

# I-DECIDE HEALTH-CARE MANUAL



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# 1// Introduction

## Aims of the I-DECIDE Manuals for Personal Finances, Health Care & Consumer Rights

This manual is part of the I-DECIDE Erasmus+ Project, an initiative whose main objective is to improve Supported Decision Making (SDM) services for persons with disabilities using Digital, Literacy and Numeracy (DLN) skills. To achieve this main goal, the **supporter** (the person who helps someone to make decisions) must have a clear understanding of what SDM means. This manual has been designed to train the supporter about specific procedures and tools to incorporate the SDM approach as a model to provide innovative support.

SDM mechanisms are a key element to implement the United Nations Convention on the Rights of the Persons with Disabilities (UNCRPD). The Convention requires Member States, decision-makers, professionals and society as a whole to overcome and abandon the **medical model of disability** that conceptualises and categorises persons with disabilities based on their impairments, deficiencies or differences. Instead the UNCRPD requires Member States to embrace and adopt the **Human Rights Approach** as a way of ensuring full and equal enjoyment of all human rights to persons with disabilities, and thus, promoting and respecting their inherent dignity. This approach also focuses on equal opportunities, non-discrimination and inclusion. The Convention, at its core, establishes that persons with disabilities have the Right to enjoy from personalised support to overcome the different societal barriers (attitudinal and environmental) that hinder their full and effective participation in society on an equal basis with others. The Convention approach establishes that the primary purpose of the support is not just to provide services or support in the best interest of the person (substitute decision-making approach) but rather to provide support or services based on the will, wishes and preferences of the person receiving support. Supported decision making is a process that allows the person with a disability to make his/her own decisions.

## SDM is the approach used throughout this manual.

The SDM approach cannot be detached from a co-production approach. Co-production implies that the supported person participates in the design, implementation and evaluation of the service or the support they receive, generating a twofold impact. Firstly, the service itself is more effective at identifying the goals to be achieved because it addresses problems identified or expressed directly by the supported person. Secondly, the supported person becomes empowered, because he or she is treated as an equal partner by professionals or other stakeholders, and his or her views are valued and respected.

Co-production is present at every stage of the SDM process described in this manual, as it demands – to the highest possible degree – the involvement of the supported person when defining the support needs, selecting the supporter, agreeing on the terms of the support provided and assessing satisfaction or evaluating the results.

I-DECIDE project partners acknowledge that the supported person's Digital, Literacy and Numeracy Skills are a key factor that can enable the person to better understand information and, consequently, weigh the pros and cons of the different options relating to a specific decision.

This manual aims to show SDM supporters how to provide or coordinate the resources to enable a person to acquire or improve their DLN skills level needed to make his or her own decisions.

I-DECIDE has developed manuals or reference guides in three important areas of a person's daily life: Health Care, Personal Finances and Consumer Rights. The procedures described throughout the manuals can be repurposed or reused in other areas of an individual's life, such as the labour market, housing or other relevant spheres after making suitable adaptations.

## How to use the I-DECIDE Manuals

**Chapter 2 'Background'** is essential to understand the aim of this manual. It describes the principles governing SDM, the processes involved and the description of tools used to carry out SDM.

**Chapter 3 'Creating an SDM service'** describes in detail how to use an Agreement as a professional tool to support a person on making decisions. You can find processes and instruments to build, develop, deliver and evaluate the SDM service. Chapters 2 and 3 are conceived by project partners as the core I-DECIDE methodology used and shared throughout the three manuals developed by the project consortium, both in the 'universal' and 'local' version.

However, it is noteworthy that the local versions include a specific section about the legal framework that the materials have been adapted to reflect and describe the local country's legal structure, context, circumstances or requirements which the supporter or the service has to take into account in order to set up SDM agreements properly.

**Chapter 4 'Health'; 'Personal Finances' or 'Consumer Rights'** focuses on the specific processes relevant to each area or topic addressed by the manual and lays out specific tools, examples, instruments or activities where SDM and the I-DECIDE methodology will or has the potential to be used. Although SDM is a common pattern between these three areas of daily life, the types of decisions or situations may differ between the three different spheres, hence the tools used in each area may be different. Professionals or stakeholders who are experienced on SDM processes or the and tools can go directly to these chapters to see examples of specific tools, good practices and procedures about helping supported persons to make decisions. Case studies have been used to illustrate how to proceed in the wide amalgam of issues or instances where SDM can be used in each of the three areas.

**Chapter 5** includes 'references' and bibliography about SDM and each topic or the manual for further reading.

**Chapter 6 'annexes'** contains as an annex, the 'I-DECIDE SDM Agreement Template'. Other relevant documents and templates developed throughout the I-DECIDE Project lifecycle (i.e. 'DLN skills assessment form'; 'SDM healthcare assessment'; 'SDM personal finances assessment'; 'satisfaction self-assessment forms' both for the supported person and for professionals or the 'Individualised SDM Plan template') are available to download on the project website. The documents work as the core package of the I-DECIDE methodology and its combined use ensure uniformity and consistency of the SDM approach by enabling a meaningful evaluation of the effectiveness and impact of the I-DECIDE SDM methodology.

Consult all the I-DECIDE materials in the **project website** : <http://www.supportgirona.cat/projectes/i-decide/>



Belgium – European Association of Service Providers for Persons with Disabilities, **EASPD**  
([www.easpd.eu](http://www.easpd.eu))



Spain:

**Support-Girona**  
([www.supportgirona.cat](http://www.supportgirona.cat))



Finland – **KVPS** ([www.kvps.fi](http://www.kvps.fi))



**Fundació Campus Arnau d'Escala**  
([www.campusarnau.org](http://www.campusarnau.org))



Greece - **EEA Margarita**  
([www.eeamargarita.gr](http://www.eeamargarita.gr))



UK – **Social Care Training**  
([www.scttld.uk](http://www.scttld.uk))

## 2// Background

### The United Nations Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities is a United Nations International Human Rights Treaty intended to develop and protect the Rights and dignity of persons with disabilities. States Parties adhered to the Convention are required to promote, protect, and ensure the full enjoyment of human rights of persons with disabilities and ensure that they enjoy full equality under the law. The Convention is the first human rights treaty of the twenty-first century and it has served as a global catalyst in the Human Rights and disability movement as it shifted from viewing persons with disabilities as objects of charity and subject to medical treatment and social protection towards viewing them as full and equal members of society, with Human Rights. It is also the only UN Human Rights instrument with an explicit sustainable development dimension.

The Convention was adopted by the United Nations General Assembly on 2006 and as of today (2020), 163 States have signed and 113 have ratified it, including the European Union and all EU member states. The Convention and its implementation is closely monitored by the Committee on the Rights of Persons with Disabilities.

