Decider

Enhancing life experiences for adults with special learning needs, trainers and parents through supported decision-making

METHODOLOGY ON SUPPORTED DECISION-MAKING

Co-funded by the European Union

This manual has been written by the European partners that have collaborated to develop the DECIDER project. If you want, **pressing on** the following images, you can read more about the mission, goals and social projects that the different organisations are carrying out in their respective countries. Dive into our stories! Discover how we support people with disabilities!

Co-funded by the European Union

Decider

Enhancing life experiences for adults with special learning needs, trainers and parents through supported decision-making

OTWÓRZMY PRZED NIMI ŻYCIE

support GIRONA

Inclusió social i suport en la presa de decisions

Social inclusion and supported decision making

Laetu per gyvenimą!

Lietuvos sutrikusio intelekto žmonių globos bendrija

VILTIS

Co-funded by the European Union

TABLE OF CONTENTS

Co-funded by the European Union

1. FROM INSIDE THE DECIDER PROJECT

1.1 Brief introduction: our objectives and contributions

DECIDER is an ERASMUS+ project that aims to cover the lack of IT educational and training resources of staff working on the field of disability, through implementing of Supported Decision Making (SDM) methodology as a support service for people with disabilities aiming at the enhancement of their autonomy, independence and quality of life.

DECIDERs' goal is in line with Convention on the Rights of Persons with Disabilities (UNCRPD) and specifically, its article 12 which refers to equal recognition before the law and enjoying legal capacity on an equal basis with others in all aspects of life. Supported Decision Making has been proven as an efficient mechanism to implement legal capacity, it gives people with learning disabilities confidence and helps them gain self-determination and autonomy, however, no country has reached a satisfactory level of structural implementation. There are several barriers to achieve this, including the lack of knowledge, mechanisms, and professional resources to make feasible the change of paradigm. DECIDERs' goal is to investigate these issues, provide resources and contribute to the support measures for people with disabilities in exercising their legal capacity.

The project will target and involve all parties who are most closely concerned by Support Decision Making:

- People with special learning needs (intellectual disability, social disability, mental health problems, etc.), who will adopt the concept of supported decision-making and will gain better control over their lives, enrich their quality of life and participation in the community;
- Parents of people with special learning needs who will be educated and guided in the concept of supported decision making;
- Teachers, coaches, educators, volunteers and other supporters who will gain updated knowledge and implement SDM Rights-based services directly to persons with disabilities, and will reinforce the shift of organizations to a supported decision-making approach service.

The project DECIDER is implemented through the collaboration of six organizations from different fields of expertise related to the field of disability such as IT, provision of support services for people with disabilities, self-help organizations, educators, trainers, people with disabilities and support professionals. The diverse typology of profiles in the partnership enables a comprehensive approach to the main goal of providing a set of innovative, ICT-based and fully accessible educational tools that enable the implementation of supported decision-making methodologies.

Co-funded by the European Union

Project implementers and partners are Association for people with intellectual disabilities from R. Poland, Association for the Care of Persons with Intellectual Disabilities "Viltis" R. Lithuania, PODDRŠKA Foundation and Campus Foundation from R. Spain, the Margarita Vocational Training Center from R. Greece and Civil Center Aktivum from North Macedonia.

The project is being implemented between December, 2020 and May, 2023, with the financial support of Erasmus + program, K2 action strategic partnership - adult education.

1.2 What have DECIDER project developed? Beyond the results…

Within the project, several tools and resources on SDM will be developed:

- **Situation analysis** regarding decision-making status and processes in the countries involved in the project. The analysis will be based on the interviews with adults with intellectual disabilities, parents, therapists and trainers. The goal is to map and document realistic experiences, barriers and challenges in supported decision making for adults with disabilities in a form of **digital guide** for persons with special learning needs, their parents/guardians and supporters.

- **DECIDER application** for persons with special learning needs helps in decision making. New technologies help persons with special learning needs by enhancing their life experience. The application called Decision Maker is an online tool that can be used in everyday life when making decisions. When the decision maker wants to make a decision – he/she will choose the best solution among suggested solutions for which he/she gathers knowledge and which best fits his/her criteria.

- **An easy-to-read brochure** for supported decision-making for people with intellectual disabilities. It will contain information about the decision-making process, acquiring knowledge, taking responsibility, seeking support. Also, the Decision Maker application will be presented in the brochure.

- **Multimedia Package on Supported Decision Making for people with disabilities, their families, and supporters.** This package will contain interactive presentations for trainers, educational films with people with intellectual disabilities, games, as well as multiple-choice tests or other surveys.

- **Guidelines for professionals on the use of ICT based methodology on Supported Decision Making**. Preparation of a methodology for supported decision-making that includes an analysis of the basic elements and good practices identified in the Guide from the previous activity, and capitalizing on

Co-funded by the European Union

the basic elements in order to develop a universal process that should be incorporated into the service delivery structure of all partner organizations.

● **Pedagogical piloting of all the materials by the relevant shareholders.** Preparations to develop a universal decision-making training program. Professionals, trainers, educators, families and people with intellectual disabilities will be involved in the piloting.

Co-funded by the European Union

2. HOW CAN YOU USE THIS DOCUMENT?

People with disabilities under guardianship do not have the right to make their own decisions about important matters. A guardian makes choices for individuals about major life issues including personal health care, finances, whether to marry and raise a family, with whom to associate, and other day-to-day decisions.

The Convention follows decades of work by the United Nations to change people's attitudes and approaches to people with disabilities. It underlines the importance of viewing people with disabilities as full people with rights, who are capable of making decisions for their lives and being active members of society.

According CRPD, this Guide declares that people special learning needs(eg. intellectual disability, social disability, mental health problems etc.) must have the same human rights and fundamental freedoms as people without disabilities.
The main target group in this Guide are persons with special learning needs who will ultimately benefit from the projects outputs and outcomes. People with special needs will be empowered and have better control over their lives. And this has a direct consequence on their quality of life.
Supported decision-making gives people with special learning needs self-confidence and help them to gain self-determination and autonomy. Another group are parents, who should
be educated and convinced to supported decision concept. And finally are teachers, trainers and other supporters.

Thanks to this Guide, a significant group of end-beneficiaries will be introduced on supported decision making process and accessible tools because so far, supported decision-making has largely been talked about as an alternative to guardianship for persons with intellectual disabilities. The range of possibilities and methods will be spread. Thanks to this, persons with special needs will improve their capacity to self-determination, independent life and full social inclusion.

SDM thought this Guide will increase awareness, updated knowledge and implement Rights-based practice for professionals in the social sector or providing services directly to persons with disabilities (PWDs) as they will become aware of the expectation that in their work they now need to meet a relevant set of learning and practical outcomes and that their job involves fundamental Human Rights such as the right to legal capacity and to enjoy the maximum standard of support available.

Co-funded by the European Union

3. RIGHTS, LEGAL CAPACITY AND SUPPORTED DECISION MAKING

3.1. What does the article 12 of the *Convention on the Rights of the People with Disabilities* says?

UN Convention on the rights of persons with disabilities (UN CRPD) enshrines the fundamental rights and freedoms of the individual in relation to people with disabilities. It is the first comprehensive treaty in the area of human rights in the 21st century.

The convention changes the very understanding of disability, recognizing that disability is an evolving concept. It is "the result of an interaction between people with disabilities and attitudinal and environmental barriers that prevents them from fully and effectively participating in society on an equal basis with others."

In the preamble of the document, it is said that “The States Parties to the present Convention recognise the freedom of persons with disabilities to make their own choices and the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support “. Very often persons with intellectual disability need help or advise of parents, relatives or guardians, assistants, social workers or friends taking decisions.

Article 12 of UN CRPD says that the „States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law. The State Parties take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.“ One of such measures is Supported Decision Making.

3.2. What is Legal Capacity?

Legal capacity is the legally established ability of a person or organization to be the bearer of subjective rights and legal obligations.

Capacity covers day-to-day decisions, including: what to wear and what to buy, as well as, life-changing decisions, such as: whether to move into a care home or whether to have major surgery. The States Parties shall recognize that persons with disabilities enjoy legal capacity

Co-funded by the European Union

on an equal basis with others in all aspects of life. There are always ways to promote people's right to exercise their legal capacity.

The Committee on the Rights of Persons with Disabilities in the General Comments to Article 12 explains in details all the points of the Article. A usual practice of substituted decision making should be shifted to the human rights-based model that is based on supported decision making. Discriminatory denial of legal capacity is not permitted, it rather, requires that support be provided in the exercise of legal capacity. It is important to that Support be provided to a person in the areas he/she desires.

It happens that some persons with disabilities only seek recognition of their right to legal capacity on an equal basis with others and they may not wish to exercise their right to support. The person must have the right to refuse support and terminate or change the support relationship at any time. Legal recognition of the support person(s) formally chosen by a person must be available and accessible. It is necessary to foresee potential risks for the exercise of legal capacity; the risks must include protection against undue influence. The rights, will and preferences of the person with disability should be observed.

In its concluding observations on States parties' initial reports, the Committee on the Rights of Persons with Disabilities has stated that States parties must "review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences".

3.3. What is Supported Decision Making

The Supported Decision Making (SDM) promotes the person's independence and self-determination to the greatest extent possible. Supported decision making (SDM) is a tool that allows people with disabilities to retain their decision-making capacity by choosing supporters to help them make choices. The SDM can be used by any person, with any type, form of disability or condition, including persons with mental health problems, chronic illness, or conditions of aging. A person who wants to get help in taking decisions selects trusted advisors - friends, family members, professionals or a team of people. The advisors serve as supporters and help a person with disability to make his/her own final decisions in various life situation.

The SDM is an entirely different type of assistance. In SDM, the person retains decision-making authority. It does not grant anyone decision-making authority; it rather structures the decision-

Co-funded by the European Union

making support a person needs in order to make their own decisions. The consequences of not being allowed to make decisions, or of having one's decisions ignored, has been associated with increased likelihood of depression, anxiety, loneliness, and may worsen psychological symptoms. There are many ways to support someone in decision-making that promotes the person's independence and self-determination. A supporter and a person with disability can make a signed agreement. The agreement provides areas of assistance in which a supporter's help is required, the responsibility of both persons, the conditions for terminating. The SDM agreements don't need to be filed in court in order to be effective. The agreement comes into force after signing by both parties. Provision of the SDM service maximazis autonomy of people with disability, helps them to become more independent and be responsible for their decisions and actions.

Co-funded by the European Union

4. ENABLING PEOPLE WITH DISABILITIES AS DECISION MAKERS

4.1 Moving towards the Coproduction Approach

The purpose of this chapter is the defining of principles of equal partnership and collaboration between service providers and users in the framework of Supported Decision Making. The target groups of DECIDER co-production methodology are the stakeholders of this project, namely adults with mild and moderate intellectual disability, professional supporters, and relatives acting as guardians of people with intellectual disabilities who have reduced legal capacity. The co-production methodology will seek to achieve stakeholders' equal and active involvement, contribution to decision making activities, ensuring the effective participation and inclusion of people with disabilities, according to Article 29 "Participation in political and public life", Article 12 "Equality before the Law" and Article 13 "Access to Justice" of the Convention on the Rights of Persons with Disabilities (CRPD).

DECIDER partners have produced **a set of recommendations** to encourage a co-productive approach in decision-making.

