Life. To be a powerful tool, these support contexts need to be modified into a **laboratory** for learning, where PwID finds opportunities to try out, to learn from mistakes, to discover talents and to receive process oriented feedback from the 'mediator'. This means that the educator, working with the PwID or with the group, creates a safe learning environment where mistakes are seen as learning opportunities, encourages to do efforts to implement metacognitive skills, models metacognitive reflections, and supports intrinsic motivation and a growth mindset.

The *cognitive methodology and educational approach* for this training is a process oriented instruction approach. The methodology suggested in Self-In, is based on the Structural Cognitive Modification theory model by Feuerstein (b.o. 1980, 2010) and the consequent mediational learning experience approach (MLE), being the basis for metacognitive reflections and stimulating a growth mindset.

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<sup>9</sup>Other approaches and methodologies are also available on the Cognition and Inclusion website ([https://cognitioninclusion.ensa-network.eu/documents/45/201104-CI-IO1-Cognitive-methods-ENG\\_ITtpX19.pdf](https://cognitioninclusion.ensa-network.eu/documents/45/201104-CI-IO1-Cognitive-methods-ENG_ITtpX19.pdf)).

<sup>10</sup>See PR2 Self-In training. This chapter 3.7. focuses on what an educator can do to support the implementation of the metacognitive skills in the context of a laboratory for learning.

Next chapter provides a general overview of the M.L.E.-model, stressing upon the general educational principles as derived from the theoretical framework. Chapter 3.7.3. focuses on how to use the educational principles for metacognitive reflection.



### **3.7.2. Cognitive enrichment: creating mediated learning experiences according the Structural Cognitive Modifiability-theory of R. Feuerstein**

According to Feuerstein (e.g. 2010) a qualitative learning situation that contributes to the cognitive competence of -and so to skills that are important for self-determination, problem solving, decision making and self-management- needs to be supported by a specific quality of learning and teaching, characterized by the use of universal strategies, not depending on language modality or content. Feuerstein, deepening the theories of Piaget and Vygotsky, names this quality *mediation*, including 3 basic mediational strategies: mediation of Intentionality and Reciprocity, mediation of Meaning and mediation of Transcendence.

**3.7.2.1.** Mediation of Intentionality and Reciprocity refers to an educators deliberate effort to share the (learning-) goals he has in mind with the PwID, and will *focus, provide meaningful stimuli or contents, alert attention, alter stimulus frequency, (re-)order events, link novel information to familiar contexts*, etc. These evidences of intentionality however, are inadequate without PwID's signs of reciprocity, showing evidence of understanding the goal, willingness to contribute to the goal, responding and/or doing learning efforts, etc.

For an educator to assess the Intentionality/Reciprocity quality of the learning situation he has created, the next (non-exhaustive) set of self-reflective questions may be helpful. Each question may be answered by a simple 'yes' or 'no', but especially invites the educator to explain 'how'.

- What's the educators specific focus and/or learning goal?
- Is this goal situated within the zone of proximal development of the PwID?
- Is the goal made explicit and shared with the PwID?
- Does the training start with some moment of mental orientation?
- Does the training include an (intermediate) evaluation and/or recapitulation? evaluation of the outcome of the training effort? evaluation of the process and/or effort done?
- Does the educator use mistakes as an opportunity to learn?
- Does the educator make 'expectations' explicit?

- Is the content related to the world and the needs of the PwID?
- Are stimuli repeated to draw the PwIDs attention? Are stimuli sequenced, simplified or reinforced?
- Does the PwID respond to the offered stimuli or questions, and does he expect a response?
- ...

**3.7.2.2.** Mediation of Transcendence is characterized by interactions in which the educator goes beyond the concrete here-and-now-training situation or beyond the immediate needs of the PwID: what has been learned is generalized or linked to new future (and even to past) situations. Each learning situation is an opportunity to learn the PwID something he or she can use at other times and places. This strategy is the one that is often ‘forgotten’ as it is often believed that PwID are not able to represent future situations or to find similarities between the here and now situation and the future (or past) situation.

Mediation of transcendence is closely related to the Intentionality issue, as now the nature of the learning goals become more specific: generalisation or transfer can only be realized when the educator goes beyond the concrete content of a lesson, and focuses on the learning, thinking, metacognitive or problem solving process that supports the way the here-and-now situation and concrete content needs to be processed. So, it intentionality -in addition to what is written in previous section -includes the intention to work on a transversal, cognitive or motivational goal.

Referring to situations or experiences in the past and/or in the future is very illustrative for mediation of transcendence. Any reference to past situations (How did you solve the problem at that moment?) and any link that is made to later (Can you think of a time that you can use what you are learning now?) helps the PwID to disconnect from the actual situation. This universal strategy of Mediation of Transcendence refers to the effort of the educator to ‘leave’ the actual situation. An event can be seen as only an isolated event, but a mediational educator will give such an event transcendent (generalized) meaning by attempting to relate the event to previous and even future events of a similar nature, and thus to extract a generality.

For an educator to assess the Transcendence quality of the learning situation, the next (non-exhaustive) set of self-reflective questions may be helpful. Each question may be

answered by a simple ‘yes’ or ‘no’ but invites the educator to make explicit how this was done.

- Are there references to past situations, challenges, successes...?
- Are there references to future situations?
- Are pieces of evidence of efforts to ‘leave’ the here-and-now situation found?
- Is a (cognitive) principle made explicit?
- Does the educator implement the ‘bridging’ technique?
- Are generalization activities part of the training session?
- Does the educator invite the PwID to (re-)imagine situations?
- Are there any strategies involved? (e.g. strategies to solve problems or to remember information taught, or is the training focused on information?)
- Does the social environment know about the goals of the training?
- ...

**3.7.2.3.** Mediation of Meaning is characterized by an educator who conveys the affective and value-oriented significance of an object, an event and especially the learning goal. These efforts must create energy, intrinsic motivation to do the efforts to learn and contribute to the learning goal and to apply the skill or knowledge in the future.

The value-oriented significance of the content or the skills that are included in the learning goal or the learning activity, may refer to how the content or skill contributes to the PwIDs’ competence and/or to the contribution to his autonomy, being or becoming a full citizen, personal development, the exercitation of rights or his Quality of Life. In this way, the activity becomes meaningful for the PwID. Meaningfulness is a condition for doing efforts to learn and to use in the future what has been learned.

Besides these more objective meanings, Mediation of Meaning also may include subjective meanings, like interests, aesthetics, traditions...Also, meaning can be conveyed in a non-verbal way by expressions of evidence of value, importance, interest, beauty, excitement...

For an educator to assess the Meaning quality of the learning situation, the next (non-exhaustive) set of self-reflective questions may be helpful.

- Is the objective value of what is learned made explicit?
- Is the subjective value made explicit?
- And the functional significance?
- How does the educator motivate the PwID?
- Is the outcome a personal meaning?
- ...

According to Feuerstein, the three universal strategies mentioned above are necessary conditions for a successful learning process. He names several other supporting strategies to be seen as situation specific interventions, referring to specific situations or related to specific conditions or challenges such as e.g. PwID's characteristics. Mediation of feelings of competence, mediation of regulation and control of behavior and mediation of sharing behavior are the main supporting strategies. They refer to the effort of the educator to develop a positive estimation of self-efficacy, inhibition of impulsivity or strategies for cooperation and modeling. This sharing behavior is critical for SLP's where participants learn from each other.

### **3.7.3. Metacognitive reflection**

**3.7.3.1.** Reflection is an analysis of the performance going on. It is essentially reflection on the micro level, an awareness of the own thought processes as we complete them. It reinforces the learning process and contributes to perform better in the future because it boosts the sense of self-efficacy, being the feeling of being capable of achieving goals. As we reflect on our performance, we gain control over that performance, understanding exactly how certain outcomes came to be and what the efforts have achieved. Reflections are metacognitive in nature, and at the same time contribute to metacognitive competence, intrinsic motivation and a growth mindset; it is concerned not with assessment, but with self-improvement (Watanabe-Crockett, 2018). Also, reflections challenge us to seek out proven strategies and to test them for ourselves; it's not about trying hard and harder, but about working smarter. (Scott J., s.d.)