### Article 12 in the framework of the CRPD

Article 12 of the United Nations Convention on the Rights of Persons with Disabilities acknowledges the right of persons with disabilities to enjoy legal capacity on an equal basis with others in all aspects of life, including their right to have equal access to own or inherit property and to control their own financial affairs. All of which is subject to safeguards which are proportional and tailored to the personal circumstances and applied during the shortest possible period.

Article 12 of the CRPD states very clearly that legal capacity is not to be confused with mental capacity, and the ability to make decisions, but it means the equal recognition of persons before the law. No one should be deprived of their legal capacity, just because the person needs help in making decisions.

Moreover, governments should provide persons with disabilities with any support they might need in their decision-making. Support can be both “formal and informal” and can constitute “arrangements of varying type and intensity”. The type and intensity of support should take into account the diversity of people with disabilities. Also, a range of appropriate measures should be available for persons with disabilities to receive adequate support, according to their will and preferences. Support could encompass providing information in plain language or easy-to-read, explaining different options, or, in some exceptional cases, articulating an opinion based on a deep knowledge of the will, wishes and preferences of individuals, stemming from a long-lasting trusting relationship between the person needing support and the person providing it. The opinions and decisions of the person with a disability should always be taken into account and respected, whatever the person providing support thinks of that decision. Implementing Article 12 of the CRPD requires a shift towards respecting Human Rights by replacing the substitute decision making approach with supported decision making models in legal frameworks and services.

In practical terms, exercising legal capacity means making decisions for oneself in all areas of life including medical treatment, housing, employment, relationships, finances, children, family planning, or property, amongst others. The CRPD recognises that persons with disabilities may require different levels of support depending on individual and social circumstances, but it compels States and public authorities to develop supported decision making arrangements of varying types and intensity, including informal and formal support arrangements. The Convention defines such arrangements as, for example, support networks, support Agreements, peer and self-support groups, support for self-advocacy, independent advocacy or advance directives.

The I-DECIDE SDM methodology, including the manuals and the core documents developed by project partners, are driven by CRPD principles so it is important that the professionals and supporters fully understand, embrace and support the Convention and its principles and obligations and are willing to apply them in their own service, organisation or in daily practice when offering support for persons with disabilities.

## About Supported Decision Making

Supported Decision Making is and must be the alternative to guardianship or other types of substitute decision-making mechanisms. Shifting towards this new paradigm and developing services based on supported decision making acknowledging persons with disabilities as valuable members of society and respecting their citizens' rights is the key to advance towards social inclusion.

## Decision Making

Daily life is full of opportunities to make decisions for every individual. Decisions may vary from low level decisions (e.g. what clothes to wear) to high level decisions (e.g. moving to live with another person). There are decisions that we make by ourselves and there are others when we prefer to ask for advice or support. When people have an important decision to make, they usually seek support and advice from friends, family or specialists (e.g. a therapist, counsellor, vocational guidance, etc.). In the I-DECIDE methodology and throughout all the documents and manuals the person helping with decisions is called the “**supporter**”. Decisions are influenced by many factors such as the upbringing of the person, life history or personal experiences, information and data available, personal values or beliefs, the individual's personality or their decision making style. Decisions are also influenced by the level of literacy, numeracy and digital skills each individual has. For example, if a person doesn't understand or knows how to use digital tools or the information and procedure to return a product or service, it is improbable that he or she will decide to go shopping online. Similarly, if a person doesn't understand the medical opinions and potential outcomes of a particular treatment, it is almost impossible for them to make an informed decision about it autonomously.

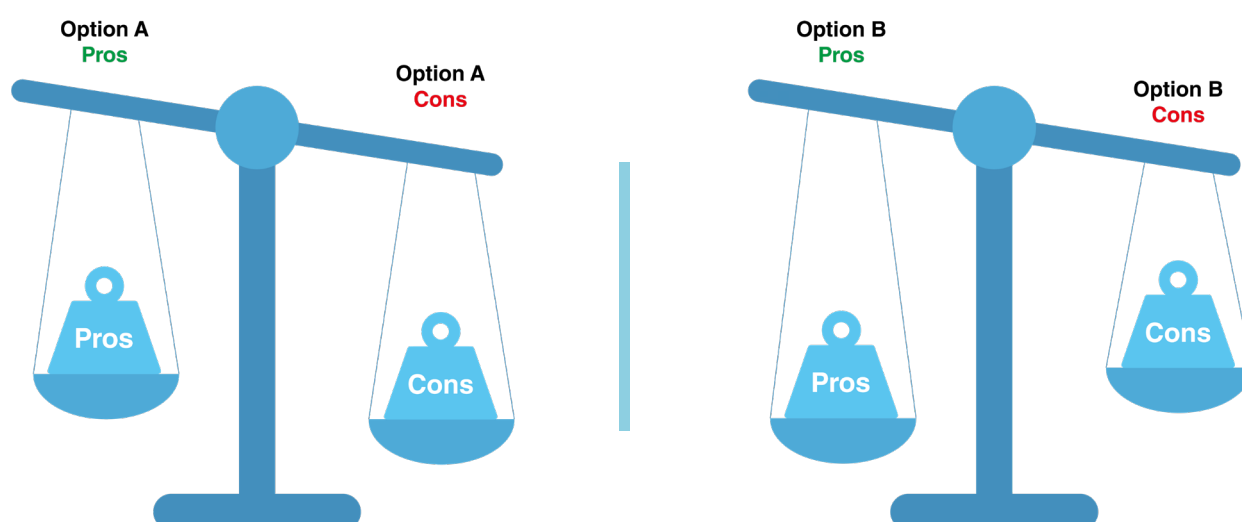


Figure 1. Comparison between different options: Pros & Cons on the Decision Making Process.

## Supported Decision Making

Supported Decision Making consists of several measures designed to create the right conditions for a person with a disability to make informed decisions on his or her own. To facilitate this, the **supporter** will study the decisions the supported person could make, provide all the necessary information to give the person a clear understanding of all available options, ensure the person weighs the pros and cons as well as the potential outcomes of each decision and help the person communicate his or her final decision.

The decision of a person with a disability must be respected even if the supporter considers it is not the best possible decision. Acknowledging this right and allowing the person with a disability to make mistakes or unwise decisions is an important part of the SDM process.

Here is one quick example of low level supported decision making.

A person might ask support to make a financial decision. The person has to decide whether to spend a big part of their savings to buy a computer and broadband or to save it for the next summer holidays. The supporter has to collect and provide information (using appropriate formats to communicate such as easy to read materials, videos, pictograms, etc.) to help the person weigh the pros and cons of each alternative ensuring the information is well understood. Finally, if requested by the person, the supporter will help communicate the decision to other people who may need this information or become a key element to implement the decision.

Supported Decision Making is fundamental to foster the social inclusion of persons with disabilities as it promotes self-determination, control, autonomy and independence.