1. Person centred planning: the approach on service planning must shift towards a person based one where the supported person him or herself is the main factor when shaping their decision-making plan and not his or her disability.
2. Experiential learning: to better adapt to the new paradigm and, in general, to adapt to the changing lives of the supported persons, special attention must be put on learning through reflection on doing from each one of the cases and from each one of the occasions where the supported person has taken a decision alone. The acquisition of skills like risk-management, responsibility and relevant to the decision digital, literacy and numeracy skills should be a core component of the support provided in the decision-making plan.
3. Train the supported person's relatives into the new paradigm: to simplify and synchronise the support strategies, supported persons' relatives must also be introduced to and trained in the new SDM paradigm and respect the opinions the member of their family with intellectual disability and encourage them to be more autonomous in decision making.
4. Specialisation of support: service providers, social workers, and other related professionals such as medical personnel must be trained accordingly at different levels (technical, legal, and ethical) to successfully comply with the new principles and be able to offer an effective and coordinated support. In this framework, there is strong need of developing ICT-based solutions to facilitate

Co-funded by the European Union

the implementation of inclusive education and SDM mechanisms. DECIDER app is an effort in developing ICT solutions.

5. Individual support: in order to offer a complete support to the supported person it is necessary to introduce and make use of all strategies and elements available in each case (e.g. personal assistants, housing services, medical personnel, public administrations, private sector, etc.).

There is of course a fundamental pre-requisite to all those recommendations, which is to have adequate legal frameworks: the introduction and development of the Supported Decision-Making principles must be supported by adjusting the laws to promote (first) and establish this approach as the only one legally valid.

Despite the limitations in legal frameworks, any organization can take the initiative and play a key role in SDM and changing the paradigm when applying co-production in service delivery by ensuring the following:

- Qualified interaction based on equality, patience, respect, and inclusion. Meaningful involvement of users and service providers (supporters or advocates, and healthcare staff) in decision-making about their future;
- Equal participation and representation of stakeholders regardless of gender, race, sexual orientation, religion, language, class, political or other opinion, national, ethnic, indigenous, or social origin, property birth, age, or other status;
- Gender-balanced representation and involvement shall be pursued in the framework of this project for all stakeholders' categories;
- All different opinions expressed shall be respected, in a spirit of listening and openness;
- Multimodal communication: The communication (in person or online) shall be adjusted to the needs and modalities of stakeholders. Alternative communication tools (i.e., images, symbols, easy to read material) shall also be developed to ensure the active participation of users;
- Holistic approach, which considers each person's strengths and knowledge; This approach requires blurring roles and shared power between service providers and users, meaning that all stakeholders will be involved in the process of SDM from the designing phase of the personal plan to testing, and evaluating the service;
- All stakeholders shall have access to useful information concerning decision making and relatable content, advice, and guidance;
- Any stakeholder's sensitive and personal data collected in the SDM service shall not be disclosed or transmitted to third parties without their formal consent. In addition, personal data shall be managed according to the Ethics Protocol of the service provider;
- The monitoring of this service is part of the responsibilities of the service provider and the facilitator;
- Users' involvement in SDM is based on their individual needs and supported by a contact person (family member or professional involved in the project) when it is needed and required by the users;

Co-funded by the European Union

- Professional supporters should have a variety and balance of specialties and scientific background.

4.2 A little story about ethical issues and human rights

Man as the only living being is free. Freedom is a privilege and a gift that other people limit in exceptional situations (e.g. breaking the law, mental illness). The right to be a free person results from the dignity that every human being has, regardless of their qualities, limitations, and disabilities.

People with intellectual disabilities can, like any human being, make decisions about themselves and their lives. Like everyone, they can make decisions that are unfavourable to themselves. It is natural for those who are close to them to want to protect them from the consequences of such decisions. The desire to protect people with intellectual disabilities from the suffering they may experience as a result of wrong choices is at the root of making choices for them, manipulating them, or incapacitating them. Meanwhile, these people have the right, as adults, to decide about their lives. No one is free from suffering, and each person experiences the consequences of their choices. Experiencing suffering, difficulties, making mistakes cannot be an excuse for other people to limit the freedom of another person. The exceptions are decisions that directly pose a threat to life.

People with intellectual disabilities need support in the decision-making process in order to make the best possible choices for themselves. It is difficult for people with disabilities to understand the conditions of the surrounding world and themselves. Support from the environment should be limited to help in understanding oneself, feelings and related needs, as well as highlighting the possible consequences of various choices in the most objective way possible. The supporter should help with the decision-making process and respect the final decision, even if they judge it to be wrong.

Recognizing the right of people with intellectual disabilities to make decisions is related to the concept of who a disabled person is and what rights they have. Over the last 50 years, it has changed. The *Citizen Model* (developed since the 1990s) is based on the idea of human rights and promotes the full participation of a disabled person in society. It is treated subjectively; it is considered that it should be made available to all opportunities that are used by the general public. The model promotes the principle that instead of constructing special programs and applying them in special institutions, people with disabilities should be supported in the environments in which they live.

Co-funded by the European Union

According to this model, it is not the disabled person who should be adapted to the environment, but vice versa - the environment should be adapted to their needs. Instead of programs prepared and run by professionals, a network of formal and informal support groups should be created for her to help her cope with the demands of everyday life. The place where a disabled person needs support is not an establishment or a special facility, but their own home, a school in the neighbourhood, or a nearby workplace. In the civic model, a person with a disability requires individual support tailored to his specific needs. The control over decisions concerning a disabled person is not exercised by the doctor or an interdisciplinary team, but by the disabled person - with possible help. The priority goal is not only to satisfy the basic living needs of the individual and change his behaviour - but self-determination and contacts with others as well as changing the environment and attitudes prevailing in it. Thus, the key elements in the civic model of a disabled person are:

a) Full participation in family life and in the life of the community - the place where people with disabilities have the right to live is the community and local environment, and not some incidental forms of social life; it is similar with the family - a person has the right to live in it, not to be torn from it and transferred to specialized institutions;

b) interpersonal relationships - being part of a community means that an individual has lasting relationships with other people, not only with those who are paid for it; natural systems of social support are not available to people living in special institutions; an important aspect is physical integration with the environment – eg living in a normal apartment in the local community;

c) functional and personalized programs - functional programming focuses on developing the skills that are needed by an individual in his specific life situation; functional programming does not disregard the need to learn, but assesses the need to acquire a given skill in terms of whether it will enable the individual to appear in the environment and contribute to its better integration;

d) flexible and individualized forms of support - their essence is to enable people with disabilities to be independent, make their own choices and control their lives.

In the modern approach to disability, it is pointed out that a person with a disability has exactly the same rights and freedoms as every human being, and that discrimination of any person on the basis of their disability is an offense against human dignity and worth. The potential, talents and abilities of people with disabilities as well as their knowledge, skills and experience should be used for the benefit of these people and society as a whole. Numerous environmental and mental barriers, which are the causes of discrimination against people with disabilities, should be identified and limited through the reconstruction of the environmental infrastructure, institutional structure, legal regulations and social awareness. Solving the problem of disability consists in rationally adapting the physical and social environment in which people with disabilities live to their needs, expectations and possibilities.

Co-funded by the European Union

Refusal to rationally adapt the environment to the special needs of people with disabilities is a manifestation of discrimination, people with disabilities have the right to autonomy and independence, including the freedom to make their own choices.

Disability in modern terms is a broad concept that includes not only damage to the body, but also limitations in the activity of people with disabilities and their participation in social life. In the light of this approach, the main issues in solving the problem of disability include removing barriers and creating facilities in human functioning.

The most characteristic feature of the intellectual functioning of people with intellectual disabilities is cognitive impairment. This damage may cause difficulties in:

a) Understanding and performing even simple tasks,
b) communication,
c) remembering and using knowledge and previously acquired skills,
d) associating, concluding and predicting,
e) recognizing emotional states, which may problems in social situations.
f) acquiring new knowledge and skills, with storing and recalling information, and with using knowledge in new situations.

Therefore, there are memory disturbances, especially short-term memory problems. Likewise, one of the important characteristics of intellectual disability is the low ability to so-called learning involuntarily, that is, unplanned, from everyday experiences and observations. People with intellectual disabilities often require teaching each task directly, they learn first of all practically by participating in life situations. Regardless of their limitations, these people have the right to self-determination.

The practice of incapacitating a person with disabilities for their benefit is a violation of their fundamental rights to freedom and respect. The task of the community in which people with disabilities live is to develop mechanisms other than incapacitation that protect people with disabilities from the serious negative consequences of their decisions.

Co-funded by the European Union

4.3 Barriers, challenges and limitations to Supported Decision Making

4.3.1 Stereotypes and stigma

There has always been an opinion that people with intellectual disabilities cannot make decisions and live independently. This opinion became a "belief" which took the form of prejudice (ideas strongly entrenched within society). People with intellectual disabilities from an early age abstain from the decision-making process and when they reach adulthood, they are not able to make decisions.

Stigma refers to the state of marginalization of a subject from society as a whole, which bears characteristics unacceptable to society. It is not an inherent social characteristic but is created through social interaction between the stigmatized individual and the members within the community. The stereotype concerns a set of generalized beliefs about the characteristics of the members of a social group. Both concepts have been studied mainly in social psychology.

Stereotypes give meaning to the world that surrounds us and are associated with prejudices: evaluation – often negative – of the person without knowing it, with attitudes of stigma: social distancing, distrust, fear; and possibly with discriminatory behaviors: avoidance, rejection and exclusion.

The person who is not taken into account is often treated less well than others when it comes to access to work, care, housing, or services such as leisure. This less favorable treatment is called discrimination. Stigma comes from a devaluation of the human being, while discrimination involves an action / act to harm and set aside the human being. (Qualitative analysis of mental health service users' reported experiences of discrimination, 2016).

Research has found that due to stigma, people with disabilities cannot claim basic human rights, independent living and equal participation in issues concerning the local community (Buljevac et al., 2012). It also seems that people with intellectual disabilities face more negative stereotypes than people with other types of disabilities (sensory, kinetic, etc.) and tend to withdraw socially and not be supported in asserting their rights (Werner, 2015).

The way attitudes will be shaped is mainly influenced by the culture of the society from which we come (Ingstad and Whyte, 1995. Nicolaisen, 1995. Bakheit and Shanmugalingam, 1997. Stone, 2001. Rao, Sharmila and Rishita, 2003). The connection of individuals with the concept of the different and

Co-funded by the European Union

the constant dependence on others (Corker, 1998), influenced and further developed the prevalence of stereotypes and erroneous beliefs (Morris, 1991).

In various surveys in recent years, while a generally positive attitude seems to prevail, in reality people's opinions tend to be more negative than expressed (Hermandez et al, 2000). The same is observed in relation to health professionals, who due to their work focus on the difficulties of individuals, which can negatively shape their opinion (Amosun et al., 2013), as well as influence their subsequent intervention. (Paris, 1993. Martin et al., 2005. Jackson, 2007. Morrison, George, Mosqueda, 2008). In addition, from a fairly young age, their participation in sexually explicit discussions is not accepted, because there is a belief that they do not have sexual relations. In this way, sexual relations are indeed not achieved due to social interference (Shakespeare et al., 1996).