As metacognition and intrinsic motivation/growth mindset are closely linked and reinforce each other, we do not divide the instructions and suggestions for reflection (see b.) into suggestions for metacognition or suggestions for a growth mindset. The mindset paradigm is -as explained earlier- a cognitive perspective. It places learning in the context of our thoughts and beliefs.

#### **3.7.3.2. Suggestions for metacognitive reflection**

Based on the M.L.E.-strategies (3.7.3.), and counting on a basic level of understanding of metacognition skills and concepts, such as the problem solving cycle and a cognitive vocabulary, the educator may initiate and elicit cognitive reflections. These reflections are characterized by a firm focus on the process, not on the content. This doesn't mean that the interaction between PwID and educator ignores content: if knowledge, understanding or practical skills are missing, the educator has to introduce these tools first -content and process are two sides of a coin and are inextricably linked to each other-. You need content (what) to think about (how).

Strategies for eliciting and initiating metacognitive reflections may be categorized in 6 suggestions:

***1. The educators' interventions are (in particular) process oriented***

a. The way the educator includes this *process orientation*, is visible in his *how* or *why* questions and reflections, not in *what* or *how much* or *how fast* questions. A simple *example* of process orientation may illustrate the difference:

- Paqui, how many people are present in this (class) room?

versus

- Cinta, how can you find out how many people are present, here in this classroom?

b. The educator may express his appreciation for what the PwID is doing, but this *appreciation will focus on the process*.

Not:

-Oh, this was fast! Good, the outcome is correct! You have 9 good answers. Good job!

but rather:

-Victoria, nice to see that you made a good plan to solve this problem. Good job, I saw you slowing down when the task became more difficult.

Appreciation is for how someone dealt with the task or the challenging situation. The appreciation is not a simple 'Good Job, Loes' but also *includes information* about what the educator observed regarding the process related efforts. This supports the PwID to develop and use a 'cognitive' vocabulary that is fundamental for the PwID to reflect on his or her efforts.

c. A main strategy that illustrates this process orientation, is inviting the PwID to develop a habit of *taking time to think before* performing a task (*mental orientation*). This mental orientation is introduced by the educator when he invites the PwID to think about the content and the process of what is at stake.

- What are you expected to do? What do you need for this? What do you want to realize? Is this new to you? Is it easy or challenging? Did you do such a task in

the past? How can you solve this problem? How did you make choices in the past? What do you have to do first, and what next? What may be difficult and at what point may you make mistakes? How will you know that you are successful?...

The educator asks this kind of *questions* to the PwID, but the PwID is expected to copy these kind of statements, and after a time to ask these questions to *himself* - automatically-. This mechanism is extremely important as a metacognitive tool, that is, it helps to focus the PwID's attention on his own thinking processes and encourages him to engage in similar small conversations with himself.

This mental orientation *self-talk* contributes to the efficiency of the problem solving or decision making, and in general to autonomy, as the PwID is not depending anymore on the instructions and help of another. He has internalized this mental orientation and gives instructions to himself.

d. To the same degree, *reflection after a learning effort*, solving a problem... is significantly contributing to the learning process. The reflection is on how the PwID did the task, what made him successful? What hindered him or caused difficulty:

- Sara, how did you solve the problem? Was it easy? Challenging? Is the outcome ok? Did you feel well while doing the tasks? How did you deal with the mistake? What can you do next time to do it successfully?...

It is clear that this reflection is on the learning or thinking process, on the strategies used: these strategies are general (i.e. generalizable) principles or rules, being the real content of transfer. This rule helps to know what to do in future similar situations.

e. A very strong strategy is to always use this *cognitive structure*: whatever intervention from the side of the educator, whatever discussion or exercise can be organized in such a way that there is a moment of mental orientation before, and a moment of reflection at the end. In between, there is the monitored performance. Each lesson, interaction or training session can be divided into *three parts*. At the beginning is a planning time important to draw the attention to

- Julian, what are we going to do today? What are we going to learn today? What did we do yesterday?

- Ester, what we learned yesterday, how can this help us today?

At the end of the session the reflection includes looking at the learning outcome (goals reached? outcomes ok? difficulties experienced and successes found, feelings about all this, what kind of effort has been done...) The main part of the training session - in terms of time spent - will be the activities that have been prepared, but they are preceded by a planning time and followed by a reflection. But during the activities, from time to time, an intermediate evaluation can be organized:

- Loes, Are we doing well? Are we proceeding? What is difficult? Do you think you will reach your (personal) goal?

These actions refer to monitoring. Planning time, monitoring and reflection... are the basics of the problem solving cycle. Including these three parts and creating a habit of always thinking before, checking during and reflecting after the activity contributes to efficient problem solving and well considered decision making.

## ***2. The educator asks questions***

This suggestion is part of the previous one. It is made explicit here to stress on the importance of *questioning*. Questions invite to think, to reflect... Providing information is not enough to invite 'cognitive' behavior. It is much more 'empowering' to ask questions than to simply offer or tell information. Telling is ok for the mere transition of information, but is not enough to invite people to address their own potential. Besides, asking questions and questioning is an invitation to active involvement.

Limited verbal and/or communication skills are seen in many PwID. Questioning therefore is for many PwID challenging. And yet it makes sense to question the PwID, even when we do not expect a (verbal) reaction. It always invites -more or less- the PwID to use his imagination, and to develop an (internal) set of words and concepts that may help him to think about ways to process information or solve problems. Also, it is by no means wrong for the educator to provide the answers to the questions by himself,



or to invite the PwID to give a non-verbal answer (nodding the head or pointing or by whatever modality). It's up to the educator to expand the simple or incomplete answer and to check if he has understood what the PwID wanted to communicate.

- Jose, is this what you mean?

It is very significant to reflect, with the PwID, on how he approached a task. The educator may ask:

-Johan, how did you approach the task?

but he also can name what he observed. He may have seen the PwID working systematically, making use of a plan, or he saw the PwID comparing to look for any imperfections; these observations may be followed by reflective questions such as:

- Loes, I saw you working step by step; was this a good plan?

or

- Did you work systematically?

### **3. Requiring justification**

To invite the PwID to think, learn or solve problems with full attention and to contribute to full insight in what is making a difference for efficient learning, thinking or decision making, it is important to (almost) continuously ask the PwID for the why, the reason of a response or answer or choice.

- Ester, why do you think this is the right answer?

Mediational educators establish the habit of challenging *both* correct and incorrect responses. In this, challenging must be accompanied by the rule of accepting as much as possible of PwID's responses (the "Yes, I saw this, but..." mechanism). The educator might say, for example:

- Maria, you are right, it could be that way. You could also look at it another way, and maybe find an even better answer.

Too often, questioning happens only when something is wrong. It may be clear that it is important to accept mistakes as a very normal phenomenon during all learning.

Mistakes are nice opportunities for learning. They invite for reflection on the causes, and what can be done to avoid mistakes. However, it is important to ask questions also when something is right or correct. Habit formation in this is important. Challenging correct answers conditions the PwIDs against the expectation that a challenge by the educator means that their answers are wrong. A response followed by a question does not necessarily refer to a mistake or failure. A *correct* challenge might be:

- Jose, yes, that's right. How did you know that should be the answer?

or

- Paqui, why is it better than this one? What would be wrong with this one? Could you, Manuel, show me/tell me how you thought about that and found the right one?

Just as is the case that a PwID can learn from mistakes, the PwID can learn from reasons of success. To reflect on the answer to the question 'Julian, how did you find the right answer?' contributes to understanding and comprehension. The PwID learns that his response is not based on coincidence, but the outcome of active, adequate, efficient efforts to apply good (cognitive) skills and attitudes. PwID very often show evidences of (learned) helplessness and - too often - attribute successes to external conditions (the task to be completed was easy or the educator helped me) and attribute failure to themselves (I'm not good at this). The suggestion to require justification of good responses, is an antidote to the (learned) helplessness by linking successes to active efforts. And it contributes to a positive feeling of competence and intrinsic motivation.

When a training is happening in a group setting, positive responses, right answers and efficient approaches contribute to a positive atmosphere. Good habits, efficient and adequate behavior are observed by the other participants, and so observational learning may happen.