## Types of decisions covered by the I-DECIDE manuals

The I-DECIDE manuals illustrate the potential of SDM in three specific areas covered by the project, namely Health Care, Personal Finances and Consumer Rights.

### Health Care

Persons with disabilities have been traditionally denied the basic right to control what happens to their own bodies. Decisions about their nutrition, medication, exercise routines, doctor appointments or other health and wellness related issues are still often made by service providers, professionals or family members in their best interest. Health related decisions can range from low level, informal or simple decisions such as nutrition, physical activity and hygiene to mid-level decisions such as alcohol use or birth control to formal and more complex decisions such as surgery procedures or consenting to advanced medical treatment.

Persons with intellectual disabilities are often excluded from health care education, training or programs, including sexual and reproductive health programs. Even when they participate in these initiatives, the information is often not clear or easy for them to understand. Consequently, when it comes to making health care decisions, people with intellectual disabilities often lack adequate information or resources to be able to make an informed decision on their own.

### Personal Finances

People with disabilities are frequently denied the right to control their personal finances and to make decisions about their own property. Making decisions in the financial sphere includes both low level and informal decisions such as how to spend money or how to elaborate their own budget, to more formal and complex decisions such as opening a bank account, getting loans or making financial investments or inheriting and managing real-estate.



## Consumer Rights

All EU citizens have their rights safeguarded by EU legislation as it ensures, amongst others: protection from unsafe products; insurance that product information is clear, consistent and accurate; access to fast and efficient ways of resolving disputes with traders to protect their consumer rights and updated legislation to maintain their citizens' rights commensurate with economic and societal changes. Even with these safeguards in place, people with disabilities may be more exposed to fraudulent misconduct and specific support should be provided to help protecting and upholding their rights as consumers.

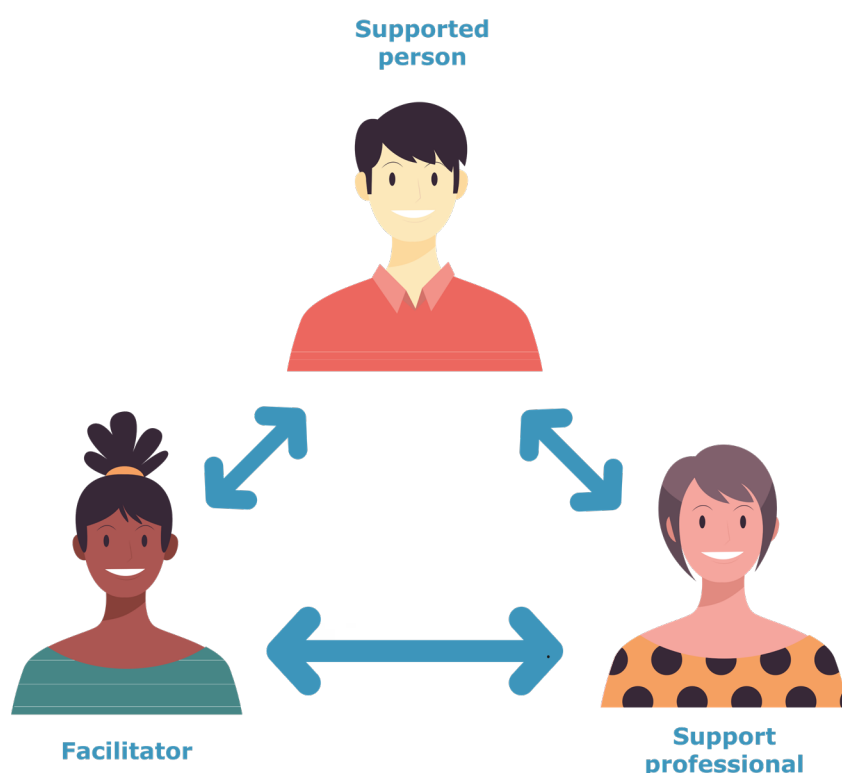
## The I-DECIDE Supported Decision Making Agreement

### What is an SDM Agreement?

I-DECIDE has developed a SDM methodology, aligned with CRPD principles, by creating the Supported Decision Making Agreement as a tool to facilitate organisations, professionals or persons with disabilities to offer or receive support in a formal and standardised way. The SDM Agreement is a written document created to formalise the SDM process and is signed by the **supported person** (a person with a disability), the **supporter**, who commits to provide guidance, support and assistance in making decisions in the areas of life defined in the document by the person, and the **facilitator**.

The SDM Agreement must be operated on a voluntary basis as the person who requires, wants or needs support must ask for this service voluntarily. The roles established in the agreement must be based on a trusting relationship with someone who will be the supporter and another person who will act as facilitator. The supported person must also be able to cancel or modify the agreement at any given time if they are unhappy with how it is working.

The I-DECIDE methodology incorporates the figure of the facilitator. The Facilitator is a third person whose role is to check and monitor the agreement to verify and ensure that it is operating as it should. If the supported person is not happy with the relationship with the supporter, he or she can ask the facilitator to talk about it and perhaps even to ask for a replacement supporter.



The central element in the SDM Agreement is the relationship between the person and the supporter. It implies an attitudinal change towards the recognition of the rights of the supported person and the acceptance of their decisions, as well as abandoning the practice of the supporter of taking the decision in the best interest of the person with a disability.

Figure 2. The SDM Agreement: a multidirectional relationship.



## Legal Framework

This manual has been created and developed on the understanding that neither the I-DECIDE SDM Agreement nor fully-compliant SDM mechanisms are part of the legal systems of the participant's countries yet. Although the Convention is a legally binding treaty, just a few countries worldwide have undertaken the necessary reforms to include, incorporate and recognise instruments based on the will, wishes and preferences of the person with a disability into their legal frameworks.

In practice, this means that:

- The SDM Agreement is not legally binding because it is not recognised under national legal frameworks;
- There are no formal records of the SDM Agreement in any public registry or approved by accredited, competent or legal bodies;
- The agreement by itself will not give any legal rights to the supporter to access or deal with services, external professionals or the social network of the supported person in order to get information, even if that information would be helpful or useful for the supporter or the person.

## Digital, Numeracy & Literacy Skills and SDM

In most situations, a combination of Digital, Literacy & Numeracy skills is required to obtain, understand and interpret the information in order to make informed decisions.

**Digital skills** are a set of competences that include the capacity to deal with information processing, communication, content creation, safety and problem solving, when operate in digital environments or digital devices (e.g. computers, smartphones, tablets, internet).

Nowadays, having basic knowledge on how to use digital tools and environments is essential, especially as there are increased online and computerised processes in public admin (e.g. tax, health, voter registration procedures or filing complaints as consumers). Increasing IT skills and computer literacy enables individuals to feel safe and more confident taking decisions.