Informing society is a way of eliminating negative attitudes, combined with its interconnection with the individuals concerned (Trawick, 1990). For positive attitudes to prevail, it is necessary to strengthen people with disabilities and to develop the belief that they have the ability to make decisions from which they will benefit themselves. It is also necessary for them to realize that for them too there is the possibility of living a normal life. It would be beneficial to create appropriate circumstances through which individuals can promote their dynamics and contribute to the community (Tervo et al., 2004).

4.3.2. Levels of Decision: high supported decision making and low supported decision making

WHO Quality Rights Specialized training course guide refers that Article 12 clearly states that all people, including people with disabilities, must have the right to make decisions for themselves and to have those decisions respected by others, and that their decisions are to be recognized as valid decisions under the law. Article 12 provides protection for both formal decision-making and informal day-to-day decision-making.[1]

This practically means that people with disabilities, including intellectual disabilities, have the right to make every decision, including what to wear, when and what to eat and drink, what to do during the day, including work, who to spend time with, such as friends and family, how to spend leisure

[1] *Supported decision-making and advance planning. WHO Quality Rights Specialized training. Course guide*

Co-funded by the European Union

time, including travel, when to shower, when to go to bed, where to live, what healthcare to receive, how to manage finances, etc. And therefore "should be routinely asked about their wishes, preferences, and decisions – for all types of decisions, large and small." [2]

Some of the decisions they make may be simple decisions of everyday life or even more occasional, but they usually require little or no support at all. Some others are more complicated and important and require more support and advice. By complex decisions, we mean decisions which may require the decision-maker to understand and process greater quantities of, or more difficult, information, or wider and/or more abstract potential effects. Such decisions usually include "managing finances and investments, medical decisions and legal decisions like wills, power of attorney and advance decisions to refuse treatment or end-of-life planning." [3]

Kinds of decisions	Routine	Occasional	Rare	Exceptional
Simple	Meals, Entertainment, Clothing	House decoration, Buying gifts	Going to the circus, Hairstyle change	Growing a beard
Important	Exercise, diet, Personal Relationships	Selection of support staff, Birth control	Medical treatment, Pets	Bereavement
Complex	Personal Relationships	Holiday	House move	Life-changing surgery

> "The amount and type of support that is required will differ from person to person and be dependent on the decision that needs to be made".[4]

Other variables that should be considered include the decision-making ability components:

[2] *National Disability Services, 2019. People with Disability and Supported Decision-Making A guide for NDIS providers in NSW.*

[3] *Supported Decision-Making from Theory to Practice: Implementing the Right to Enjoy Legal Capacity, Rosie Harding and Ezgi Tascıoglu*

[4] *Supported Decision-Making, A Framework, Developed by People First (Scotland).*

Co-funded by the European Union

- **Information** – the amount and quality that is available to the decision-maker and how understandable it is.

- **Number of options** and how familiar they are to the decision-maker and how readily they can be compared to each other in the process of weighing them up.

- **Awareness and understanding of consequences** of deciding on any of the options, including the attitude of other significant people in the decision-maker's life.

- **Personal security** – this is made up of confidence, level of self-esteem, previous experience of making decisions, awareness of rights, willingness to risk disapproval versus drive to seek approval.

- **Linking and connecting ideas** – since most decisions have different elements and components such as "if this, then that..."

- **Communication –** both in ability to hear and understand information and to articulate one's own ideas, preferences and reservations and includes the ability to seek clarification of information

- **Comfort with new experiences and with risk –** where the decision-maker has had very limited experiences and has a fixed pattern, it will be much more likely that there will be discomfort in deciding to try something new or unfamiliar. Similarly, if the person has been brought up to be afraid of risk, that will affect decision-making.

Some decisions need low level of support, others medium level and others high level.

The following diagram shows the different level of support that is needed depending on the kind of decision but also considering the aforementioned variables according to the Framework for Supported Decision-Making that was developed by People First[5].

- In general, **low-level support** involves the supporter providing information, perhaps discussing the decision and possible outcomes or consequences with the decision-maker and reviewing the decision at a later point (if this feels necessary).

[5] *Supported Decision-Making, A Framework, Developed by People First (Scotland).*

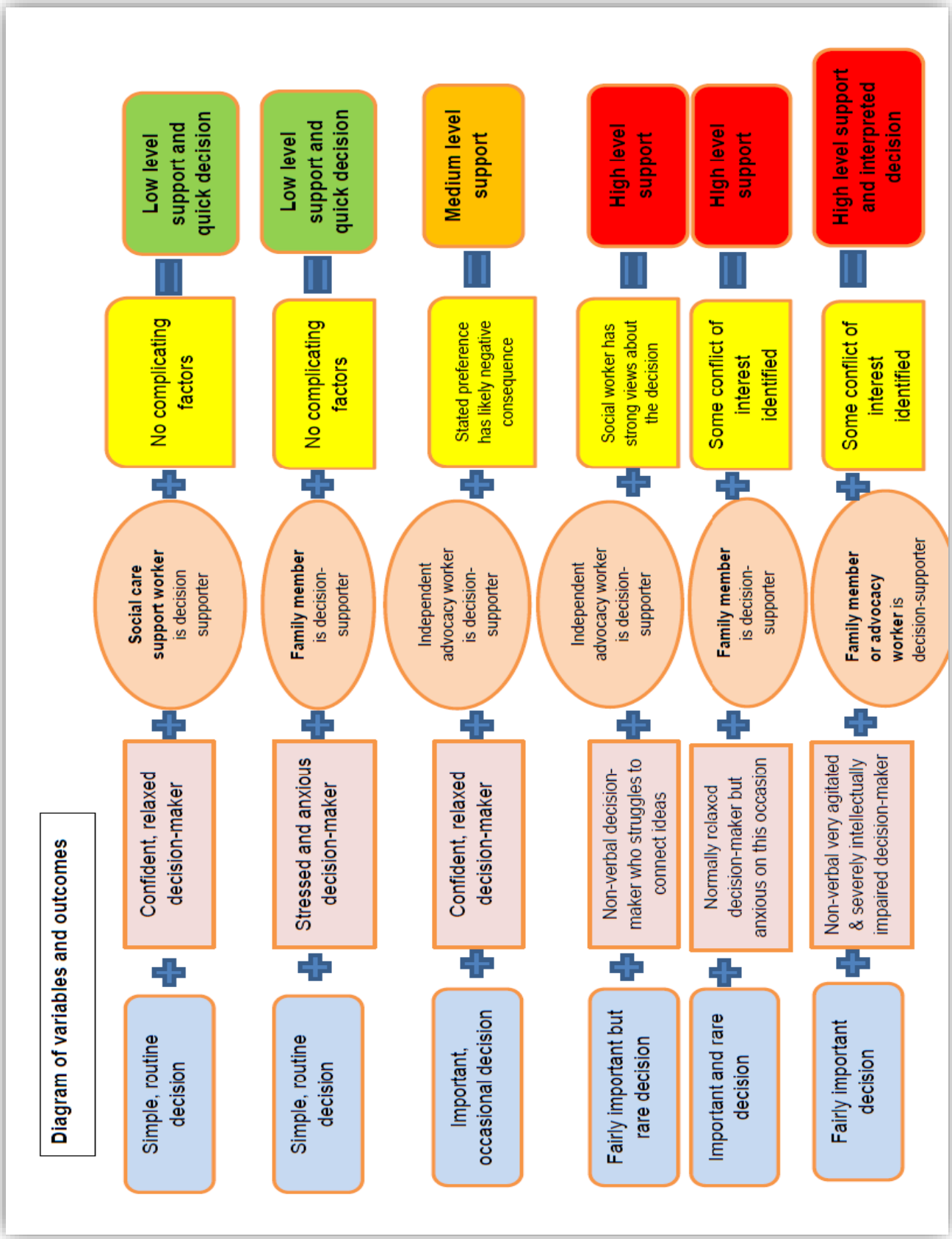
Co-funded by the European Union

- **Medium level support** would include all of these elements, but more time will be allocated for the supporter to discuss the decision and the different outcomes and consequences with the decision-maker. The decision-maker may need more time to make the decision or may feel less confident in making the decision.

- **High level support** also incorporates the elements mentioned above but the support is expected to take place over a longer period of time, with more input from the supporter regarding exploration of options, and it is possible that the information relevant to the decision needs to be shared on a few occasions – when the decision-maker is ready to receive it – and the decision made reviewed on a few occasions to ensure the decision-maker is committed to the decision and genuinely wants to follow through with it.

- **Interpreted decisions** is where the person is either unable to verbally communicate will and preference or has great difficulty in doing so. This could be because of limited communication or severe intellectual impairment or for any other reason. In this instance, the decision-making supporter has to interpret what the person's will and preference are or are most likely to be. The supporter does this through close relationship with the person, intimate knowledge of the person and his or her likes and dislikes and skillful reading of the facial expression, body language and sound cues given by the person.

Co-funded by the European Union



Co-funded by the European Union

4.3.3. Understanding the severe and complex disabilities

People with severe and profound intellectual disabilities usually present a large percentage of multiple handicaps (cerebral palsy, vision or hearing problems, emotional disorder etc.). These people will have more difficulty in school, at home, and in the community. A person with more severe intellectual disability will need more intensive support his or her entire life[6].

The following table shows the classifications of intellectual disability severity and the support needed depending on the severity.

Table 1. Classifications of Intellectual Disability Severity (adapted from Clinical Characteristics of Intellectual Disabilities, 2015).

Severity Category	Approximate Percent Distribution of Cases by Severity	DSM-IV Criteria (severity levels were based only on IQ categories)	DSM-5 Criteria (severity classified based on daily skills)	AAIDD Criteria (severity classified based on intensity of support needed)
Mild	85%	Approximate IQ range 50–69	Can live independently with minimum levels of support	Intermittent support needed during transitions or periods of uncertainty
Moderate	10%	Approximate IQ range 36–49	Independent living may be achieved with moderate levels of support, such	Limited support needed in daily situations

[6] *American Association on Intellectual and Developmental Disabilities.*

Co-funded by the European Union

			as those available in group homes	
Severe	3.5%	Approximate IQ range 20–35	Requires daily assistance with self-care activities and safety supervision	Extensive support needed for daily activities
Profound	1.5%	IQ <20	Requires 24-hour care	Pervasive support needed for every aspect of daily routines

The right of people with severe and complex disabilities to decide can be realized with more support on how to make those decisions. [7] "However sometimes, no amount of support will enable a person with a disability to make a very difficult or complex decision." [8]

In these cases, some countries provide for either interpreted decision-making where others substitute decision making.

A recent research showed that "the amount of support available to disabled people from frontline care professionals appeared to reduce in an inverse relationship to the complexities of the decision they needed to make. So, for example, whereas day-to-day financial matters were relatively well supported, there was very little engagement with more complex financial decisions, which were instead passed on to more senior levels within an organizational setting."[9]

[7] *National Disability Services, 2019. People with Disability and Supported Decision-Making A guide for NDIS providers in NSW.*

[8] *Supported Decision-Making, A Framework, Developed by People First (Scotland) pg12-13*

[9] *Supported Decision-Making from Theory to Practice: Implementing the Right to Enjoy Legal Capacity, Rosie Harding and Ezgi Tascıoglu*

Co-funded by the European Union

4.4. Facilitators, enablers and cooperation mechanisms to SDM

4.4.1. A paradigm shift

After the legal change promoted by the Convention on the Rights of the People with Disabilities, the people with disabilities and/or mental illness can make their own decisions. This implies that the professionals and, also, the families that try to support them need to change their beliefs around mental health and disability, their approaches and their methodologies. In some cases, that could mean respecting the choices of the people with disabilities although these cause problems or generate undesirable consequences. Mainly, the professionals must recognise that they are human beings and, therefore, they have the right to commit mistakes and learn from the consequences associated with those.