#### ***4. Cognitive modeling***

A mediational style is supported by an educator who shows (i.e. models) explicitly how he or she - with enthusiasm - solves problems, approaches tasks, deals with failure, inhibits impulsivity, talks to himself, reflects on what he is doing or did, mentally orients himself... The educator not only shows, i.e. non-verbally, his mode of thinking or problem solving, but also makes explicit the self-talk - what he is asking questions or is talking out loud to himself during these actions. By doing so, the PwID sees and hears how the educator is dealing with problems, mistakes, successes, self-reinforcement, etc.

Besides being a model for the PwID himself, whenever possible the educator asks a peer, e.g. another PwID in case there is a group session going on, to show (and verbalize) how he or she is dealing with the tasks. This is an important strategy, as everyone is - often unconsciously- more willing to learn from someone with who he can identify himself.

Also, the willingness to learn from what is seen and heard, will not be very present when the model is a mastery model, i.e. someone who always performs tasks perfectly; it will be more present when the model is a coping model. A mastery model shows behavior that - according to the PwID - may be too difficult to acquire, while a coping model shows some imperfection and so, achievable behavior.

## ***5. Promoting task-intrinsic motivation***

When the interventions focus on the process that leads to a result, and not on the result itself, the educator cannot use forms of reinforcement derived from behavioristic models (operant learning, punishing, ignoring,...). After all, the purpose of operant conditioning is to link reinforcement (e.g. reward) to desired behavior, which means the outcome. For (classical) behaviorists, everything that takes place between a stimulus (S) and a response (R) is unobservable and therefore not possible to be influenced (See the Black Box-idea). Rewards, point systems, response cost systems,... (extrinsic reinforcement, as they come from outside) are in other words linked to thinking or problem solving outcomes instead of thinking processes. It is well known what are the limitations of these classical operant procedures: as soon as rewards disappear, so does the motivation to perform this 'desired' behavior, and so, also the behaviour disappears. This is because the source of the motivation lies outside the individual.<sup>11</sup>

Although largely subject to purely theoretical discussions, a cognitive approach proposes to promote task-intrinsic motivation. The source of this motivation is to be found in the task and/or in the person, such as the challenging nature of the task, the person's openness to challenge, or the feeling of competence. The examples of (task-) intrinsic rewards below show that extrinsic and intrinsic reinforcement cannot be purely separated.

### **a. Intra-individual evaluation and praise**

Inter-individual evaluation is evaluation of progress or performances compared with the performances of others. Intra-individual evaluation happens when the achievements of a PwID are compared with his own previous achievements. By opting for the intra-individual evaluation, the feeling of changeability and being able to learn more or do things more independently is reinforced. A growth mindset and positive self-esteem is at stake. Comparing with others leads to competition and so to a feeling of failure when you are not the best.

This suggestion, for sure, includes as much as possible the process dimension that will be intra-individually evaluated.

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<sup>11</sup>There are situations that benefit from behavioral procedures, but these strategies need to be implemented carefully and well considered and to be gradually and as soon as possible faded out.

- Cinta, you managed to take into account more elements at the same time than last time when we were practicing this.

#### b. Social rewards

Since e.g. materialistic or activity-related rewards draw the attention on the reward following the outcome, and not on the learning, thinking or problem-solving process preceding the outcome, social rewards such as a pat on the shoulder, a wink, etc. are chosen more often to praise the ongoing effort. Also here, to be efficient, the PwID is consequently informed about what he is rewarded for, giving particular attention to the effort and the process that is leading or has led to an outcome.

#### c. Self-reinforcement

Research (albeit from a cognitive-behavioural perspective) indicates that self-reinforcement (such as self-rewarding by telling yourself that you did a good job “Yay! I did it!”) is much more powerful than any external reinforcement. For sure, self-reinforcement must be based on proper self-evaluation, and this has to be taught.

#### d. Intrinsic rewards

There are few known examples of purely intrinsic kinds of reward. The most frequently mentioned is the reward where the successful performance of a task or assignment is rewarded with a more difficult or complex task. Here the openness to challenges is both nurtured and addressed. Intrinsic motivation manifests itself in taking risks, accepting challenges, finding pleasure in solving problems, and so on.

- Maria, you were successful in traveling by bus to your sister; you had to take one bus to arrive at your destination. I am pretty sure that you will be successful also when you travel to your friend Jose, although you will need to change the bus once.

## ***6. Support transfer and generalisation***

This suggestion refers to one of the main strategies that defines a mediational intervention, i.e. transcendence. New experiences, skills are linked to contexts different from the learning context (other environment, different level of novelty, etc.). It is important to support the PwID during his attempts to apply skills in different situations, especially by creating a safe environment, to create ‘try outs’ within the zone of proximal development and by giving as much as possible feedback and inviting for reflection.

- Let’s try, Cinta, we both know you can do it, and no problem if things may not go well, we are here to find out how to deal with it...

As long as necessary, the educator (or the professional who supports the PwID in everyday working or living context) guides the PwID through the steps of the mental orientation (see 3.7.4.b) by asking process (and content) related questions.

- Paqui, you have learned how to prepare for shopping during the training, and now you want to go to the bakery and the pharmacy. Let’s think together how etc...

Many cognitive psychologists suggest to prepare for transfer at the time of the training, by inviting the PwID to imagine situations or times where what is learned may be applied. The educator creates or elicits ‘imaginary bridges<sup>12</sup>’. This is not easy, and it may take a time, but it is found that also PwID can develop this way of thinking about and imagine future contexts. Too often, professionals assume that the PwIDs are not able to do this... although, they do believe that these people are able to dream and fantasize.

Referring to situations or experiences in the past and in the future is very illustrative for mediation of transcendence. Is this new for you? How did you deal with this last week? When can you use what you are learning now? Any reference to past situations (How

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<sup>12</sup>This suggestion refers to a technique developed by R. Feuerstein, and is called Bridging. This strategy has been included in the Erasmus project Triade 2.0 and is extensively explained in the Educators Guidelines for the use of the MNAM platform that has been developed to help PwID deal with ageing. See <https://www.ivass.gva.es/Triade2.html> for information on the project and on the bridging technique.

did you solve the problem at that moment?) and any link that is made to later (Can you think of a time that you can use what you are learning now?) helps the PwID to disconnect from the actual situation. The general intellectual and verbal level will, for sure, have an impact: for one PwID, it will be the educator who will have to verbalize the link with the past or the future, instead of the PwID; for another PwID, it may be that the educator can expect that the PwID can give examples of situations or contexts where what is learned can apply. Also, the level of abstraction (the more or less the principle or the cognitive skill is generalizable or transferable) or the complexity may have an impact on what is possible for. It is clearly easier and more concrete to ask a PwID ‘Joke, when is it important to slow down?’ compared to ‘When is it important to adapt your behavior?’. Or, asking for a situation in the past - one that the PwID already and truly has experienced - will be easier to remember and (re-)imagine compared to a future hypothetical situation that the PwID not yet has experienced.

### **3.7.3.3. From external to internal speech**

The main challenge to initiate and elicit metacognitive reflections is the need for a very consequent implementation of the aforementioned suggestions, although the educator’s interventions do not actually appear that difficult (see examples below). The educator is expected to be intentional and explicit about teaching or supporting metacognitive skills (see 3.7.2.), without overdoing or overwhelming the PwID: pick spots and let other opportunities go.

It is often observed that the focus is on content more than on process, and that questions and self-talk are only questions and self-talk from the side of the educator, while this external self-talk needs to be transferred to the PwID and become self-talk produced by the PwID. This may be - after all - a main goal: to foster self-reflection, to emphasize the importance of personal reflection during and after learning experiences, to encourage PwID to critically analyze their own process, but also their feelings or beliefs and how this may have influenced their learning or performance.

Also, suggestions given by the educator to direct the thinking process of the PwID are often prescriptions or instructions about how to deal with a situation, how to solve a problem, etc. while the interventions of the educator should be invitations for the PwID to produce these (self-)instructions by himself. It is fine to give instructions such as

“think about different alternatives to solve this problem”, as long as this is not the final goal. The final goal is to help the PwID to generate this instruction himself. “What may you do before setting up your plan to deal with this problem?” inviting the PwID to initiate himself the consideration of different alternatives, and giving the PwID as much as possible time and space for his initiative and so to contribute by himself to the implementation of the problem solving cycle.