**Literacy** skills are related to a person's ability to both read and write a short, simple statement about his or her everyday life. An illiterate person is one who cannot write such a simple statement. It's obvious that an individual who has a good basic grasp of reading, writing and also IT skills, has more opportunities to make decisions that align with his or her own wishes and preferences.

**Numeracy.** Being numerate means having the confidence and skill to use numbers and approach problems from an analytical or mathematical perspective. Numeracy skills can be used in all aspects of life – at work or at home, in basic everyday living activities, as consumers, in managing our own finances, as parents helping our children learn, as patients making sense of health information – and help individuals and citizens understand the world that surrounds us.

Numeracy complements literacy and is sometimes called 'mathematical literacy'. Both skills are needed in order to fully function in modern life.

Being numerate means being able to work with numbers and other mathematical concepts to apply them in a variety of contexts to solve different problems. Being numerate is as much about thinking and reasoning logically as it is about 'doing sums'. In daily life, there are many situations where a good standard of maths and numbers is useful to decide on one particular option. In particular, exercising consumer rights usually requires interpreting bills, receipts and invoices and understanding dates in order to calculate the duration of goods' warranty, amongst others.

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For all the above, the I-DECIDE project has developed tools to evaluate and assess the skills level in each of these three DLN areas.

The evaluation and assessment of a person's DLN skills is not an essential but rather a very useful complementary part of the I-DECIDE methodology and was an essential element in the project's funding. The project was able to demonstrate that taking part in SDM improved the DLN skills of all participants. We recommend that future SDM schemes consider monitoring DLN skills to capture this learning gain. This would mean that when the SDM Agreement is formalised, the supporter will explain these SDM tools to the supported person and how monitoring their progress in these areas will be useful for them. At the beginning of the Agreement an initial DLN assessment of the supported person's abilities in these areas will be carried out by the supporter. If it is seen that some areas need to be improved, the supporter will inform the supported person and his or her support network, so that they can provide the most suitable training and resources to help the supported person to progress. At the end of the support period it is possible to undertake a second DLN assessment to demonstrate the progress made.

## I-DECIDE Assessment Tools

The goal of the assessment is twofold. Firstly, to show that the supported person has already started making their own decisions and secondly to monitor and evaluate the progress made by the person with self-assessment tools developed in the I-DECIDE project ('supported person periodic self-assessment' and 'supporter periodic self-assessment'). The specific self-assessment tools include all the details about how to administer the surveys and how to interpret the collected information. Ensuring that all parties are aware of the progress and the evolution of the person and the support received sharing and contrasting the results with the person enables and empowers the supported person and demonstrates the benefits of co-production and contributes to shift from substituted to supported decision making.

## 3// Creating a SDM service

### The I-DECIDE Supported Decision Making Agreement in practice

This section is about how organisations that aim to guarantee the rights of persons with disabilities and their autonomy by providing support can implement the I-DECIDE methodology on supported decision making using the SDM Agreement as a basis of its service.

### The SDM Agreement as a professional task

Fully implementing the Convention and its Article 12 requires updating and reviewing the roles of staff working in services providing support to persons with disabilities as their competences, skills, approaches or attitudes may be fundamentally changed. From a legal perspective, abolishing the substituted decision making model and adopting a supported decision making model to guarantee the rights of the person and help them to exercise legal capacity is an obligation.

Apart from legal decisions, low level decisions are present in the daily life of all individuals and in practice the I-DECIDE SDM model should be used to guarantee fundamental rights of person with disabilities, such as autonomy and independence, especially at this low level.

The purpose of this manual is to show how the I-DECIDE methodology can be applied in daily life decisions.

Professional obligations under the I-DECIDE SDM Agreement include:

- A duty to provide the support service. By signing the agreement, the professionals and persons involved compromise to support the person with a disability.
- A multidisciplinary professional approach. SDM Agreements do not belong to any particular profession by definition, although SDM Agreements may involve an amalgam of professionals such as social workers, lawyers, health professionals, disability practitioners or others professionals with experience in the social sector or in providing support for persons with disabilities. Social Networks – families, friends, flat-mates or other acquaintances – have to know about the existence of the SDM Agreement and how it works. This is because a) they may help in the effective operation of the Agreement b) they may provide an innovative way to support the individuals.
- Confidentiality. Standard confidentiality procedures and GDPR regulations apply when dealing with sensitive information.
- SDM Agreement follow-up. Recording information collected during the task or actions is essential and appropriate. A decision making diary or log-book is the best way to help communicate and evaluate the progress made and it also assists professionals when providing support or coordinating with the facilitator. Support professionals can use the organisation's management system or database or use their own, but it must include the following items:
  - Name of the Supported Person
  - Name of the Facilitator
  - Date and number of every working session
  - Specific decision to be made
  - Particular tools used / actions carried out
  - Observations about progress
  - Date of end of the process for each decision
  - Date and number of working sessions with the supported person

Success is not in making the SDM Agreement itself, but in creating an environment in which supported decisions can be made.

## Roles in the I-DECIDE SDM Agreement

The three main roles in the I-DECIDE SDM Agreement are:

- **The supported person**
- **The supporter**
- **The facilitator**

There are three general principles that must be respected by all the parties in the I-DECIDE SDM Agreement:

1. All the work and actions conducted under the SDM Agreement will be based on the wishes and preferences of the supported person.
2. The final decision has to be undertaken by the supported person.
3. All decisions have to be accepted by the supporter, regardless of his or her own personal or professional point of view.

Recognising the right to legal capacity and to make decisions means recognising the right of the person with a disability to make mistakes, assuming as a positive fact that every choice might come with risks associated.

The requirements and roles of each of the parties are:

**1) The supported person** will need to be able to:

- Express a wish to receive support or to end the support;
- Communicate their preferences and express their wishes;
- Develop a trusting relationship with another person(s) whom they wish to receive support from (the supporter);
- Indicate what kind of decisions or areas they may need support with;
- Be aware that they are making the final decision (and not the supporter).

**2) The supporter**

The supporter can be anyone in the person's immediate environment, family, friends, and social network or from a professional support service. The I-DECIDE methodology envisages the use of a professional supporter who will be able to coordinate resources and services available to the person, although we recognise that this may not always be possible to achieve in every country. Preferably, the support professional should have a background on social education or social work as the main task will be to guide and support the person in the decision-making process.

### ■ Skills and values required

- Ability to respect and value the supported person's autonomy and dignity and understand and respect the supported person's goals, values and preferences.
- Ability to respect the particular decision making style of the supported person and recognise when and how support may be offered to the person.
- Ability to form a trusting relationship with the supported person and to spend as much time as required to support the person to make each decision.

- Empathy, assertiveness and the ability to communicate clearly with the supported person in an appropriate and accessible manner.