Then, the *Supported Decision Making* is based on -and promotes- the respect of the human rights of the people with disabilities. This strategy teaches them how they could, at least, analyse the risks before making a decision and how to weigh their possible results. Moreover, the *Supported Decision Making* implies that the professionals should try to build a bond with the people with disabilities. But, this relationship can never mean that they decide, as reference figures, without considering the preferences, desires and objectives of the supported people. Behind the *Bond of Support*, the professionals must explain the process to obtain the collaboration of the people and their participation throughout the different phases. They will encourage them, giving them the necessary tools and advice, to make their own decisions considering what they want to achieve in their lives.

On the other hand, the professionals, to implement and facilitate the *Supported Decision Making,* must clarify these most difficult and complex issues using an adapted language, always finding that the people with disabilities understand the importance of deciding on their lives. We could say that they have the right to define their future, establishing their goals and developing their vital projects. In fact, the Decision Making process has three cornerstones: (1) the *Bond of Support,* (2) the *Agreement* that both the people with complex needs and the professionals should sign and (3) a constant review of the conditions and outcomes derived from this contract. The professionals will take into account that the people that need support

Co-funded by the European Union

can decide what services they will receive and, really, how they want to obtain it. The people with disabilities will write, jointly with the professionals and families, the conditions and requirements of the agreement. In consequence, the *Supported Decision Making* supposes a, always into the possible limits, a symmetric relationship in which they are the protagonist instead mere spectators.

Summarizing the previous observations, the protagonist of the decision making are, under any circumstance, the people with complex needs. And the professionals only can provide their support when, where and how these people decide, looking for their collaboration and cooperation.

4.4.2 Community Based Services

Traditionally, the people with disabilities have not had the opportunity to decide on their lives. Previously to the legal change already mentioned, they could not make decisions nor protect their rights. Often, the public authorities preferred to prevent possible setbacks and social conflicts by enclosing them into institutions given their behavioural problems and symptoms. On the contrary, nowadays, the professionals are contemplating other ways to support them without using violent treatments or without causing their social isolation.

The professionals consider that social inclusion is a necessary condition of any psychological and social intervention. We should not deny the right of the people with disabilities to establish, reinforce and maintain their social relationships with their families, friends and neighbours. Therefore, the services must be based on a community approach considering that the relationships that the people have built or could build are the best mechanism to ensure their recovery, well-being and happiness. If these groups, especially vulnerable, are away from their communities, the professionals cannot wait for a quick improvement of their psychological equilibrium nor of their quality of life.

The people with disabilities, as the rest of the persons around them, have social and affective needs. If we don't take into account these needs and feelings, adopting this community approach as a work strategy, we could generate frustration and undesirable behaviours that, precisely, the professionals pretend to prevent. These social needs that the professionals should attend are:

Co-funded by the European Union

a) The people with disabilities need social and emotional support from families, friends and communities. This support necessarily implies understanding of the moods and internal conflicts that these groups with disabilities could experience because of their circumstances.

b) The people with disabilities also need to provide support to their families, friends and communities feeling that they contribute with their well-being. In fact, related to this need, the professionals will find that the people with disabilities need to feel that their contributions are useful and have impact on their social circles.

c) Finally, the people with disabilities need to feel that they are part of their communities and, in consequence, need to build a social identity that defines aspects of their personality giving them common objectives. We should remind the professionals that the community could be considered a source of self-esteem, vital goals and self-confidence.

Then, the community based services are the mechanism to satisfy these crucial social needs. And, at the same time, are the way to improve the self-esteem and self-confidence of the people with disabilities. In consequence, this approach promotes the psychosocial balance of the people with disability, preventing their social isolation and their adaptive behaviours.

Finally, we should highlight that the community based services promote, as we have introduced previously, the collaborative and cooperative work between professionals and people with disabilities considering the reciprocal respect is the most important principle. Then, the professionals that work with this approach should establish the active participation of the people with disabilities and, jointly, they must achieve an agreement considering what contributions their families, friends and communities could provide to facilitate independent living.

4.4.3 Training on Human Rights and Supported Decision Making

Given how the legal paradigm has changed, the professionals need to know the content of the *Convention on the Rights of the People with Disabilities.* But, also, the professionals need to receive training on *Quality Rights*, an initiative promoted by WHO. This means that we should provide knowledge about:

Co-funded by the European Union

a. What are Human Rights? Moreover, the professionals that support the people with disabilities need to know the interconnections between these Human Rights. In fact, as article 12 of the mentioned convention remarks, the people with disabilities have the right to make their own decisions and, consequently, the professionals should provide support to promote the decision making. Throughout these decisions, the groups with complex needs will be able to control their lives, defining their own vital project.

b. The professionals should learn how to establish a solid *Bond of Support* and agreements *with the people with disabilities*, always taking as a reference point their preferences, wishes and will. Further, Human Rights imply taking into consideration their will, even when the professionals think that the possible consequences derived from the decisions will be problematic. We will remind the professionals that the mistakes are learning opportunities. And these negative experiences could be defined, then, as knowledge and vital lessons for life. After all, the people with disabilities need to overcome their difficulties, obstacles and resolve their problems by themselves to improve their skills and, thus, increase their autonomy.

c. The professionals should learn how to identify the stereotypes, stigma and abusive situations to prevent the negative impact that these unfair experiences could have on the people with disabilities. Beyond that, the professionals should transmit their knowledge to help and empower the most vulnerable groups to detect when someone is harming their rights. We need to keep in mind that the people with disabilities have the right to protect their freedoms and their right to make decisions without more interference than the limits imposed by the norms.

Related to the Supported Decisions Making, the professionals should acquire and train skills to identify the needs and desires of the people with disabilities. These skills imply learning what needs the most vulnerable groups often want to satisfy (and what obstacles they frequently find to achieve it). Additionally, the professionals should have competences as: active listening, rhetorical techniques and other communicative

Co-funded by the European Union

strategies to facilitate the understanding of the emotions, thoughts and decisions of the supported people.

At last, the professionals need to obtain strategies to establish, define, review and adapt work plans to ensure that the support provided is the most appropriate to each person with complex needs. One of our main aims is to personalize the attention the people with disabilities receive based on, as we have highlighted, Human Rights and community based approach. Then, as we will show throughout the methodology, broken down into different phases, the most vulnerable groups have a vast spectrum of needs and wishes and have to face different difficulties. All that implies an enormous effort to describe them to adapt the services provided to the specific circumstances that the people with disabilities are experiencing.

4.4.4. Assessing and managing risks: decisions and learning processes

When people with disabilities make decisions, they have to take into account the risks that those choices imply. Often, the people interpret them only as final consequences [10]that should prevent. But, those appear before, much earlier in the decision making, and are not always frustrating failures and losses. On the contrary, the risks teach us important lessons about how to manage challenging situations and how to resolve problems. People with disabilities should consider –and analyse- the risks even when they are identifying what alternatives have to satisfy their needs.

Therefore, we understand the risks as psychosocial processes. These processes show how the people's emotional and thinking patterns and their behaviours place them in a damaging position. We have to consider, at the same time, their needs, problems and

[10] The traditional definition of risk mainly contemplates the negative consequences that the people have to face **after** making their decisions. We have underlined **after** to show that both professionals and people with disabilities forget what risks could appear **while** they are making these decisions. Beyond the final results caused by their choices, we will focus our attention on the risks that emerge while the individuals are thinking what they will do. Then, we do not only take into account the risks as "losing money", "breaking emotional relationships" or "health problems". We will analyse the psychosocial processes implied in the decision making. Those will influence if the people can prevent, manage or reduce the final risks and, therefore, will define their *Risk Position*.

Co-funded by the European Union

conflicts. Related to this brief definition, developed in the following pages, the risks arise from the interaction between people with disabilities and their environment. Then, it is important to know how a specific situation influence them, motivating their decisions and actions. In equal measure, it is fundamental to discover how their acts have impinged and will influence their environment. In fact, this interpretation respects and promotes the human rights and social values recognised in the *Convention on the Rights of the People with Disabilities*.

As we have commented, these psychosocial processes, understood as risks, place the people with disabilities in a vulnerable position. We will name this "Risk Position". Depending on its severity, determined by different circumstances that we will describe below, the individuals could suffer losses and hurtful experiences.

In the decision making process, people with disabilities carry out different actions:

(a) Identify what alternatives and options they have.
(b) Identify their resources (knowledge, skills, tools, money, social support…) and plan how to use them.
(c) Value and weigh the possible solutions, understanding them as strategies to resolve problems and conflicts and action plans to achieve the personals aims.
(d) Put into practice the action plans and strategies causing desirable and undesirable consequences.

Commonly, people with disabilities -also the professionals that support them- focus their attention only on the last mentioned action, when they want to materialise their plans. Then, would they be assuming that the rest of described acts don't imply risks? We have found that when people only take into account the final consequences triggered by their choices, the risk assessment is not the most appropriate. Given these circumstances, we think that it is essential to analyse the risks that people should observe to make the best decision. To make easier this assessment, we have developed the ***Scheme of Risks and Learning Processes***:

(1) The professionals have to consider how the *Number of Perceived Alternatives* affects to the people with disabilities that need to make a decision. If the attended people perceive many options, they will find problems to analyse them with depth. Surely, people will not be able to contemplate all the potential negative and positive consequences. On the other hand, people with disabilities could have not the sufficient alternatives to satisfy their needs and resolve their problems. In these two scenarios, the professionals should keep in mind the possible cognitive, emotional and social risks. The most vulnerable groups could

Co-funded by the European Union

experience anxiety and overwhelming worries. In any case, the professionals and, clearly, people with disabilities need to manage these risks that could affect negatively to the strategies and plans conceived.

We have to highlight that the *Number of Perceived Alternatives* takes as starting point how the people with disabilities contemplate and interpret their world. This means that, beyond the objective circumstances, it is important to know from what position the individuals perceive their problems, conflicts and social networks. For this reason, the professionals should also identify if the people with disabilities tend to overestimate or underestimate their options increasing the probability of suffering the psychological effects commented previously. For example, when someone tends to overestimate his/her alternatives, they could perceive that have many options within his/her grasp.

(2) People have to identify what resources they will use to achieve their objectives satisfying their needs thus. In fact, the professionals should encourage them to reflect about what resources are the most appropriate to face a concrete situation. Likewise, if the people with disabilities really want to resolve their problems, they have to think how to use their resources. Before using them, they need to prepare an action plan. In this phase, the professionals also should assess if the individuals are overestimating or underestimating their resources. The professionals should keep in mind the following risks:

(2.1) If they have overestimated their resources, probably they will make decisions and act thinking that can use resources that they don't have really. In these cases, their plans will be based on unrealistic premises and their chances of success will decrease.

(2.2) If they have underestimated their resources, likely they will not include all the resources that really have in their action plans. This could affect to their strategies to resolve problems and conflicts. Even, it could push them to rethink their goals renouncing to satisfy essential needs or to assume that they will never reach some aims.