As an illustration, and not as a list of statements that has to be memorized - and so, with some hesitation... -, the following list is a sample of statements often heard while a educator is inviting for reflections:

- Cinta, what do you need to do next?
- Johan, tell me how you did that.
- Julian, what do you think would happen if \_\_\_?
- Loes, when have you done something like this before?
- Sara, how do you feel if \_\_\_\_\_ ?
- Ester, yes, that's right, but how did you know it was right?
- Paqui, when is another time you need to \_\_\_ ?
- Maria, stop and look carefully at what you're doing.
- Jose, what do you think the problem is?
- Juan, can you think of another way we could do this?
- Manuel, why is this one better than that one?
- Adrian, where have you done that before to help you solve this problem?
- Manuela, let's make a plan so we don't miss anything.
- Alessio, how can you find out?
- Loes, how is \_\_\_\_\_ different (like) \_\_\_?



The aforementioned suggestions and the examples of metacognitive questions are very focusing on the *cognitive process*. At the same time, they invite to reflect on feelings, motivation and personal beliefs. In addition, examples of questions, more specifically focused on the mindset, may be:

- Loes, what was difficult, easy for you?
- Johan, what was your main challenge during the session?
- Julian, what moment where you most proud of your effort?
- Lien, what needs improvement?
- Cinta, at the beginning, where you sure you could do it?
- Paqui, how did it feel when it was hard at the time that....
- Maria, what can you learn from this?
- Manu, what steps can you take to help you succeed?
- Ester, where can you get constructive feedback?
- Julian, what did you learn today?
- Jose, what mistake did you make that taught you something?
- Juan, what did you try hard at today? How did you persist when it was hard? And what was helpful not to give up? Did you change your mind after doing this?
- Manuela, what were some of the most interesting discoveries you made while working on this project?
- Joyce, what are your greatest strengths, and what are the biggest areas for improvement?

### **3.7.4. Shaping a modifying environments and creating a Laboratory for Learning.**

Self-In considers whatever situation that aims to promote self-management self-determination, independent living, as a potential Laboratory for Learning. By doing so, not only the distal goal of improving self-management is clearly present, but also goals to realise conditions for self-management on the level of the PwID are explicitly at stake. This refers especially to goals related to the acquisition of a growth mindset and metacognitive skills, as they are a particular challenge for people with an intellectual, and thus a learning disability. Besides the specific cognitive methodology addressing the cognitive development of the PwID (see 3.7.2.), also a powerful learning environment needs to be shaped to realise the final outcome. Self-In chooses to use the concept of Laboratory for Learning, to refer to a desired, supportive learning environment, conducive for real autonomy.

A laboratory for learning is a powerful environment that creates safety, accepts mistakes and failure, challenges the learner, invites for effort, reflects on progress... This section will deal with some specific characteristics that are closely related to the target group and the metacognitive goals of Self-In. Powerful learning environments are intrinsically linked to the development of self-regulation, and so, they are very metacognitive (Potter, 2004). Reflection is a key concept in this. On the content, powerful learning environments need contents that are meaningful for the learners: as well linked to their personal goals to support on an intrinsic motivation, as to the zone of proximal development of the learner.

With Feuerstein (e.g. 2010), introducing the concept of Shaping modifying environments, we don't have the intention to create a teaching environment, but rather a learning environment, always structured to accelerate cognitive adaptation. This includes structured interactions that require the learner to communicate and think empathetically and logically, and situations that require him/her to work with others, learn useful everyday routines, anticipate the results of certain actions and so much more. Feuerstein describes key characteristics of a modifying environment as a high degree of access and openness to society's opportunities, conditions of positive stress, a planned and controlled encounter with new tasks, and individualised and specialised instruction and mediation.

We limit this section to some conditions that we - in our daily work - found to be significantly contributing to cognitive empowerment of PwID:

#### **3.7.4.1. Meaning and intrinsic motivation**

PwID are very willing to participate into whatever learning situation, as long as they may define their personal goals and as long as it contributes to participation into mainstream contexts of regular employment, sports, regular and independent living. PwID become ready to learn when the experience will help them deal with life situations, such as performing tasks relevant to their social role. Working towards these goals is the only right starting point for a training, a support or a learning activity. It is a challenge for the educator to use methodologies that equip the learners with the cognitive, motivational and affective prerequisite tools to realise the learning goal and the future active performance in real life.

#### **3.7.4.2. A safe environment**

No learning will be successful, as long as the learner doesn't feel safe: a warm relationship with the educator or the peers, being unconditionally accepted as you are, knowing that mistakes will be accepted and will be the starting point for learning, strongly feeling to be supported while doing efforts, always finding a buddy to rely on...

**3.7.4.3.** The educator works with the learners, accepting that they have a wealth of experiences: he may benefit from this as these experiences may serve as a resource to make learning meaningful.

**3.7.4.4.** Cooperative problem solving by discussing and sharing possible approaches and reflections with team members and learning from each other, supports the development of metacognitive skills and intrinsic motivation. The learning process will be found more important and rewarding, than the mere outcome of an assignment. A growth mindset is the real outcome.

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## ANNEX 1. SELF-INCA TOOL



# SELF-INCA TOOL

Each of the statements below refers to a set of skills. Please read each of them and indicate to what extent you consider the participant in self-management learning programs as able to perform them adequately.

To enable us to analyse the data, please provide the information requested below. Your answers will be treated as strictly confidential.

TRAINER'S NAME: \_\_\_\_\_ Age: .....  Male  Female

**PARTICIPANT IN SELF-MANAGEMENT LEARNING PROGRAM**

NAME: \_\_\_\_\_ Age: .....  Male  Female

Please, express your point of view rating from 0 (Not yet competent) to 6 (Expert). And, of course, you can use the numbers in the middle if your position falls between the extremes.

Please use the following scale to rate the level of competence for each item.

0= Not yet competent, not yet demonstrated appropriately

1= Beginner demonstrated but beginning stage of development. Numerous inconsistencies and inaccuracies in performing this skill.

2= Advanced Beginner demonstrated but in the early stage of development. Some inconsistencies and inaccuracies in performing this skill.

3= Competent, demonstrated meeting standard for competence. No inconsistencies or inaccuracies in performing this skill.

4= Proficient demonstrated above standard competence for this skill. More accomplished and practised, demonstrated with ease.

5= Advanced demonstrated competence as exceeding standard with fluency and accuracy.

6= Expert, demonstrated proficiency as expected of a very highly experienced. Demonstrates outstanding knowledge, skill, and delivery of this competence.

	Not yet competent	Expert					
	0	1	2	3	4	5	6
<b>CRITICAL THINKING - the ability to use strategies that increase the possibility of achieving a desirable outcome.</b>							
1. They express concepts, been able to give some examples.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. They identify crucial points of a topic.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. They judge whether a topic is relevant, applicable, or has any implications in a specific situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. They use different strategies to solve problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. They describe the strategy used to decide reasonably.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>EMPATHY - the understanding of another person's emotions, experiences and values, and the provision of appropriate responses.</b>							
6. After being with a friend who is sad about something, they can show empathy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. They get caught up in other people's emotions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. They can tell how people feel.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. They can identify when people are happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. They notice right away when a friend is angry.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>ASSERTIVE COMMUNICATION- the ability to directly state your feelings and needs in a respectful manner.</b>							
11. They ask appropriately for information and clarifications without being excessively intrusive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. They adequately support their points of view even in the presence of those who think differently.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. They can say no in assertive way to someone without making them feel bad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. They criticize something or someone in a friendly way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. They share both positive and negative feelings with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>EFFICIENT COMMUNICATION - use of relevant communication strategies, domain-specific codes and tools depending on the context and the content.</b>							
16. They can describe to others their point of view of an issue or subject.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. They can present oral speeches to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18. They use new technologies to communicate to others more effectively.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. They can identify the components of the non verbal communication (such as look into the eyes).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. They can identify the components of the verbal communication.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>SELF-REGULATION - awareness and management of emotions, thoughts and behavior.</b>							
21. They can be calm when facing stressing situations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. They can manage compromising situations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. They take responsibility to find solutions to problems and difficulties.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. They are able to identify the supports needed to achieve their goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. They are able to identify the 3 components (thoughts, emotions and behaviours) producing discomfort.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>FLEXIBILITY- the ability to manage transitions and uncertainty, and to face challenges.</b>							
26. They show interest in new things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. They are willing to try something new.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. They come out with original ways to solve difficulties or problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. They can look for information using different sources to start new path.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. They are able to look for new ideas and opportunities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>COLLABORATION - engagement in group activity and teamwork acknowledging and respecting others.</b>							
31. They describe the different areas of participation: personal, organizational and community.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. They search for information on social networks.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. They know platform related to PwID and the defence of their rights.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. They identify 2 self-advocacy groups in the community.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