### ■ Main tasks to be undertaken by the supporter

- To assess the skills of the person in relation to decision-making in the specific areas included in the SDM Agreement.
- To build and implement, jointly with the person, an Individualised Support Plan to help the person to take decisions.
- To research materials and resources to help the person to understand the information they need to make their own decisions.
- To assist the supported person to obtain advice from different sources.
- To support the person at meetings with outside organisations, professionals or persons in order to obtain information and explore options.
- To help the person analyse the different options.
- To verify the person has understood the pros and cons of the options involved in a decision.
- To help the person communicate the decision(s) to his or her family and others and to enable a good implementation of the person's choice. When necessary the supporter will advocate for the decision to be implemented.
- To help the supported person to complete interviews and assessments.
- To observe and record all the activities and actions arising from the SDM Agreement.
- To assess and record (if so chosen) the impact of SDM on the DLN skills of the person supported.

### 3) The facilitator

The facilitator works on the support relationship externally and is seen as a safeguard and advisor during the different steps of the SDM Agreement. The facilitator will be responsible for advising and guiding the person and the professional when formalising each support agreement. His or her role can be understood as a specialized manager of the relationship between the person and the support professional: the facilitator helps creating it, monitoring it and helps solving any doubts or conflicts that may arise on both sides. Conceptually, the facilitator acts as a double safeguard, as ensures the quality of the relationship between both parties, but also prevents or avoids situations in which the person's rights are not respected.

The facilitator's role can be summarised as follows:

- To provide advice on how the SDM Agreement works.
- To help the person identify suitable supporters.
- To assist the person and the supporter in resolving any disputes.
- To make regular contact with participants to check that support arrangements are working.
- To monitor and record the termination of the SDM Agreement and to inform the support network of the supported person that the agreement has ended.

The facilitator needs to have a complete understanding of the terms of the SDM Agreement and should be able to communicate, using suitable language, both with the supported person and the supporter using mediation strategies and soft skills such as assertiveness.

The supported person or the supporter may approach the facilitator to clear their doubt arising from the process to improve the SDM agreement's scope and content or to terminate the agreement.

The facilitator, as conceptualised in the I-DECIDE methodology, can be another professional – ideally from the supporters employing agency or service – or a peer from the supported person's social network or a family member who has the required knowledge and skills.

## How to set up and deliver an SDM Agreement

In practice, the process of completing an SDM Agreement will be carried out through four main stages, from requesting the service at the beginning to evaluating the support received at the end of the process. The next diagram summarises the four stages of the I-DECIDE SDM Agreement process.



Figure 3. I-DECIDE SDM Agreement: main stages.

### Stage 1: Requesting the SDM service

The person with a disability who might require it will ask for support to make decisions in different spheres of their life. Usually, persons express their wishes to someone working in a support service used by them or to a professional or a peer they are acquainted with. In practice, persons who will potentially act as supporters and receive the demand of support must also be able to recognise the suitability of the SDM Agreement (as defined in the I-DECIDE methodology) for a particular person in order to encourage them to request such a personalised and individualised SDM service. The professional or person who identifies the need or receives a specific request for support from a person with a disability should report it to their organisation, manager or supervisor. From that point, a meeting with the individual requesting support should be organised to introduce the SDM Agreement, including a potential facilitator selected from a list or a pool of persons prepared and skilled to exercise that role. The facilitator will explain to the supported person all the details about their rights and how to use the agreement as a tool to deliver the supported decision making service. The facilitator is also in charge of introducing the different professionals or persons involved and its roles and the stages or processes that will occur once the SDM Agreement is formalised.

## Stage 2: Identifying supporters

Identifying a person or professionals to provide support is an essential part of the process. It is crucial to understand, acknowledge and respect that the person requesting the support has the right to choose the person who will provide the support. The approach used in this manual assumes that the supporter should preferably be a professional or a person with the skills to form a trusting relationship with the supported person. The facilitator will help the person to identify a supporter. The supported person could ask for more than one supporter, depending on the kind of decisions to be made. An interview will be held between all the parties to confirm the suitability of the proposed person to fulfil the role of supporter in the SDM Agreement.

## Stage 3: Defining the scope and content of the SDM Agreement

Identifying a person or professionals to provide support is an essential part of the process. It is crucial to understand, acknowledge and respect that the person requesting the support has the right to choose the person who will provide the support. The approach used in this manual assumes that the supporter should preferably be a professional or a person with the skills to form a trusting relationship with the supported person. The facilitator will help the person to identify a supporter. The supported person could ask for more than one supporter, depending on the kind of decisions to be made. An interview will be held between all the parties to confirm the suitability of the proposed person to fulfil the role of supporter in the SDM Agreement.

### ■ Scope

In the I-DECIDE SDM Agreement, an adult with a disability or a supported persons may voluntarily, without undue influence or coercion, authorise his or her supporter to do the following:

- To assist the supported person to understand the options, responsibilities and consequences which may arise from specific decisions that the person may want to take. For instance, a person may request support to decide where to live, which support or services they want, who they want they want to live with, where they want to work, how to administer personal finances, how to spend money as a consumer, how to use health care services or other decisions related to lifestyle, among others. The Agreement should describe, with the highest possible level of detail, the areas in which the person needs to be supported to make decisions.
- To assist the supported person in accessing, collecting or obtaining relevant information to make decisions.
- To assist the supported person in understanding or interpreting the information provided.
- To assist the supported person in communicating their decision to other people.
- The Supporter is not authorised to make any decision on behalf of the supported person.

Identifying a person or professionals to provide support is an essential part of the process. It is crucial to understand, acknowledge and respect that the person requesting the support has the right to choose the person who will provide the support. The approach used in this manual assumes that the supporter should preferably be a professional or a person with the skills to form a trusting relationship with the supported person. The facilitator will help the person to identify a supporter. The supported person could ask for more than one supporter, depending on the kind of decisions to be made. An interview will be held between all the parties to confirm the suitability of the proposed person to fulfil the role of supporter in the SDM Agreement.



Once a decision is taken by the supported person and the decision is communicated to other professionals, family member or peers, the supported decision making ends and the phase of implementing the decisions starts. Implementing decisions usually requires the combined actions of other support services or professionals, including family members or external stakeholders.





■ Contents

In order to create a SDM Agreement, professionals should ensure the following elements are explicitly stated in the document.

- ✓ The names of the Supported Person, the Supporter and the Facilitator
- ✓ A description of the three different roles
- ✓ As detailed a description as possible of the decisions in which the supported person needs support for in each relevant area
- ✓ The length and/or review date of the agreement
- ✓ Procedures to amend or cancel the agreement

**Stage 4: Delivering & Evaluating the SDM Agreement**

This stage describes the relationship between the three parties involved and the different actions to undertake during the I-DECIDE SDM Agreement, especially focusing on how to proceed to evaluate the process. The following diagram summarises the different working sessions in the I-DECIDE pilot phase.