Above all, when people with disabilities tend to underestimate their resources, the professionals should value their self-esteem and what negative beliefs they have on their competencies. For example, if the individuals think that they don't control their

Co-funded by the European Union

environment and that cannot change their circumstances, probably they will believe that have insufficient resources to satisfy their needs. We could translate this as people with disabilities, after weighing their resources, feel that they are not ready to face their daily challenges because of they don't have the necessary knowledge, skills and/or social support to overcome them.

(3) After planning how to act, people with disabilities need to assess their possible solutions. These potential solutions are, in practice, different strategies and action plans. This implies that they have contemplated carefully their options. To each of these alternatives, they have thought different ways to resolve their problems and to reach their wishes. Then, professionals should take into account the *Assessment of the Possible Solutions*. In any case, people with disabilities tend to assess their action plans considering mainly the *Expectations of Result*. This means that they will imagine the causes and consequences of their decisions and actions. It is frequent to find people worried for the results derived from their acts, thinking further how those will affect to their self-esteem. The risk appears when people need to make an important decision, but their forecasts related to the possible results of their acts are, at least, not very optimistic. In these cases, the people's motivation could decrease and this circumstance would influence their performance given that they will assume that their action plans are not effective. Summarizing this process:

> (3.1) People with disabilities have more or less optimistic expectations related to the results that their acts will have. They wonder <<will we achieve our goals and satisfy our needs?>>
>
> (3.2) After that, they will assess their plans and strategies basing on their *Expectations of Result*. If they believe that their efforts will not obtain promising results, then, how will they evaluate their strategies? At the same time, the strategies planed could influence their expectations.
>
> (3.3) Depending on the *Expectation of Result* and *Assessment of the Possible Solutions*, people could see how their motivation and self-esteem diminish while their negative feelings increase. Moreover, the professionals should keep in mind that the performance depends on the motivation and on the emotional balance.

(4) People with disabilities already have assessed their possible solutions to their problems and conflicts. Now, they should make a decision. They will choose the action plan that, probably, gives better results. This implies that they have compared their range of strategies, basing on their *Expectations of Result* and *Assessment of Possible*

Co-funded by the European Union

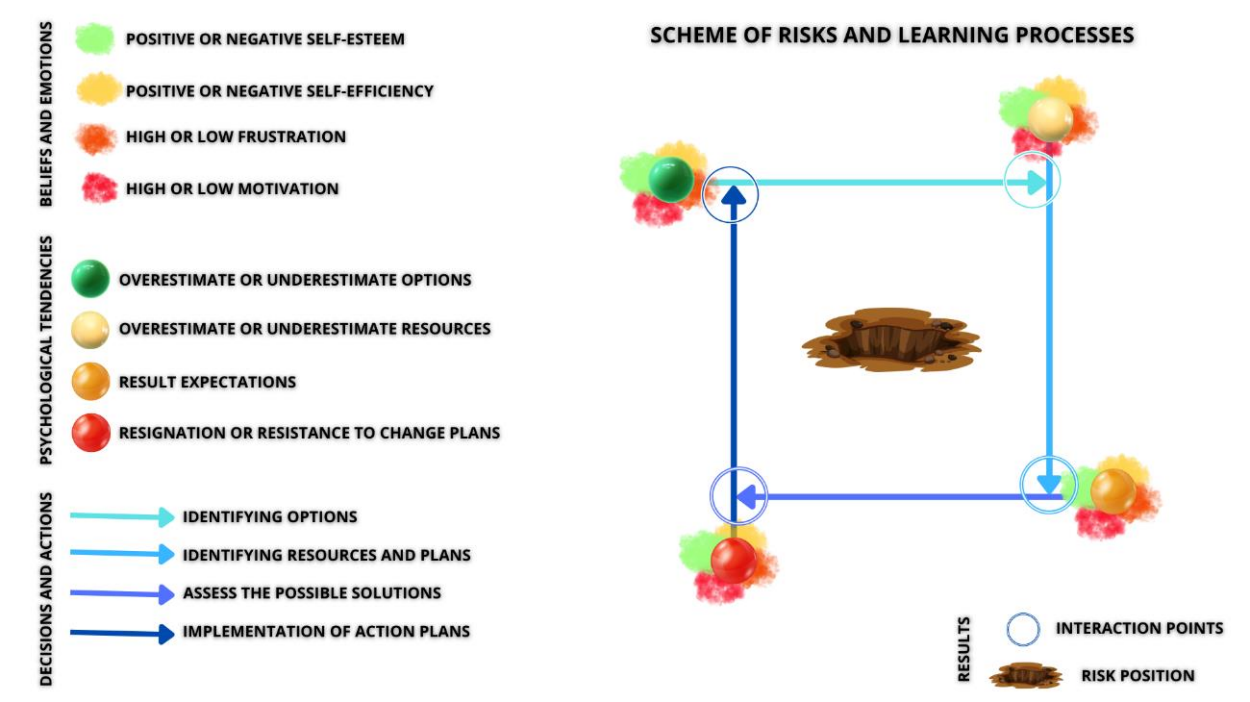
Solutions. After that, and considering their emotions, worries and hopes, they can choose what plan they will put in practice to achieve their objectives.

The professionals should remind to people with disabilities that, frequently, when they are putting in practice their strategies, the situation could demand them change aspects of their plans. Even the best action plans need to be modified. In these circumstances, the main risk that could appear is the stiffness. People with disabilities should keep in mind that they will need to change their actions. Above all, if they want to overcome their challenging situations and prevent setbacks. Then, at this point, the professionals have to consider two tendencies:

> (4.1) When people refuse changing their plans, trying to impose their wishes without contemplating their real circumstances. We could interpret that as *Tendency of Resistance to Change*
>
> (4.2) On the other hand, the people could change with extreme ease their plans, ignoring their own needs, desires and objectives. Here, we could include these individuals that accept immediately the influence that other people try to exercise on them. Also, we contemplate within this group those that assume their circumstances (difficulties, problems and conflicts) as immutable facts. In this case, people with disabilities show the *Tendency or Resignation to Change*.

In these scenarios, people with disabilities could experience frustration, anxiety and other negative emotions. But, moreover, they could see how their motivation plummets.

Co-funded by the European Union



The professionals should not forget the learning processes. Those are present in all the phases of the decision making. In fact, probably, the most important aim of this European project is promoting skills to make better decisions, using digitals tools to achieve this objective. And, if the professionals pretend to support people with disabilities to develop these abilities, they need to keep in mind that those imply learning processes. However, at this point, we have to underline that we will consider, mainly, two types of learning processes:

(1) *Beneficial Learning Processes:* These learning processes that allow people resolve their problems and conflicts and achieve their objectives, satisfying thus their needs. These processes will have adaptive results.

(2) *Harmful Learning Processes*: Learning processes that hinder them overcome their difficulties and carry out their projects. Those will have results not very adaptive.

Basing on the *Scheme of Risks and Learning Processes*, we will take into account that people with disabilities have learned to overestimate their options and resources to deal with their negative emotions. We could interpret this psychosocial tendency as self-protection mechanism. Frequently, people with disabilities don't know how to manage their frustration, fears, insecurities or, even, the anxiety caused by the daily

Co-funded by the European Union

uncertainties. Moreover, as they have difficulties to identify and understand their own feelings, they don't even know what emotions they have to deal with. On the other hand, sometimes, their families, friends and therapists don't provide them useful tools to help them to manage their emotional reactions, experienced specially after unpleasant livings.

If their anxiety and frustration decrease considerably after overestimating their alternatives and resources, this strategy could become in a psychological trend or pattern given its apparent usefulness. After all, the people learn from their successes and failures[11]. And reducing their negative feelings supposes, in their view, a truly success regardless of the used methods. Nevertheless, in this way, people with disabilities will never know how to manage their emotions. As, probably, they will not be able to achieve their objectives, their demotivation, frustration and insecurities will increase. When it happens, they could begin to underestimate their resources, ignoring even these supports that their families and therapists can really provide them. After that, it is very frequent to find that their self-esteem is terribly damaged. If they think that they don't have sufficient opportunities or resources to achieve their aims and, furthermore, their motivation and self-esteem are extremely low, what *Result Expectations* will they have? Surely, they will believe that their action plans and strategies will not have the desirable results.

The professionals could study how these *Harmful Learning Processes* promote and strengthen the psychological tendencies described, as, for example, the tendency to underestimate resources. At the same time, these learning processes feed the negative emotions and consolidate the erroneous beliefs that hinder to people with disabilities develop skills to manage correctly their problems. Above all, professionals could use the *Scheme of Risks and Learning Processes* to organise the information expressed by the service users. Also, this method could be useful to understand and explain the problems that the individuals find when they make decisions. Here, we have to highlight that the *Risk Position* depends on these learning processes, harmful or beneficial. We recommend professionals act on the points where the psychological tendencies, throughout their emotional consequences, reinforce themselves.

[11] The people with disabilities learn from the negative and positive consequences of their acts given that, after making their decisions, reflect on these results. In some situations, they will assess deliberately their decisions to understand why they have not –or have- achieved their aims. Instead, under other circumstances, they will try to discover what it has happened instinctively dragged by the frustration or any powerful emotions. In any case, their acts are means to satisfy their needs and to resolve their problems and conflicts. If their decisions don't have the desirable results, then, probably, they will have to rethink their action plans. We are basin these premises on the Operant Conditioning.

Co-funded by the European Union

After defining the risk as process, the professionals should take into account that people with disabilities can learn, positively, from their emotions, decisions, actions, failures and successes. In fact, our efforts must be intended to enable their *Beneficial Learnings* and personal development. The professionals have to consider:

(a) After making decisions, people could learn that they have more options and resources than those that they believed. Or, instead, they could learn to pinpoint how many alternatives and resources really have to satisfy their needs when they tend to overestimate them. After all, people need to identify what means they have to resolve their problems, if they pretend to prepare an effective action plan. Moreover, they need to appreciate their real skills.

(b) Basing on their resources and options, people could learn to make accurate forecasts about the consequences that their acts will probably have. This is very important because their expectations could determine their self-confidence and motivation, affecting, at the same time, to their self-esteem. Therefore, accurate and optimistic forecasts -above all when people have sufficient knowledge, skills and social support- could encourage them to put in practice their plans.

(c) People with disabilities need to learn to rethink their plans when the circumstances have changed. To do this successfully, a healthy self-esteem, self-confidence and a minimal motivation are essential because those ensure that, at least, people will reflect on the shifts that they have to do. In any case, this implies to assess both their problems, circumstances and plans throughout the decision-making process. Moreover, people should learn to protect their rights and interests when their families, friends and neighbours try to influence their decisions, ignoring their needs.

Therefore, under this new perspective, the risks could be understood as opportunities to:

(1) to increase the self-consciousness,
(2) to increase the self-esteem,
(3) to increase the self-confidence,
(4) to develop abilities related to emotional management,
(5) to develop strategical skills implied in the decision-making process.

Co-funded by the European Union

5. HOW TO DESIGN *SUPPORT PLANS?*

5.1 Supported Decision Making Process: An overview

People with disabilities have needs, desires and preferences. And to satisfy them, they need to make their own decisions. Their families, friends and neighbours must respect their choices, even if they consider that those are erroneous. Frequently, people with disabilities need support to know how to act and, in these situations, the professionals also could ignore their plans considering that those are not appropriate or could cause problems. But, as we have highlighted before, in other chapters, people have right to make mistakes. How could we guarantee that the professionals respect this right and the decisions made by people with disabilities? The Supported Decision Making answer this question.