35. They can describe the functions performed by the representative person of a self-advocate group.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. They share tasks and resources with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. They willingly work together with others providing the necessary contributions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. They provide opinions, help and advice on what to do to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. They show respect and appreciation for the work of others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. They ask what to do to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>GROW MINDSET - belief in one's and others' potential to continuously learn and progress</b>							
41. They are able to monitor their own learning process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. They are responsible for their learning process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. They come up with different strategies to achieve their goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. They are able to verbalize the mental strategy used.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. They identify rights to learn in a group activity.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>LEARNING MANAGEMENT - the planning, organising, monitoring and reviewing of one's learning</b>							
46. They use diagrams or drawings to connect one thing to another.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47. When they learn something new, they ask questions to see if they are right.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48. They participate actively in meetings, group discussions and stimuli proposed by the educator.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49. They complete exercises and activities that have been proposed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50. They plan their own learning process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## ANNEX 2. STUDY CASES.

## **STUDY CASE 1.**

**IVASS Self-management program.**

**Topic: Rafalafena's internal rules and regulations**

## **1. CONTEXT: IVASS AND RAFALAFENA'S OCCUPATIONAL CENTER.**

### **1.1. IVASS (Valencian Institute of Social Services)**

IVASS, with its own legal status, assets and resources, is a public organization with competences for managing several policies of the Generalitat Valenciana in the fields of: social welfare, elderly people, dependency and care of people with intellectual disabilities. In addition, it protects and guardianship persons with judicially modified capacity.

IVASS comprises 6 daycare centers, 10 occupational centers, 11 day and night residences and 5 sheltered homes where its 820 professionals dedicate their efforts to the attention and care of 1,200 people with social care needs. Finally, it provides them the necessary support for their integral development, in a participatory manner and through a quality service.

### **1.2. Rafalafena's occupational center.**

The self-management program presented in this case study was carried out in Rafalafena's occupational center in 2012. This half-board care resource is located in the City of Castellón de la Plana (174,364 inhabitants), capital city of the province of Castellón, in the Autonomous Community of Valencia. The local economy is based on industry, tourism and craft-work.

48 people with intellectual disabilities attend regularly the center from Monday to Friday. Moreover, 10 professionals work in the center (1 psychologist-director, 1 psychologist, 1 physiotherapist, 1 social worker 5 workshops trainers (and 1 caregiver). The workshops carried out in the center are: 1) pottery; 2) plastic arts; 3) daily life activities; 4) Cognitive stimulation; and 5) personal life skills.

Rafalafena's center provides adults with intellectual disabilities the supports needed to empower their personal, labour and social autonomy. It also promotes the participation of the people with intellectual disabilities in the community as citizens with full right and carries out initiatives to improve the quality of life of them and their families.

**Rafalafena's mission:** Improve the participation of people with intellectual disability in the community.

Rafalafena offers services to increase the personal and social autonomy of its users such as adapted sporting activities, occupational therapy, physiotherapy and specific tailored activities. In addition of the activities carried out in the center workshops, it should be highlighted those aimed at improving the visibility of PwID in the neighborhood and those to make them to learn which community services and resources are appropriate and available for them such as sport facilities, public administrative services (local and regional), cultural offer (public library, theatre and auditorium) or shopping activities (market and local shops). They are activities that usually are undertaken outside the center once they have finished their daily assistance (evenings and weekends). As a result of this community orientation, the center carried out the self-management program which is following described.



## **2. RAFALAFENA´S SELF-MANAGEMENT PROGRAM**

### **2.1. Self-management program planning**

The two educators in charge of the program (the center psychologist and one of the workshop teachers) started to plan the self-management program by carrying out an informal research of the documents published in Spain about similar programs.

Once they had a clear idea of how to accommodate the program in the Rafalafena´s center, they defined the objectives and expected results, the methodology and a first draft of the activities to be carried out. All this information was turned into a concrete proposal (see self-management program care sheet in annex 2) which was approved later by the management of the center.

The key planning challenge for educators was to implement a self-management program which would gracefully combine: a) what learners wish to learn and the topics they want to work on; b) the possibilities that offer their local context/community; and c) the center resources and capacities available for the program.

The program was planned to be implemented during 6 months (from January to June) with fortnightly meetings of 2 hours in length. It was also needed a room equipped with an interactive digital blackboard and internet access.

Finally, it was agreed that people with intellectual disabilities should sign a participation agreement before starting the program.

### **2.2. Participants´ recruitment.**

From the very beginning, it was clear for educators that the self-management program did not fit the needs and capacities of all center users due mostly to the lack of the cognitive/social skills and personal autonomy of some of them. Therefore, it was needed to carry out a selection of those participants who would more benefit from the program. Two skills were considered as crucial in the selection procedure: a) cognitive skills; and b) social autonomy skills.

Professionals used the following methodology and tools to assess the participants program suitability: a) their experience and knowledge about the users; b) records of users kept in the organizations such as the individualized supports plan; c) and two specific assessment tools: a) the Spanish version of the ICAP (Inventory for Client and Agency Planning); and b) the Wais Scale (Wechsler Adult Intelligence Scale).

From a practical viewpoint, the key elements to be considered by the educators were: a) participant behavior (public and within the group); b) their reflection capacity; c) their tendency or readiness to participate in others center activities; and d) their capacity to give sense of what would happen in the self-management program.

Additionally, it was agreed to apply certain degree of flexibility in the selection process. For example, educators were not sure if 2 participants had the appropriate skills to take part in the program, but eventually they were invited to participate because educators considered that the program would be stimulating for them.

Finally, the reasons showed by participants to take part in the program were: a) to learn new things; b) socialize with colleagues from other centers; and c) to visit different places. According to educators, there was another “hidden” reason to take part in a self-management program: “to get out of the routine of an occupational center”.

### **2.3. Profile of the participants**

The 9 participants in the self-management program were all users of the Rafalafena’s center. They were persons with mild intellectual disability and with certain degree of autonomy in the activities of the daily life. According to the QoL model, they needed intermittent supports in the skills required to live in the community. The participants had language and reading skills of the second level of primary school; and good level of comprehensive and expressive language. Mostly of their limitations were manifested in the cognitive skills that demand to intervene in their abstract thinking.

The learners lived in Castellón city or in the surrounding neighborhoods. 5 of them lived with their families; 3 lived in sheltered homes; and the last one lived with his mother in an elderly residence.

The analysis has not found any social or economical characteristic of the group to be relevant for the case study.

#### **2.4. Working methodology.**

In addition of the 2-hour meetings, the activities implemented during the program were: group discussions, specific learning activities, meetings with key decision makers (IVASS General Director, Castellón's majoreess...) and activities to make learners to reflect about the selected topic (Regulations that govern Rafalafena's center).

For those participants with reading and writing difficulties, the pedagogical team had to adapt the evaluation tool (Satisfaction questionnaire with pictograms - annex 1) and produce appropriate learning resources (for example, to become accessible the internal rules and regulation that govern Rafalafena's center - see annex 3).

As it was mentioned before, the program was jointly led by a psychologist and workshop trainer whose primary role was to monitor and invigorate the meetings. Once the learners chose the topic to work on (Rafalafena's internal rules and regulations) the educators established the topic objectives, planned the sessions needed, searched for the pedagogical resources and activities needed to cover the topics. The educators had also to search for pedagogical resources available (or create them), arrange visits and interviews with key stakeholders.

#### **2.5. Program implementation.**

The heart of the program was 9 meetings where the topic was discussed. Around these meetings emerged different activities (see table 2.2.) which complemented the topics worked in the classroom and contributed to reach the program objectives.

In addition, it was also decided there was not necessary to create a group operating rules or to appoint a group speaker, secretary or chairperson, but they might be useful to consider in future self-management programs.

During the first meeting, the psychologist and the workshop trainer explained the program (objectives, activities, working methodology...) and the behavior expected from the participants (participation, respect, keeping to your speaking time...).