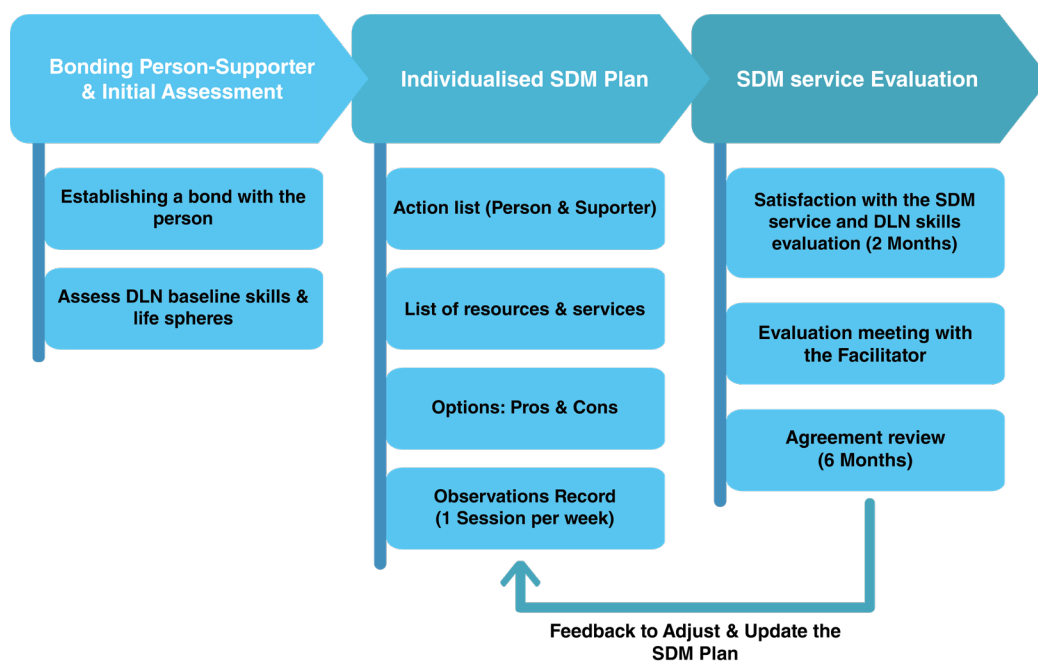


Figure 4. SDM Service & Agreement Evaluation: Working sessions

The next subsections provide insight and describe each process involved in the follow up and evaluation of the SDM Agreement.

**Establishing the SDM Relationship: Bonding & Initial Assessment**

During the first set of interviews between the supporter and the supported person the working relationship should consolidate and grow. Only after a trusting relationship has been developed can the supporter ask the supported person about his or her wishes, will and preferences and assess the skills of the person. It is not appropriate to evaluate, assess or ask the person about their wishes, will and preferences during the first meeting as the relationship would not have been properly established.

The first introductory interview must be focused to explain the different roles within the SDM Agreement and to understand the preferred methods of communication used by the supported person (e.g. verbal, non-verbal, use of special communication techniques or alternative methods). The information gathered during this session is essential to help the professional individualise and adapt the SDM Agreement and its processes to the supported person.

During the second interview, the supporter or the professional will observe, explore and preferably record how the person likes to make decisions (e.g. does the person take decisions slowly or impulsively? Is the person clearly determined and commits with his or her own decisions? Etc.) The supporter must respect the preferred decision making style and the pace of each individual. This session should be used to ask supported persons about their fields of interest and their social or professional networks in order to identify common points and build the relationship with them using soft skills.

The third and, if necessary, following sessions should be focused to assess the level of autonomy and skill the person has in relation of the three areas or life spheres dealt in I-DECIDE. Partners have developed as part of the project's methodology different documents designed help the support professionals. If a DLN assessment is required, this would be the best time to do it.

## The Individualised SDM Plan

Once the initial assessment has been done the supporter and the supported person will have a clear idea about the needs of the supported person and their wishes and preferences. At this stage, it is important and appropriate to ask the supported person for specific areas, topics, situations or issues where the person needs support taking decisions. The supporter, according to the I-DECIDE methodology and as defined in the SDM Agreement, must record as the first item of the Individualised SDM Plan the issues or areas arising from the working sessions and interviews that the person considers important to receive support in. The Individualised SDM Plan must include actions to be carried out for each issue, **in order for a decision to be made**, and the actions should be adapted to the skills and abilities of the person previously assessed with the assessment templates provided. The Individualised SDM Plan must include or reference the resources, services or individuals from the social or professional network(s) of the person that will be involved in each action, as well as the timetable of action to develop the plan effectively.

As a reference, the Individualised SDM Plan should include, but not be limited to, information about how to:

- Search sources of information;
- Coordinate actions with other support services or professionals to get information (e.g. identifying training opportunities to increase DLN or other daily life skills needed to make decisions);
- Communicate with the support services and the supported person's social networks about the issues included in the SDM Agreement;
- Specify the actions to ensure the information and actions are well understood by the supported person;
- Identify the different options with pros and cons for each issue or decision;
- Support the person to get advice from an expert;
- Proceed to communicate the decision made to the person's support services or social networks;
- Actions to help implement the decisions made by the person.

Following the elaboration of the SDM Plan, the next task will be to coordinate the resources available to implement the individualised plan for SDM. It is important to record observations and comments about the plan's effectiveness (i.e. did the actions developed help persons achieving their goals? and efficiency (i.e. quantify the amount of work or time needed to achieve the goals). Recording this information has two main objectives: first, to empower the person to identify and ascertain the progress made by getting direct feedback and, second, to improve the SDM process by adjusting the actions, tools or communication strategies with the supported person.

The frequency of the SDM working sessions will depend on the complexity of the issues to be decided and the actions to be conducted. As a general rule, one session per week is desirable.

## Evaluation of the SDM service

Evaluation is a necessary step in the I-DECIDE SDM methodology as it fosters the opportunity to improve and adjust the tools and procedures established both in the SDM Agreement and the SDM Plan. The core concept of evaluation is to control the process continuously. 'Control', here understood as a live and dynamic process, means adjusting tools used and making changes in procedures so the person is more able to take decisions under similar conditions. Frequent evaluation ensures better quality in the I-DECIDE SDM process.

### a) Satisfaction with the SDM Agreement or Service

I-DECIDE Project partners consider that it is the satisfaction of the user with the SDM Agreement and the service provided both in decision making and in implementing a decision which is crucial to ensure a long lasting relationship with the support professional or with a service based on the I-DECIDE methodology. Satisfaction assessments are encouraged using the documents provided at least every two months, (even though the frequency may vary on a per-case basis) with both the supporter ('supporter periodic self-assessment') and the direct beneficiary or the person with a disability ('supported person periodic self-assessment'). Self-administration of these surveys is envisaged as the results will be used to make changes in the process, adjust the actions or try different tools to improve the support provided to the person. Transparency is important on the evaluation process and the results of the assessment should be shared with the supported person and the professional providing support.