Through this process, a *facilitator* will intervene to advise both people with disabilities and professional about:

(a) How they can build a *Bond of Support* based on the mutual trust, cooperation and human rights.
(b) How they can resolve problems and conflicts that could emerge in the decision-making process.
(c) How they should prepare action plans based on agreements that determine what role the professionals will play. Above all, the professionals have to remember in which areas people with disabilities need support.

Therefore, the *facilitators* should ensure that people with disabilities have their interests protected and, also, have to promote the most correct communication between professionals and them.

On the other hand, people with disabilities and professionals, under the watchful eye of the *facilitators*, will write a *Support Plan* where they will express the aims that they want to achieve and what specific actions they will carry out to satisfy their needs. This implies that, in this *Support Plans*, people with disabilities should identify the available options, resources and selection criteria. Furthermore, this *Support Plan* pinpoint the need that people with disabilities have and provide information to know what interventions the professionals have to undertake.

Co-funded by the European Union

5.2 Decision-Making Process and its cool tools step by step

First phase. Building the *Bond of Support*

As professionals, we need to build a *Bond of Support* with people with disabilities. This social link should be based on reciprocal confidence. Moreover, we should ask them what they need and what objectives they have. On the other hand, people with disabilities and/or mental illness need to know our functions and professional role. This situation offers us a good opportunity to discover what people expect about our interventions. We could correct these unrealistic expectations to prevent misunderstandings, motivational problems and future disappointments.

The professionals -and also the *facilitators*- should take into account four dimensions of the *Bond of Support* to ensure that people with disabilities are receiving the best possible attention:

- **The Development:** the professional interventions have an objective. This means that the *Bond of Support* should be interpreted as an instrument to promote the skills of people with disabilities and their autonomy to make their own decisions. As metaphor, the *Bond of Support* is a tree that we want to irrigate and nourish with tips and emotional understanding. But, always, taking as a reference point the preferences and wishes of the people attended. From its beginning, and even implicitly, the *Bond of Support* implies a plan of development given that one of the first necessary actions that the professionals must realize is to identify the needs, problems and projects of the people with disabilities. These vital projects will be our compass.

- **The Affective Reciprocity:** Frequently, people with disabilities feel that the persons around them (family, friends and professionals) don't take into consideration their emotions, future plans and decisions. For this reason, the Affective Reciprocity is a cornerstone of the *Bond of Support*. The professionals cannot pretend that people with disabilities listen and follow their recommendations, if they don't listen nor respect the preferences and projects of these groups with complex needs. Therefore, the

Co-funded by the European Union

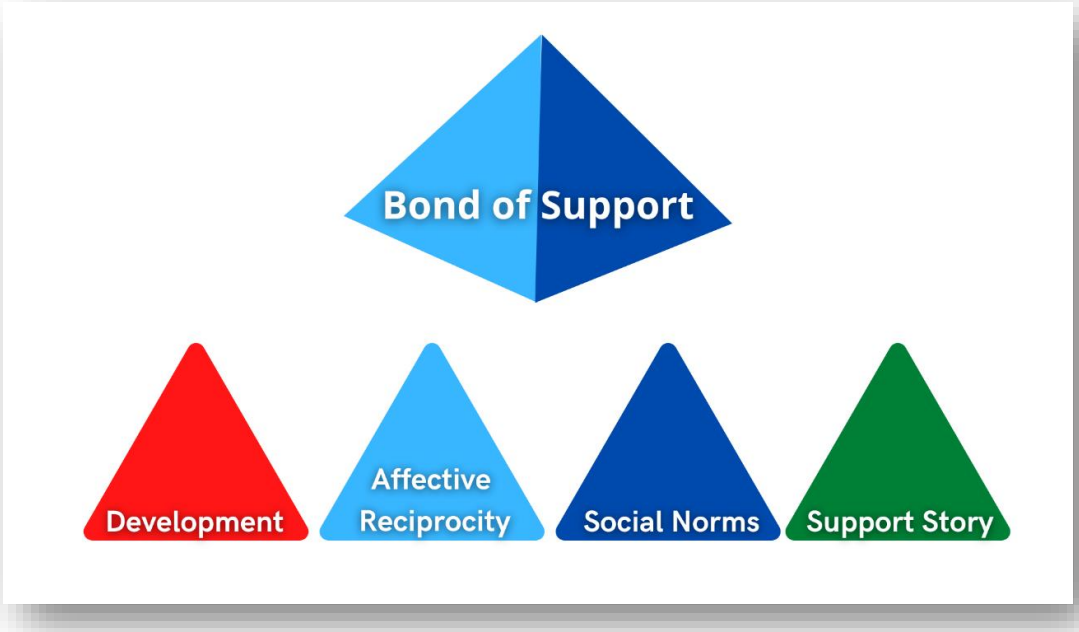
professionals have to actively listen to their stories and needs and transmit to them that they have the right to express their opinions.

Beyond these essential requirements, we recommend to the professionals that, to establish this *Bond of Support*, they should explain to the people with disabilities that themselves had to make decisions, sometimes committing mistakes. In fact, from psychology, the professionals could adopt self-disclosure. Using this technique, they would explain some personal experiences –including their own goals, dreams, fears, feelings, successes and failures- to show that they lived difficulties that they had to overcome.

- **The Support Story:** The talks, recommendations provided by the professionals and the experiences lived together have written the Support Story. These livings will influence the future of the *Bond of Support* determining, at least in part, the quality and nature of the relationship. We advise the professionals to use this story to remind people with disabilities all these difficulties that they have jointly overcome. And, also, this story, given certain setbacks and insecurities, could be a source of motivation, self-esteem and confidence.

- **The Social Norms:** Finally, the professionals should be conscious that the *Bond of Support* implies to establish a list of rules. These norms will define how the professionals and, also, people with disabilities interact. We cannot understand them as immovable stones given that the social relationships shift constantly.

Co-funded by the European Union



Pyramid of the *Bond Support* that shows the importance of promoting the balance between its different dimensions.

We pretend to show, through this graphical metaphor, that the *Bond of Support* must have a minimum balance. This means that the professionals should not focus their attention on a unique dimension, obviating the rest. For example, if the professionals just promote the Affective Reciprocity, people with disabilities could abuse their confidence. Instead, if the professionals focus their attention on the norms only, people could feel that the support is extremely rigid. Further, the professionals must ensure that the *Support Story* is full of positive memories and experiences, but, at the same time, they should remember the relevance of promoting the search of new vital horizons.

Observation: in annexes, the professionals and *facilitators* will find a complementary tool that we recommend using to gather and assessing information related to the *Bond of Support* and its four dimensions. This tool could be useful to consider aspects of the relationship between people with disabilities, professionals and *facilitators* and know how those change while they write Support Plans and make decisions using the app and the rest of digital materials developed in this European project.

Co-funded by the European Union

Second phase. *The Support Plan:* identifying and assessing the available options, considering benefits and risks

People with disabilities and professionals have built a *Bond of Support* based on three pillars: (a) cooperation, (b) respectful treatment and (c) promotion of independent living. But, now, people with disabilities, supported by the professionals, need to prepare a *Support Plan* which will define the main objectives that they pretend to achieve and the strategies that could allow reach them.

In this *Support Plan*, people with disabilities should identify the need that they want to satisfy or what project they would like to develop. After all, probably, they have many needs, wishes and projects in mind. However, they have to choose which of their aims they will prioritizes given two conditions:

(a) They don't have sufficient resources to achieve all their objectives at the same time.

(b) Likewise, to reach one specific goal, previously people have to achieve other objectives and carry out necessary steps.

After deciding what they want to prioritizes, people with disabilities have to look for different available options. For example, if they need –or rather want- a computer, the professionals should help them to find information about what alternatives the technological market offers them. Further, people with disabilities have to determine how they will make the decision and, therefore, what criteria will guide them to choose only one alternative. To choose the best one, considering mainly their interests and circumstances, they need to compare and assess the options. As we have explained previously, in this project, the European partners have developed an app. This app allows to people with disabilities identify different existing options, define their selection criteria and compare all that information to facilitate the decision-making process.

The professionals have to take into account that each alternative are related to negative and positive consequences. And people with disabilities should analyse them before. Given the importance of preventing negative consequences, the *Support Plan* must

Co-funded by the European Union

contemplate the assessment of them. Among other aspects, people with disabilities, jointly to their *supporters*, should value the implicit risks that will appear throughout the decision-making process. Before, we have explained how the professionals should understand and analyse the risks, promoting the *Beneficial Learnings Processes*.

Third phase. Assessing the *Supported Decision-Making Process*

In this phase, people with disabilities already have made their decision, supported by professionals and *facilitators*. Likewise, they know and have to face the consequences and impact that their actions have had. They have experienced successes or/and failures throughout the decision-making. For this reason, people with disabilities need to assess the results of their efforts and of their action plans to, probably, rethink them or undertake other projects. To encourage them to make this assessment about benefits, losses and setbacks, the professionals, guided by the *facilitators*, also should analyse the *Supported Decision-Making Process.* In fact, it is essential to discover if the provided support has had the expected results. Or, on the contrary, people with disabilities consider that the support received has been insufficient, not very respectful or, even being useful, it is necessary to make changes. In any case, the professionals have to keep in mind the unquestionable importance of carrying out appropriate evaluations.

In the light of these arguments, the professionals should not understand this assessment as, only, a final task without impact on the rest of the *Supported Decision-Making* process. Although we have exposed this under the third and final phase, the professionals and *facilitators* could consider the evaluation a cross activity.

The professionals and people with disabilities should contemplate if:

(a) The professionals and *facilitators* have listened actively the needs, preferences, worries, problems and circumstances of people with disabilities.

(b) People with disabilities have perceived that the professionals and *facilitators* have paid attention to their thoughts, feelings and doubts.

(c) The professionals and *facilitators* have respected the priorities and projects defined by people with disabilities.

Co-funded by the European Union

(d) People with disabilities feel that they have determined their priorities and projects.

(e) The professionals and *facilitators* have ensured that the *Bond of Support* is based on mutual respect and reciprocal confidence, promoting the cooperation instead of the imposition. (To assess the *Bond of Support*, we could use the template collected in annexes).

(f) The professionals have encouraged people with disabilities to identify their needs, to reflect on their future and to analyse the risks before making any decision.

(g) People with disabilities think that they have had the fundamental information, advice and support to identify their needs, plan their projects and assess the possible negative and positive consequences related to each available option to achieve their goals.

(h) The professionals have respected the decision made by people with disabilities.

(i) People with disabilities really think that they have chosen freely the best option according to their interests and priorities.

The professionals should determine if people with disabilities are pleased with the results obtained after weighing their achievements and the consequences of their decisions. But, also, the professionals and facilitators have to identify if these people value positively the method used to support them through the decision-making process. Therefore, both what aims people with disabilities have reached and how they have achieved them are important issues that the professionals have to include in their evaluations. *Decision Maker*, an app that unfolds a virtual environment where people with disabilities can collaborate with professionals to make decisions, help to pick up the essential data to value the provided support and services.