This first meeting worked also as an informal needs analysis where the participants showed their wishes, discussed and voted the topic and activities they were interested in. In this way, it can be stated that the participants took an active part in the planning of the self-management program.

Learners take active part in the program planning by chosen the topics they want to work on.
--

The rest of the meetings were devoted to implement activities aimed at covering the topic which was chosen by the participants as it can be in table 2.7.

**Table 2.7. Meeting and activities of the self-management program: “Internal rules and regulations that govern Rafalafena’s occupational center”..**

Meeting	date	Features/activities carried out/learning resources developed
Kick-off	31 <sup>st</sup> /01	Program objectives and rules; and discussion and voting the topic.
2	14 <sup>th</sup> /02	Objective: to know the internal rules and regulations which govern the life of people with intellectual disabilities within the center. What are the rules? Who wrote it? Users rights and obligations; legal tutors rights and obligations; infringements and penalties.  It was explained what are the rules. In the next sessions, it was explained the different sections.
3	28 <sup>th</sup> /02	What does it mean to have rights? And to have obligations?
4	14 <sup>th</sup> /03	Rights.
5	4 <sup>th</sup> /04	Obligations.
6	18 <sup>th</sup> /04	Infringements and penalties.
7	2 <sup>nd</sup> /05	Discussion to prepare the presentations and materials in the self-management groups encounter at the end of the program.
8	16 <sup>th</sup> /05	Presentations rehearsal
9	26 <sup>th</sup> /05	Public event: encounter of participants in the self-management groups.

**Source: IVASS internal information**

**TIP**

Some questions during the first meeting discussion are key to understand the needs and interests of the learners:

- What would you like to learn about in this group?
- What would you like to know?
- What do you have interests in?
- What things do affect your life you would like to ask questions about?
- Which are your worries?

During the third session of the program, it was detected that it would be needed to use pictograms and easy-to-read texts to ensure that the participants understand the rules and regulation document (see annex 3). In fact, they were the participants themselves who proposed to ask IVASS to make this adaptation for all IVASS users, and not only for the self-management group. Participants wrote an official form and sent it to IVASS Official Headquarters, requiring to have a meeting with the Ángel Bonafé (General Director) (Figures 2.2 and 2.3.).

**Figure 2.2. Register of the official requirement form. Source: own elaboration.**



**Source: IVASS internal information.**

**Figure 2.3. Meeting with Ángel Bonafé (IVASS' General Director). Source: own elaboration.**



**Source: IVASS internal information.**

Additionally, the psychologist had to adapt all the session contents by using pictograms and easy-to-read language.

The last activity of the program was a day-meeting with other 2 self-management programs to exchange experiences (Figure 2.4.). In addition of the leisure activities, the agenda of the meeting was divided into 2 parts:

- Exchange of experiences about what each group has learnt and the activities carried out.
- What issues/topics you would like to deal with in future self-management programs?

Finally, the learners, helped by educators, filled out a satisfaction questionnaire (annex 1)

**Figure 2.4. Self-managers encounter. Source: own elaboration.**



**Source: IVASS internal information.**

## **2.6. Program evaluation and results**

The evaluation of the program was carried out combining three methodologies: a) learners with intellectual disability filled out an adapted satisfaction questionnaire (Annex 1); b) learners behavior continuous observation by the two professionals involved in the program; and c) educators discussions during the center multidisciplinary meetings.

The professionals involved in the program stated to have observed a general improvement of the participants taking part in the self-management program. Overall, learners improved their ability to function behaviorally in a group. Specifically, it was observed a better functioning of the group (better listening skills, greater willingness to take the initiative in participating and keeping to the speaking time).

It should also be highlighted two issues stated by educators which made difficult to carry out a better evaluation. Firstly, the daily life activities occurring outside the center are beyond of the scope of the program and center evaluation. Secondly, it was impossible for the professionals to lead the group, invigorate the meetings and evaluate the participants' progress at the same time. Therefore, if the aim of a given self-management program is to carry out an objective quantitative behavioral evaluation, it would be needed the presence in the group of a third educator devoted specifically to observe and take note of the learners group behaviors (length and quality of the participation/interactions; and how many times a person speaks, asks for the floor, takes the initiative...).

Related to the conflicts among the participants, apart from the logical common frictions (inappropriate laughter and complains, and the issue that a few of them did not get along very well...), the educators stated that the group worked smoothly. Only one important conflict was reported (see table 2.8.). No one participant dropped out.



**Table 2.8. Dealing with a conflict within the self-management group.**

Several male participants were attracted by the same female participant. Additionally, she was not able to control her emotions many times, going through a wide range of emotions during the self-management program. Those days she was disturbed, everything looked wrong to her but also to her followers.

At the same moment that her inappropriate behavior was interfering with the functioning of the group, educators changed the group dynamics in order to make her and the participants reflect on what was happening in the group. In addition, educators had to speak one-to-one with her a couple of times in order to make her understand the impact of her behavior in the functioning of the group and the need to modify/control her behavior/emotions if she wanted to keep participating in the program.

**Source: IVASS internal information.**

Furthermore, the families of the participants showed satisfaction with the program and were reported at the end of the year about the activities developed by it, but they did not take part in the program design, implementation or evaluation.

Summing up, the self-management program was positively evaluated by the professional's team and integrated within the educational program of the Rafalafena's center. Additionally, educators stated that the most important results achieved by the program were:

1. Learners enjoyed a lot taking part in the program;
2. The participation of people with intellectual disability in the center organization increased.
3. Participants have now a greater sense of belonging to the group.
4. The group is now more cohesive.
5. Participants saw the program as a tool very useful for them but also for rest of the center users not taking part in the program, and for the whole organization.
6. Good acceptance of the program by the key external stakeholders (legal tutors, politicians, police...)
7. Production of some accessible learning materials such as the transcription of the Internal Regime Regulations to an easy reading text (see annex 3)

8. The program reached some impact i the wider community through the IVASS dissemination activities (social media and press releases) and the final public event.

**TOOLS: TEMPLATES AND ARTEFACTS TO BE USED BY EDUCATORS.**

- **Tool 1. SATISFACTION QUESTIONNAIRE.**
- **Tool 2. SELF-MANAGEMENT CARE PROGRAM SHEET.**

## **Tool 1. SATISFACTION QUESTIONNAIRE**

**SELF MANAGEMENT PROGRAM**  
**SATISFACTION QUESTIONNAIRE FOR PARTICIPANTS**

1. ¿Do you like meeting with the self-management group of your center?



I do not like it



Average



I like it a lot

2. Do you find interesting today's topic?



No, I do not



Average



Yes, I do

3. ¿Would you like to meet with people from other self-management programs?



No



I do not care



Yes

4. Do you discuss with your families or relatives what we talk in the meetings?



No, I do not



Average



I discuss it a lot

5. Would you like keep being in the group?



No, I would not



Average



I would like it a lot

6. What other topics would you like to talk about?

**Tool 2. SELF-MANAGEMENT CARE PROGRAM SHEET.**

<b>SELF MANAGAMENT USERS CARE PROGRAM SHEET</b>
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**PERSONAL DATA:**

Surname: (* ) To be filled out if individual program	Name:
<b>Group: To all center users.</b> (* ) To be filled out if group program.	

(\* ) User name or initial. This sheet is valid as much for individual programs as for group ones, filling in the corresponding boxes.

Current date:	Program start:	Review:
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<b>NAME: SELF-MANAGAMENT PROGRAM</b>
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<b>1-OBJETIVES</b>
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<u>General:</u>
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- Give the chance to participants to improve their knowledge, have a say, participate and decide about the issues related to their own life.

<u>Specific:</u>
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- To acquire knowledge about the issues and topics proposed by the group.
- To acquire social and personal autonomy skills.
- To acquire communication skills.
- To acquire skills to take part in meetings.
- To acquire skills to reflect and exercise a critical judgment.
- To acquire decision-taking skills.

## **2- ACTIVITIES**

- Participant meetings to deal with the topics of interests.
- Group dynamics.
- Visit to places of interests.
- Meetings with other self-management groups to share knowledge and experiences.
- Meetings with citizens' representatives.

## **3. METODOLOGY**

- The group will have with two professionals who invigorate the group with the objective to work the topics and reach the objectives.
- The group will coordinate with other self-management programs.