The facilitator is also the person in charge of supervising not only the SDM Agreement and monitoring the process, but also the progress made by the person or by the supporter. The facilitator's role encompasses being aware of the quality of the relationship between both parties. The review and use of the results of the self-assessment tools could be the starting point. Timely scheduled and accurately recorded interviews with the person and the professional supporter involved in the SDM agreement should help the facilitator channel the necessary amendments to improve satisfaction of both parties and spark the necessary arrangements in the agreement or the SDM Plan that the supported person and the supporter might consider beneficial.

### b) DLN skills progress assessment

The project considered DLN skills to be an important and fundamental element in decision making and the I-DECIDE project plan provided for them to be evaluated periodically with specific tools and forms developed to be conducted every two months. As the DLN skills assessment process is also a live and continuous process, registering the progress can evidence areas where the supported person needs to improve. The supporter will inform the supported person and his or her support network about the result of the DLN skills assessment in order to provide the most suitable training and resources. An improvement in the person's DLN skills may be linked with a good score when evaluating the satisfaction of the person and the supporter or professional.

### **c) Agreement review, renovation or modification**

Every six months the whole agreement has to be revised and feedback will be shared with the three parties involved in the process. Receiving feedback from the facilitator is highly encouraged at this stage of the process. When required, an extension of the agreement will be made, including new issues or modifying or updating existing ones. In other cases, the SDM Agreement will not be renewed because the person doesn't want to receive support anymore or simply because it is not needed.

## 4// I-DECIDE Health-care Manual

### Introduction

According to the 1948 World Health Organisation (WHO) definition, ‘health’ is a «state of complete physical, mental and social well-being and not merely the absence of disease or infirmity». Health and the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition or disability recognised in human treaties and in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Governments have the responsibility to take care of their citizens’ health, which can only be fulfilled by providing adequate support and allocating appropriate and sufficient resources. Health is a crucial element of an individual’s quality of life and people with disabilities often face discrimination whilst seeking to enjoy the highest attainable standard of health, as their quality of life is interpreted differently from the rest of the adult population and, as a result, their health standards and the resources available for them, tend to be lower. According to the Council of Europe, «the education and health-care systems and labour market fail to engage and include persons with disabilities or there is insufficient level of assistance and reasonable accommodation available». (CoE Disability Strategy 2017-2023).

The I-DECIDE Health-care Manual aims to tackle these inequalities by providing a methodological framework for professionals providing support to persons with disabilities and complex needs. The I-DECIDE Methodology develops a process of supported decision-making to increase personal independence and autonomy of persons with disabilities, whom traditionally have experienced a denial of both choice and control regarding decisions affecting their own health and managing their own lives, from basic decisions in daily routines to large scale plans and important decisions regarding health-care.

People with disabilities often need support to realise their right to self-determination and when this is not provided, the “care” environment often determines what a person’s health choices should be, rather than the person themselves. Individuals with a disability routinely interact with health services, rehabilitation services or social services, which often prioritise decisions according to their institution’s existing arrangements, professional expertise or according to the wishes and preferences of their family. Increasing the person’s independence, autonomy and effectively exercise choice and control over decisions affecting their own life can be related to an increase on quality of life and personal outcomes.



Figure 1: Elements of Health

The I-DECIDE SDM Methodology is an approach based on the UNCRPD and exemplifies how an SDM Agreement, used as a professional instrument, can be applied in the different aspects of an individual's life, but especially in the wide amalgam of health-related decisions (see figure 1). Health is an important sphere of everyone's life and taking care of health implies a variety of choices and decisions that an individual has to face throughout their life to achieve or maintain a good level of health. Those decisions can be simple or complex because health, as a whole, covers a lot of different areas and aspects and is an ever-changing element that varies in everyone's life.

It is noteworthy to clarify that individual differences in Digital, Literacy and Numeracy (DLN) skills and levels of the person can play a crucial role in the decision making and supporters are required to ensure that the relevant information is presented to an individual in the best possible manner so as to maximise their understanding of the decision they must try to make.

Choices related to health can vary depending on the environmental, social and personal circumstances of the individual and can vary from one individual to another, depending on the precise moment and on the particular life situation. For example, a person can decide to smoke, even though they are fully aware of the negative consequences associated with it, or they can choose between two treatments prescribed by the doctor at a given point to treat an illness. For this specific reason, it is of the utmost importance for every individual to have all the information available about a specific area of health that affects him or her. Prior to making a decision, all the positive and negative consequences should be collected by the supporter, along with all other options available, so that the supporter may fully analyse them and so be in a position to best support the individual with a disability to make their own decision using the I-DECIDE SDM Agreement as part of the SDM process.

People with disabilities often face discrimination when they try to access the necessary information and the support they need to collect relevant information about health-related issues. It also needs to be in a comprehensive but accessible format and often requires the support of a third person to gather it and interpret it. Supporters must embrace the value of pluralism and acknowledge that there are multiple ways to live one's life and make life choices.

Enabling persons with disabilities to make choices regarding their own health connects with the core idea of the theory of social capital. The overarching outcome of this theory is that possession of 'social capital' improves health and mental health outcomes by just enabling individuals to activate the support of already existing networks to protect and support them when experiencing recurrent issues in health like depression, substance abuse, alcoholism or other potentially cross-sectional health issues with the potential to relapse. The participation of several individuals contributes to build individual resources or 'capital' that can be drawn on to empower people and help them promote their self-interest. The theory of social capital evolved into the concept of mental capital, broadening the perspective to include cognitive and emotional resources, including people's cognitive ability as well as their flexibility and efficiency in learning and/or emotional intelligence or social skills and resilience when facing stressful situations. (Gould, N. 2010).

The quality of life desired by people with disabilities is as multifaceted as everyone else in society. Just taking prescribed drugs is not sufficient because instead of focusing on symptomatology and relief from symptoms, a 'recovery' approach aims to support an individual in their own personal development, building self-esteem, identity, and finding a meaningful role in society. 'Recovery' does not necessarily mean the restoration of full functioning without support, (including medication where needed). Instead it means developing appropriate supports and coping mechanisms to deal with health and mental health experiences as part of their normal daily life rather than having 'support' provided by only health services - as the usual definition of rehabilitation implies. Also, major economic, cultural/political differences, the variability of socio-economic contexts, legal frameworks and health strategies all complicate the use of SDM instruments & strategies in any particular country. A spectrum appears to exist in Europe between low and middle income countries with large-scale, stand-alone institutions and minimal welfare services, as opposed to the high-income countries that are 'de-institutionalised' and have comprehensive welfare systems. These differences have major implications for the nature of health services and mental health services, the types of coercion people experience in each country, the remedies for addressing them and the availability and adequacy of the support received by individuals. In that sense using SDM Strategies intended to improve quality of life of individuals also provides an opportunity to enhance the training of professionals working in health or support services.