Co-funded by the European Union

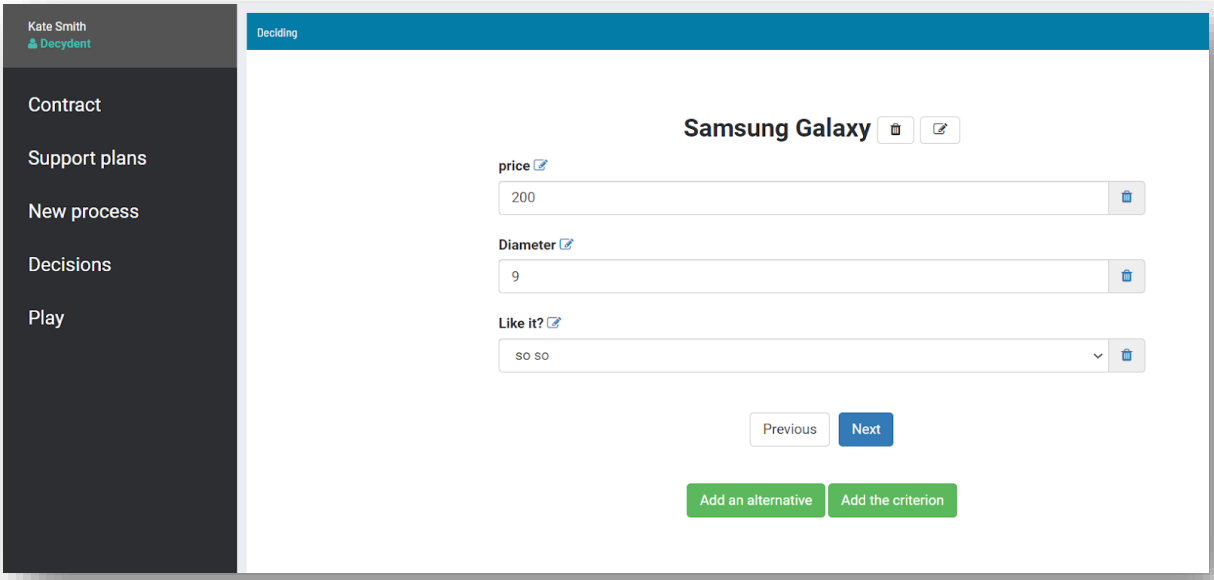
5.3 *Decision Maker* app: Learning to make decisions

Decider application is an application of *Supported Decision-Making*. This application is aimed at people with intellectual disability and assumes supporting these processes by therapists.

Besides decisions to make there are also a supported *Decision Agreement* and *Decision Supporting Plan* which are closely connected with the decision process implemented in the application.

The process realized by a decision maker consists of some steps. The first step is choosing possible solutions among which person who makes the decision will be choosing.

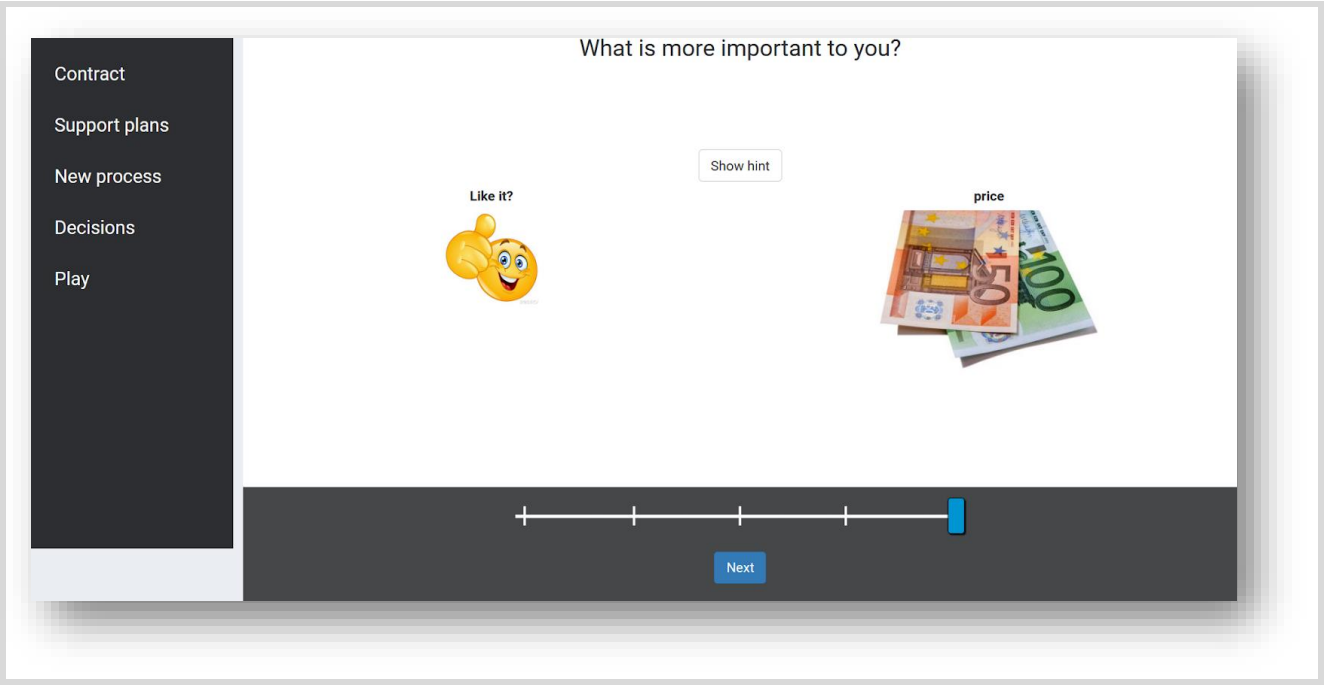
In the application, solutions are presented together with traits which describe them. For instance, if the decision process goal is to choose a tablet user should consider price, diameter, color or subjective opinion if the user likes it.



Co-funded by the European Union

Pic. 1 Solution with parameters

After checking possible solutions and filling parameters' values of the solutions time for the next step. A user shows his or her preferences so a user has a chance to inform the algorithm in the application what is the most important for her or him. It means that if the user is looking for the cheapest tablet the price would be the most important parameter of choosing the best solution. To do this, an user should play a game in the application. A user is presented with pairs of parameters describing solutions. A user must show which one of the two presented is much more important for her or him. A user is presented with all possible pairs of parameters. Algorithm in the background makes calculations to find the solution that fits best.



Pic. 2 Screen with a game to find parameters' hierarchy

To check if a user is conscious of his/her hierarchy, the application asks a user to set the parameters in exact order to show his/her preferences. Then the application checks if the order is the same as the result of comparing parameters two by two. After these activities the application presents a user ranking of the solutions showing the solution which is the best fitted to her or his. Displayed list is ordered from the solution best fitted to the solution worst fitted.

Co-funded by the European Union

To be able to make this process the therapist should previously prepare the structure of the decision process. This is done when the therapist is logged to the program.

THERAPIST's account

Below the procedure of creating a subject of decisions is described.

Step 1

A therapist should discuss with a person with intellectual disability the issue. They should find all possible solutions and should also discuss parameters of the solutions which will be the basement for making assessment and the final decision.

Step 2

After having the scheme of the decision process therapist should prepare some data constructing the shell of the decision process.

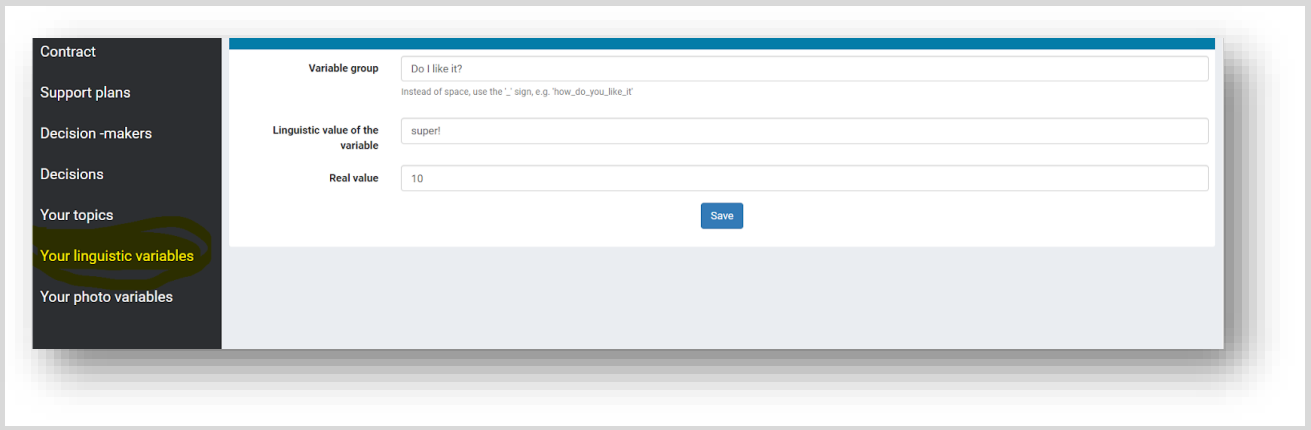
Each parameter consists of:
- a name, which will be off of course presented to the decision maker;
- a type of the parameter.

There are four types of parameters: numeric, linguistic, set of images.

Numeric is simply a number, for instance price, diameter of the tablet, distance from one point to another, age of someone etc. Defining a parameter which is just the number therapist must also think about so-called direction of the parameter. In case of some parameters less means better, in another case a bigger value means better. To have this taken into consideration during the algorithm always the worst value must be inserted as first and the best value must be inserted at the second in the relative fields. Linguistic parameters are linguistic values with which a number in the background is joint.

Sometimes there's no way or it's quite unnatural to express something in numbers and it's better to express something in linguistic values. Linguistic variable consists of a list of expressions joined with relative numbers.

Co-funded by the European Union



Pic. 3 Definition of a linguistic variable

Third type parameter is a set of images. Instead of writing something or choosing from a list of linguistic variables, the user can point one of the pictures. Of course in the background exists a number assigned with the picture. This is very useful when a user does not understand numbers but can recognize banknotes and coins. So pictures of coins and banknotes presenting prices should be used.