## **4. SCHEDULE**

- The group will meet every fortnight and there will be quarterly encounters of self-management groups.
- The program will be carried out the second and third term of the school course.

## **5. TARGET GROUP**

- Center users with appropriate cognitive capacity and autonomy level to fully take part in the program.



## 6. RESOURCES

- **Human resources:** a psychologist and a workshop teacher.
- **Material resources:** classroom; media and educational materials.

## 7. FOLLOW-UP AND EVALUATION

- The follow-up will be done by writing minutes of the meetings carried out.
- Program indicator:
- Annual percentage of sessions carried out compared with the number of sessions planned.
- Acceptance criteria: accomplished when > 50% of the sessions planned.
- Annual evaluation according to final results.

## 8. PERSON RESPONSIBLE OF THE PROGRAM (Production, application and follow-up)

Name and surname: C.E.

Position: Psychologist

## 9. REMARKS

## **STUDY CASE 2.**

**Cercioeiras' Self-management program.**

**DAY CENTRE AND RESIDENCE (LISBON)**

## **CERCIOEIRAS FOUNDATION**

Cercioeiras is a Social Solidarity and Public Interest Cooperative that has advocated the rights of People with Disabilities for over 47 years.

This organisation for the Education and Rehabilitation of Citizens with Disabilities is a Social Solidarity and Public Interest Cooperative, with its headquarters at Calle 7 de Junio, no. 57, Barcarena, Lisbon.

Cercioeiras was founded in October 1975 by a group of families and rehabilitation professionals who were dissatisfied with the care their sons and daughters with intellectual disabilities were receiving.

The aim of this entity is to defend the rights of People with Disabilities, supporting their participation in social and professional life, promoting the full exercise of their rights as citizens through an integrated range of actions and services.

It is an organisation that strives for excellence in the sphere in which it operates, one that stands out for its organisation and sustainability, from a customer-centred perspective and with a view to fully meeting their expectations and needs. They work to strengthen competitiveness and effectiveness, always with full respect for the principles of social responsibility and sustainable development.

### Resources:

- Residential unit.
- Activities and inclusion skill-training centre from 18 years old.
- Early intervention: from 0 to 6 years.
- Resource Centre for inclusion: the professional comes to the ordinary school to work with students in the community.
- Activities of animation and support to families: working with children in programmes to inspire families and give them a break.
- Curricular Enrichment Activities: children.
- Bank of Equipment and Technical Aids.

**Vision:** to be an organisation of excellence and a model for the construction of an inclusive society.

**Mission:** to integrate, educate, rehabilitate and care for customers and their families, with excellence and sustainability.

**Values:**

- Respect for the person: Ethical values.
- Quality and excellence: continuous improvement of the services provided, with the participation of stakeholders and in compliance with legal requirements.
- Social responsibility: co-responsibility involving stakeholders in the construction of a more just and inclusive society.
- Innovation and entrepreneurship: being open to change, participating with creativity and flexibility. Promote teamwork.
- Environmental responsibility: contribute to the improvement and care of the environment.
- Diversity: promote diversity and equal opportunities regardless of cultural origin, ethnicity, social background, religious beliefs, sexual orientation, gender, ideas, physical characteristics and personal style.

<https://www.cercioeiras.pt/pt>

## **Daycare resource and Cercioeiras Residence**

### **Background**

The Activities and training centre provides care to a total of 95 people with different profiles within the population with ID. There are people with a high degree of dependency and more autonomous people with a moderate intellectual disability.

Regarding the context of the Residential Unit, from the 50 PDI that are integrated, 16 of them are in the care of the organization. The others PDI have different routines, from going to their families on the weekends or on holidays and others due to aging process of their parents are going less to home. This is a complex matter for the future where we have parents and PDI in an aging process together.

To participate in the centre's activities, the person has to pay a monthly fee depending on their income and socio-economic situation (accordingly with the rules of Social Security). To be admitted, the criteria laid down in the regulations of the Portuguese authorities in social issues. There is currently a huge waiting list for admission to the centre and the residential unit. As well as meeting the established criteria, one has to be a member of the entity. From Monday to Friday, the 50 PDI of the RU are in the activities and training centre from 8:30h to 17:00h.

The self-advocate group comprises residents, although it has been extended to people who come for the day centre service. However, they have shown no interest in participating in the activity.

On the other hand, it must be stressed that the community is evidently highly sensitised to the collective, as the centre has been operating for over 40 years.

The work done in the community has improved the visibility and sensitivity of the people in the neighbourhood towards people with ID. As the Director explains, it is a continuous effort.

### **Features of the Service:**

The centre has been operating for 47 years. The residence has the following staff:

- 1 technical director.
- 2 socio-cultural activities technicians.

- 1 social services technician.
- 21 residence assistants.

The Activities and Training Centre (most professionals provide care to both residence customers and day centre customers) is composed of:

- 1 technical director.
- 1 physiotherapist.
- 3 Technician in Psychomotor Rehabilitation.
- 2 occupational therapists.
- 1 social services technician.
- 1 socio-cultural activities coordinator.
- 7 occupational activity monitors.
- 14 occupational activities assistants.
- 1 driver.

The specific characteristics linked to the self-management programme are the values focused on the defence of the rights of persons with disabilities and person-centred treatment. The institution follows the quality of life model of Schalock and Verdugo. The level of quality of life is evaluated annually on the San Martín scale (Verdugo et al., 2014).

**Figure 2.5. Participants in the self-management group.**



**Source: Cercioeiras**

**Figure 2.6. Dog grooming workshop.**



**Source: Cercioeiras**

Cercioeiras offers services to provide comprehensive care to the person and to their family. The programmes cover the different aspects of the person: emotionally, in terms of personal and social autonomy, as well as participation in the community. There are occupational workshops, sensory and cognitive stimulation rooms, adapted sports activities, occupational therapy, physiotherapy, volunteering, external car wash and dog grooming services.

## **CERCIOEIRAS SELF-MANAGEMENT PROGRAMME**

### **Planning the self-management program**

Aligned with the motto ‘nothing for you without you’, the team of professionals stated that the participation of users in the meetings of the Board of Directors and planning of the service was important. It was necessary to explain clearly the purpose of this programme and the defence that people with ID decide about their lives. Some families, at first, showed reluctance because, according to the basis of this programme, decisions should be made by the individual him or herself and not by the families. Little by little, families have come to understand this new approach, supporting it and performing the role expected of them. People with ID were also initially involved in the planning and dissemination of the group.

In a first phase it was explained through workshops that a group of self-managers was going to be formed, as well as the aims, meetings and importance of the participation of users in the Board of the Centre. All the users of the centre were asked if they wanted to be part of the group of self-managers. It was explained to the stakeholders in more detail what the groups consisted of, how often they would meet, what work a person who is a representative of others does, etc.

A group of 10 people was created. Since the group was formed there have been some members who have left and others have joined; sometimes the same people; sometimes because the group decides that a certain person should leave because they do not carry out their task or because they disturb the other group members (they decide it by vote). Currently, all participants are residents, perhaps because it is their home and they feel more involved and concerned about everything that happens in their environment.

Participants in the programme elected a chairperson and a vice-chairperson. These two are the ones who meet with the Board of Directors, team meetings and family members.

Once the group was constituted, it carried out a dissemination work through networks, information in the assemblies of members and through the website. On the website there appears the group of self-managers, its objectives and the members (<https://www.cercioeiras.pt/pt/instituicao/auto-representantes>)



The group of self-representatives was born from the need to give voice to people with disabilities, with the main objective that people with disabilities can know their rights and ensure they are respected.

The group has been meeting for several years, and the Cercioeirias entity is currently in the process of including the objectives and programme of self-managers in one of its strategic lines for the next 3 years.

This strategic approach has two main objectives:

- Customer satisfaction.
- Social inclusion and participation

### **Recruitment and profile of participants**

The group is composed of residents with a profile of personal autonomy that allows them to understand the content of the meetings and present their position. There is no need to conduct any questionnaires or tools to decide who participates and who does not. The main requirement is that the person show interest and understand what is being said and the objective for which these groups have been formed.

They are people who voluntarily want to be in this programme and who take on group work and are responsible for the tasks assigned.