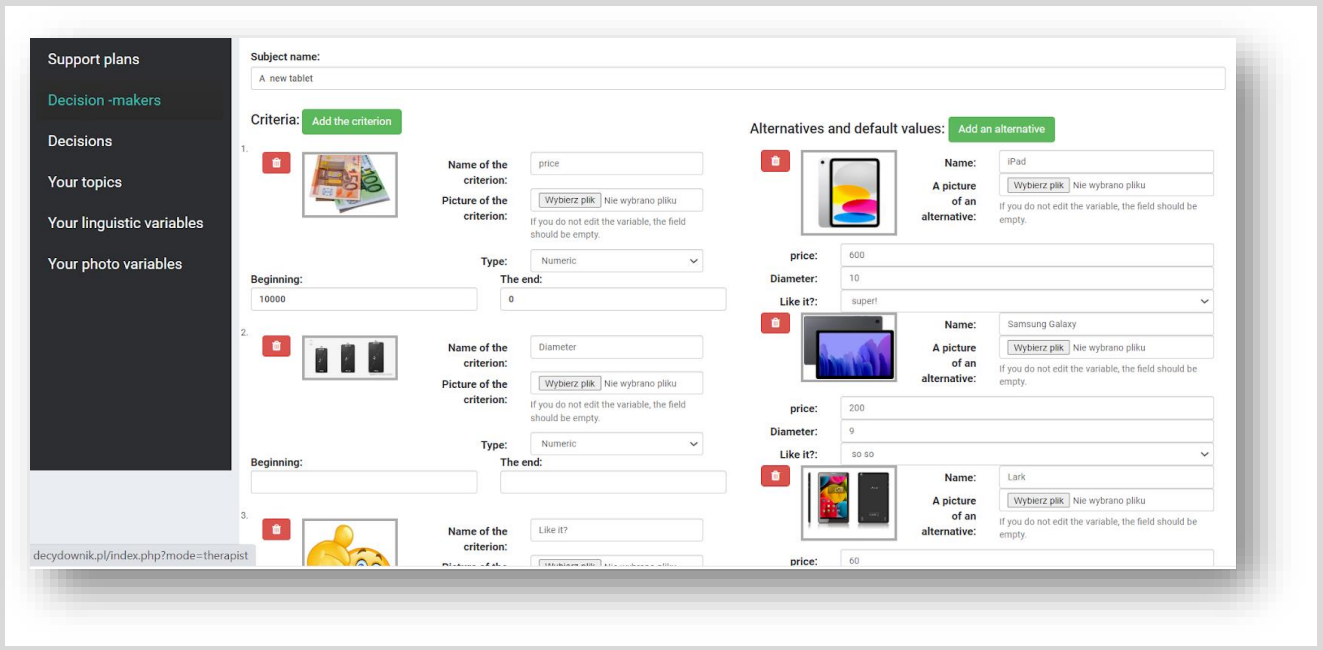
Definition of necessary variables (linguistic and images) is an action which should be made by a therapist before preparing criteria.

Another field describing parameter is a picture. Pictures as a graphic representation of parameters are very important because they are used during the process of creating computer hierarchy of users' needs or preferences.

Step 3

After preparing a set of parameters the therapist should prepare solutions.
Solution definition consists only of name, photo which is not mandatory and default values of parameters if necessary.

Co-funded by the European Union



Pic. 4 Defining parameters (criteria) and solutions (alternatives)

Step 4

After defining all items, therapists can start cooperation with a person who makes the decision. Such a person must log into the system and choose a prepared topic. During the decision process it's possible to change the scheme of this process. If a therapist and a decision-maker agree that additional solution should be added or if they agree that there is too little parameters - these data can be changed. It's important to realize that these changes are connected only with this decision process. The general definition of the decision topic is not changed.

Let's summarize therapist steps:

1. Define with decision maker possible solutions and parameters characteristic of the solution
2. Define types of parameters
3. Prepare parameters' pictures and solutions pictures if needed
4. Log in to the Decider application as therapist
5. In the application define linguistic variables if they are new for Your account
6. Define pictures for image parameters

Co-funded by the European Union

7. Create a new topic in the system
8. Add agreed solutions with names and pictures. You can also define default values of parameters for every solution.
9. Add criteria defining their name, picture, type and other options which are connected with choosing type
10. save topic
11. At the list of topics click on the button and choose “Add hints”. Define hints which will be used during the game.
12. Ask decision-maker to log into the system and go through the decision process

Some advices

1. It's always good to discuss with decision-maker possible solutions and criteria. This causes a decision-maker to better understand the process.
2. While creating the topic, prepare hints it will help you during cooperation with decision maker
3. At the end of the decision process, when the ranking of solutions is ready, talk with a decision maker that he or she is the only one who makes the decision. Ranking is only a suggestion of the system and a decision-maker is responsible for her/his own decision.

Co-funded by the European Union

ANNEXES

Tool to describe and analyse the *Bond of Support*

The following template has been designed to:

(a) Promote and extend the Supported Decision-Making process and its assessment, remembering that this evaluation allows us to know how the support provided has affected to the quality of life of people with disabilities.

(b) Complement the information gathered using the app *Decision Maker* and the rest of digital tools.

(c) Gather data about the four dimensions (Development, Affective Reciprocity, Social Norms and Support Story) that professionals, people with disabilities and *facilitators* should take into account to build, reinforce and value a robust *Bond of Support.*

(d) Analyse the balance of the *Bond of Support*, considering their four dimensions, to rethink and plan the professional interventions to ensure the cooperation of people with disabilities.

Co-funded by the European Union

DIMENSION: DEVELOPMENT	DIMENSION: SOCIAL NORMS	DIMENSION: SUPPORT STORY	DIMENSION: AFFECTIVE RECIPROCITY
What objectives and vital projects has the person with disabilities defined?	What norms have you established – implicit or explicitly- jointly with the person with disabilities?	What positive experiences of support did the person with disabilities have with you? What problems have you resolved jointly?	Lists and describe specific difficult situations in which the person with disabilities respected the Affective Reciprocity
1) 2) 3) 4) 5) 6) 7) 8) 9) 10)	1) 2) 3) 4) 5) 6) 7) 8) 9) 10)	1) 2) 3) 4) 5) 6) 7) 8) 9) 10)	1) 2) 3) 4) 5) 6) 7) 8) 9) 10)

Professionals could use this template to describe how is the *Bond of Support*. And, above all, we recommend using this tool to analyse if they have to change their plans of intervention, prioritizing, for example, the *Affective Reciprocity* or the definition of *Social Norms.* The professionals should act on these four dimensions at the same time to

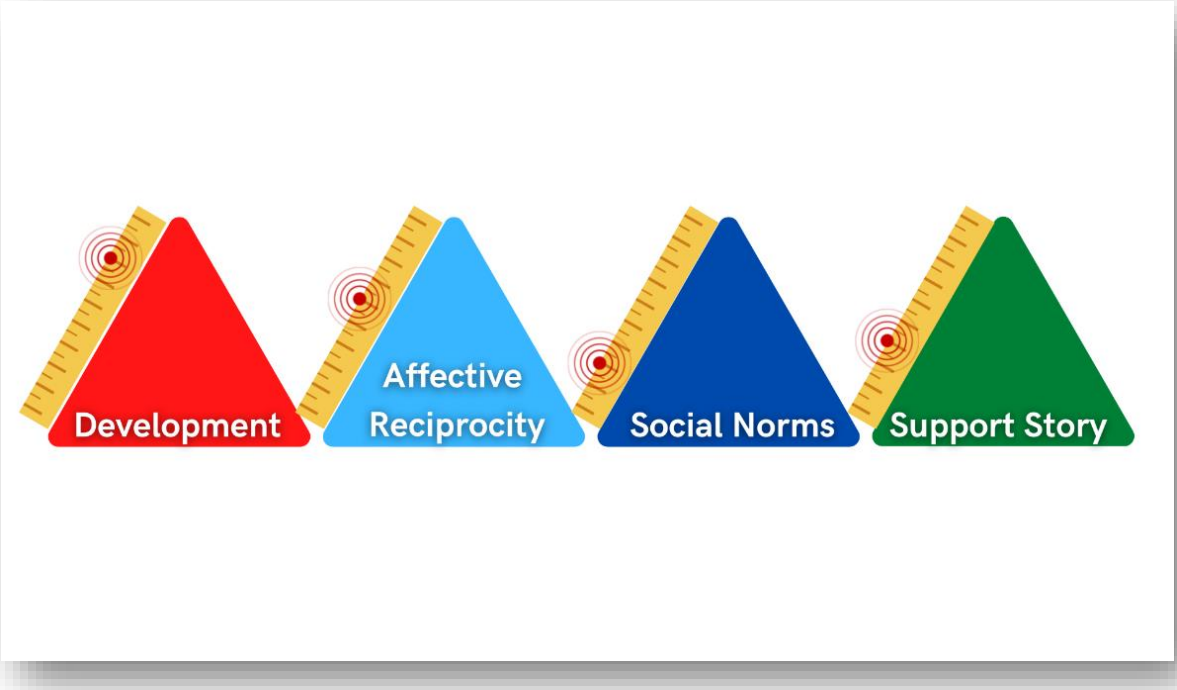
Co-funded by the European Union

prevent imbalances. To assess the equilibrium of any *Bond of Support* throughout the decision-making process, they have to contemplate that:

(a) When they write, for example, objectives or vital projects expressed by people with disabilities, each of those has a value of one point.

1 Objective = 1 point.
1 Social norm = 1 point.
1 Problem resolved = 1 point.
1 Experience of Reciprocity = 1 point.

(b) Frequently, the professionals will find that different dimensions have different values. This situation is not always a problem. But, depending on these differences and their magnitude, the professionals should develop more one aspect or another. Imagine that, after supporting a specific person with disabilities, we have written only 2 experiences (therefore, we have 2 points) under the dimension *Support Story*, but, we have 9 (9 points) rules gathered under *Social Norms*. In these circumstances, as the difference is extremely big, the professionals have to focus their attention on *Support-Story* because the person could think that she/he has must respect many norms without having experiences that demonstrate how the professionals can help them. When will the difference too much? If the difference is larger than 3 points.



Co-funded by the European Union

BIBLIOGRAPHY

Ballester, L. 1999). *Las necesidades sociales. Teorías y conceptos básicos.* Madrid: Editorial Síntesis.

Bauman, Zygmunt. (2013). *Vida Líquida*. Barcelona: Paidós

Browning, M., Bigby, C. & Douglas, J. (2020). A process of decision-making support: Exploring supported decision-making practice in Canada. Journal of Intellectual & Developmental Disability. https://doi.org/10.3109/13668250.2020.1789269

Canadian Association for Community Living (2014). A statutory framework for the right to legal capacity and supported decision making for Application in Provincial/Territorial Jurisdictions in Canada. The Working Group on Legal Capacity and Supported Decision Making. Available at: https://cacl.ca/wp-content/uploads/2018/05/Draft-Statutory-Fmwk-Legal-Capacity-June-9.pdf

Conde, M., Menéndez, F., Rivero, M., & Sanz, M. (2013) *Psicología de la Motivación. Teoría y práctica.* Sanz y Torres.

Committee on the Rights of Persons with Disabilities (2014). General Comment No 1, Article 12: Equal recognition before the law, CRPD/C/GC/1, (Adopted 11 April 2014). Available at: https://undocs.org/en/CRPD/C/GC/1

Cuetos, F., González, J., & De Vega, M .(2018).Psicología del Lenguaje Editorial Médica Panamericana.

Domínguez, F., Fernández, E., García, Beatriz., Jiménez, M., & Martín, M. (2010). *Psicología de la Emoción.* Madrid: Editorial Universitaria Ramón Areces.

Co-funded by the European Union

Entelman, R. F. (2009). *Teoría de conflictos. Hacia un nuevo paradigma*. Barcelona: Editorial Gedisa, S.A.

Goleman, D. (1996). *Inteligencia Emocional*. Barcelona: Kairos.

Maslow, Abraham. (1973). *Hombre autorealizado: Hacia una psicología del ser*. Kairós.

Ovejero, A. (2010). *Psicología Social. Algunas claves para entender la conducta humana.* Madrid: Editorial Biblioteca Nueva.

Piaget, Jean. (1976). *Seis estudios de psicología*. Barcelona: Barral Editores

United Nations General Assembly. (2006). Convention on the Rights of Persons with Disabilities and Optional Protocol. Available at: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

White, M., & Epston, Eric. (2008). *Medios narrativos para fines terapéuticos.* Barcelona: Paidós Terapia Familiar.

Young, Jock (1999). *The Exclusive Society: Social Exclusion, Crime and Difference in Late Modernity.* London: Sage

Co-funded by the European Union