The group currently consists of a total of 10 people aged between 20 and 50 years; 2 of them are people who have reduced mobility (needing a wheelchair).3 participants have a sufficient level of literacy, the others participate with the support of images, symbols and accessible language. They follow the European easy reading regulations (short sentences, simple words, images, etc.)

The group was trained in 3 phases:

1. The technician explained through workshops what the programme consisted of, the objectives, the role of the representatives, the topics that could be addressed in the meetings.
2. Stakeholders were introduced and we explained to them in more detail everything related to the group.

3. Appointment of the group members and functions: chairperson, vice chairperson and rest of the group.

The main reason for wanting to participate is the motivation to want to make proposals for improvement, to feel they are part of the organisation and defend their rights.

### **Support Staff**

The support staff consists of technicians; in this case occupational therapists. They need to be sensitive to the programme, be able to promote self-determination and have the available time to carry out this programme and meet with the group.

There is a facilitator in the group who works with and respects the group's decision. It is important that she understand that she does not lead the group but facilitates it: any opinion is valid. The group decides which proposals will be implemented and which will not.

The role of the facilitator involves motivating towards new learning and towards the discovery of new perspectives of thought. The role of the facilitator involves training and supporting the process. With the group, draw up the schedule for one year ahead, with content regarding: how many actions they are going to carry out, of what type, how they are going to publicise it. For example, if they want to participate in a volunteer program.

## **Self-management Programme**

### **General Aim:**

The group of self-representatives arose from the need to give a voice to people with disabilities. Its main objective is to train these people so that they know their rights and ensure they are respected.

### **Specific objectives:**

- Learn to speak for themselves.
- Self-knowledge.
- Know what they need and how to get it.
- Know what they do well and set their own goals.
- Make decisions about their lives and have a voice in decisions that affect them.
- Learn to get information so they can understand things that interest them and learn new skills/competencies.
- Know and exercise their legal rights and responsibilities, to be treated as equals in the community.
- Learn to solve problems, listen and learn.
- Learn to ask others when they need help.
- Be capable of defending the right to full integration, independent living and equal opportunities in their community.

### **Group objectives:**

- Adapt institutional documents to facilitate their reading.
- Contribute to the activity plan and evaluation report.
- Participate actively in and collaborate in events and institutional projects.
- Prepare articles for the Newsletter of the Institution.
- Develop dissemination actions on the Rights of Persons with Disabilities.

**Functions of the self-management group support technician:**

- Support in the creation of the group and work with it, providing the necessary information in an understandable format.
- Create an environment of trust, listening and respect.
- Facilitate interpersonal communication.
- Promote autonomy, creativity and the pursuit of expected objectives.
- Regulate group dynamics.
- Guide the reflections of the participants.

**No. of participants:** 10 people plus the facilitator.

**Participation of people in the programme:** they participate at all times and throughout the process; In fact, the programme is designed by them with the help of the facilitator. The programme, as it is designed by the group itself, is conceived with the necessary adaptations.

**Meeting venue:** the meeting venue, like the rest of the centre's meetings, is the centre's meeting room.

**Equipment and technology:** computers and tablets are used; they also use flashcards to express: 'I agree'; 'I have a question'; or 'I disagree'.

**Frequency:** 1 hour every 15 days and calls. The meeting announcement is placed on the door of the meeting room. They follow a timeline. Minutes are taken of each meeting. The minutes are taken in accessible language.

**Content:** The people in charge sometimes include the agenda in the call (which is placed on the meeting room door and communicated to the group); other times the topics come up in the same meeting. Topics may refer to the group they represent; the rest of the centre users who don't participate know that they have talk to the representatives to address the issues in the meeting. Personal issues may also arise that can affect a group in some way and are also addressed, e.g. if someone does not want to share a bedroom with another person. The topics that are usually dealt with are in relation to rights, the organisation's strategic plans, mourning, family issues, sexuality, couples, activities, and volunteering.

**Activities:**

- Meetings.
- Role-plays as exercises in dispute resolution.
- Video viewing.
- Campaigns on rights and visibility.
- Decision-making on very diverse topics: where they want to go on a trip, leisure, the organisation of the centre, volunteering and issues that come up from them or that their fellow-residents have passed on to them.

**Tangible results achieved:**

- Video about rights.
- Document on Rights in easy reading format.
- Adapted documents of the organization.

**Incidences and conflicts:**

Conflicts often arise in relation to the fact that everyone wants to talk and participate. The improvement of these skills (turn-taking, listening to the opinion of others and accepting that you do not always agree with what they have to say) is done through role-play; this demands great effort and continuous work on the part of the educator.

**Sign-ups and Drop-outs:** during these 3 years the composition of the group has remained stable, as the members have adapted to each other and have learned to work as a team. This took time and at first there were those who left voluntarily and those who the group decided to remove. The group does not accept people who lose their temper or make others uncomfortable.

There is no waiting list to enter. It is made up of people who are currently interested in this programme.

**Figura 2.7. A participant in the self-management group.**



**Source: Cercioeiras.**

## **PROGRAMME EVALUATION AND RESULTS**

Annual objectives are planned and the degree of achievement of each of them is evaluated. Questionnaires are used to see the degree of achievement and assessment of the dimension of self-determination.

### **Indicators:**

- Minutes of meetings and resolutions.
- Outcomes achieved in relation to those planned: the assessment is very positive. They carry out awareness-raising campaigns on rights; they have successfully launched volunteer projects.
- A key indicator is that the person wants to continue in the program.
- Through the satisfaction survey (see Annex I and II, prepared in accessible reading)
- Those included in the St. Martin's Quality of Life Scale

### **Results at the personal level:**

It is rated positively that the people who make up the group have improved in:

- Self-esteem.
- social skills and communication: they are less shy and better defend their position.
- Expressive ability.

Everyone perceives that the role they play is very important and that the voice of these people must be heard. The group of professionals has a very positive assessment of the programme.

In relation to whether their life goals or objectives have changed at the individual level, it cannot be claimed that it has been achieved (this comparison has not been made), but it has been found that their quality of life has improved, measured through the quality of life scale.

The community is more involved, everyone benefits from this active participation. Participation dignifies the person.

Each person has their Individualised 2-Year Plan. Their plan states whether the person is part of the group of self-managers and what support they need for it.

### **Barriers and challenges:**

The main barriers arose at the start of the programme. Families found it hard to understand what they were doing in the groups and that the decisions had to be taken by the people with a disability. Some professionals also found it difficult to accept that the decision is a matter for the individual person, sometimes perceived as a space that was used to express complaints about professional staff.

They solved it with clearer and more effective communication, and with joint meetings.

## **SKILLS TRAINING**

It is valued that the necessary skills to be in the group of self-advocates are:

- those of respect for others.
- understand, with the necessary support, the issues addressed in the meetings.
- show an interest in participating and desire to work.
- take responsibility for the commitments undertaken.

The groups have not received prior training. They receive the explanation and decide whether to participate or not; Then, as they develop in the group, they continue or not; and this decision to continue is made by the same participant or the group depending on the tasks performed and the relationship with the other group members.

### **Metacognition**

In relation to metacognition, self-determination is worked on at all times; It is a cross-cutting competence within the programme. Thus, decision-making and elections are fully incorporated into the model. In addition, it is prioritised that the chosen options emerge from the group. They are also invited to put themselves in the place of the other person, to reflect on what issues come up and to inquire about other positions of thought. This would be within the competence related to "teaching to think", which involves working on motivation, reflexivity, assessment of several answers, choosing, seeing the results and changing actions and decisions based on them.



## **COMPLIANCE WITH ERASMUS PRIORITIES**

**The centre and programme promote the following areas of work in relation to Erasmus priorities:**

**a) Social inclusion:**

- Volunteer projects: animal protection and food distribution.
- Very active role in the community.

**b) Digital transformation**

- Tablets and computers are used. They practice during the meetings.

**c) The environment and combating climate change**

They participate in at least three annual actions related to the environment:

- Beach cleaning.
- World Earth Day.
- Defence of animal rights. They are members of an animal shelter. This is linked to an environmental movement.

## **DISSEMINATION OF THE PROGRAMME**

From the beginning of the programme, the team explained what they were going to do to the partners and relatives, as well as to the centre professionals. They explained in assemblies and posted it on the website; they also used their monthly newspaper.

Additionally, in the group of self-, managers, dissemination articles are written, photos are selected, etc. News items are also posted on the centre's bulletin board.