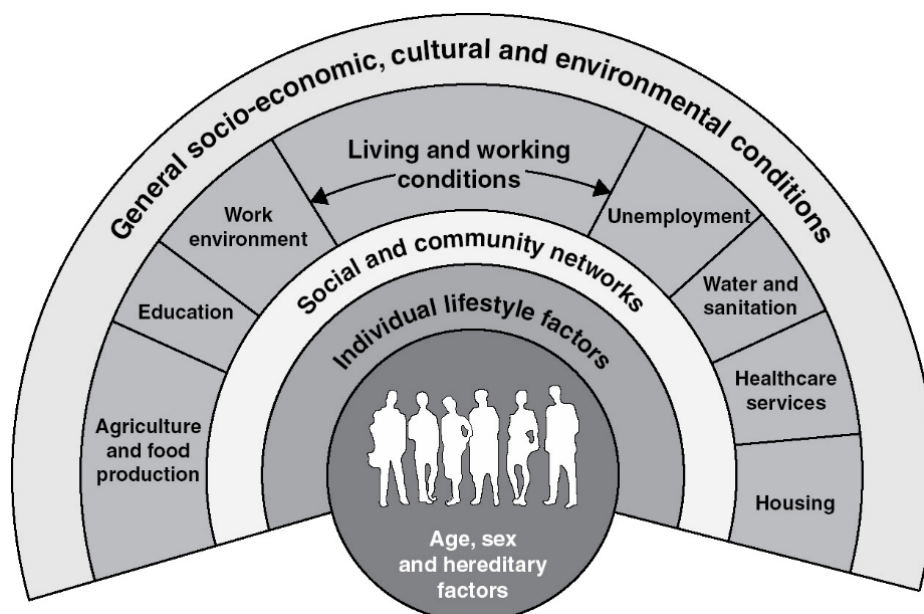


Figure 2: Dahlgren and Whitehead (1991) diagram. Layers of influence on health. Social ecological theory to health

In the following chapters we will present case scenarios where the I-DECIDE SDM Methodology can be used, followed by a rough outline of the individualised support plan which the supporter should be able to design to enable the service user to make an informed decision about specific health-care related issues. We must always have in mind that the ultimate goal of the supporter is to build the autonomy of the service user in order for him or her to take health-care decisions consciously and with as little support as possible.

## Basic Vocabulary

The development of an international glossary of terms applying to health-care and services for people with disabilities is not a task for this manual. However, it is important to recognise that when dealing with health-care services, professionals or situations, the terms and vocabulary used have an identity on their own. Technical and complex words are very often found during interactions with doctors, nurses or the health system in general and for this reason both the service user and the support professional must become familiar with them to understand and make an informed and conscious decision. Familiarity with these terms should increase through daily interaction with the supporter and the sessions conducted with the participation of the user and the health network of professionals or services. I-DECIDE **strongly encourages the use of the «glossary of terms for community health-care and services for older persons»** elaborated by the World Health Organisation.

## SDM Tools & Strategies in Health-care

Defining with the utmost level of precision the precise tools and strategies that can be used in health-care scenarios is out of the scope of this manual, as it would be impractical. However, from the range of literature consulted during the elaboration of the present document, a selection of good practices is presented, all are compatible with the I-DECIDE SDM Agreement and the individualised support that follows the constitution of the agreement. Understanding them and choosing the most appropriate one for a person is, however, contingent on the level of technical expertise of the supporter, the external professionals working in the local health services (i.e. doctors, nurses, psychologists, psychiatrists, etc.), and the willingness of the supported person to try new approaches. Additionally, the level of development of current practices in a given region or country may further limit possible choices, as some of the practices described may have legal or administrative implications.



**Advanced Psychiatric Directives:** Advanced Psychiatric Directives allow for freely made decisions designed to bind oneself and/or direct others to take specific action in the future. Decisions included in these directives could encompass simple treatment preferences or other information (e.g. instructions on who to contact or not contact or who is appointed as a formal / informal supporter in medical issues, contact information, details of mental and physical illnesses, treatments, indicators for relapse, and preferences for care in the event of a future relapse or crisis situation). These directives are written by an individual in collaboration with his or her clinician (care coordinator, psychiatrist, project worker or GP) with the aid of the supporter, if needed. It is noteworthy that most individuals, supporters and experts in the medical field are unfamiliar with advanced psychiatric directives. Medical and other professionals often show concerns about the individual's capacity to decide about treatment due to the traditional over-reliance on specific professionals and their opinions, particularly in the medical field. To increase efficiency and validity, joint crisis planning meetings should be encouraged with the participation – if possible – of all the professionals involved in the elaboration of advanced psychiatric directives, including the supporter and the individual. This strategy could potentially mitigate the risks of coercive treatments by helping others to respect the wishes and preferences of a person during crisis situations.

**Crisis Cards** constitute a form of advance planning and advocacy tool. Crisis Cards can include details about what should happen in the event that a person experiences a crisis situation and is referred to professionals. It is a concept similar to the 'Care Passports' operating in different countries, but with a specific approach in crisis situations. Crisis Cards are conceived as an advocacy tool aiming to ensure an individual controls their future treatment and at the same time promotes his wishes and preferences by explicitly stating his/her autonomous choice in that regard.

**Special Health Cards** are conceptualised as a sort of priority pass cards addressed to especially vulnerable people who need individualised attention. The card is requested either by the person, by doctors or by the legal representative (family or professional) of the vulnerable person. Whereas regular health cards aims to identify people as soon as they access a specific health service, the distinct characteristic of a special identification card aims to prioritise accessibility to the system for persons with disabilities by:

- reducing waiting times for being visited and adjustment of spaces (if possible);
- providing easy access to hospitals and individualised attention during transportation in emergency situations;
- helping health-care professionals better identify special needs and provide tailored communication and special attention; ensuring timing flexibility during the consultation to suit the needs of the individual; ensuring accompaniment and support by a family member or caregiver unless their support may affect or hinder the delivery of medical treatment.



**Family Group Conferences** are conceptualised as a voluntary consultation process in which an independent co-ordinator or supporter facilitates a series of discussions between an individual and her or his key social network. The individual selects friends and/or family, or professionals, to discuss issues of concern and seek solutions, including composing a plan which sets out the steps to be taken. Clinicians may have a background support role, or could have roles in facilitating any outcomes of decisions that involve clinical care decisions.

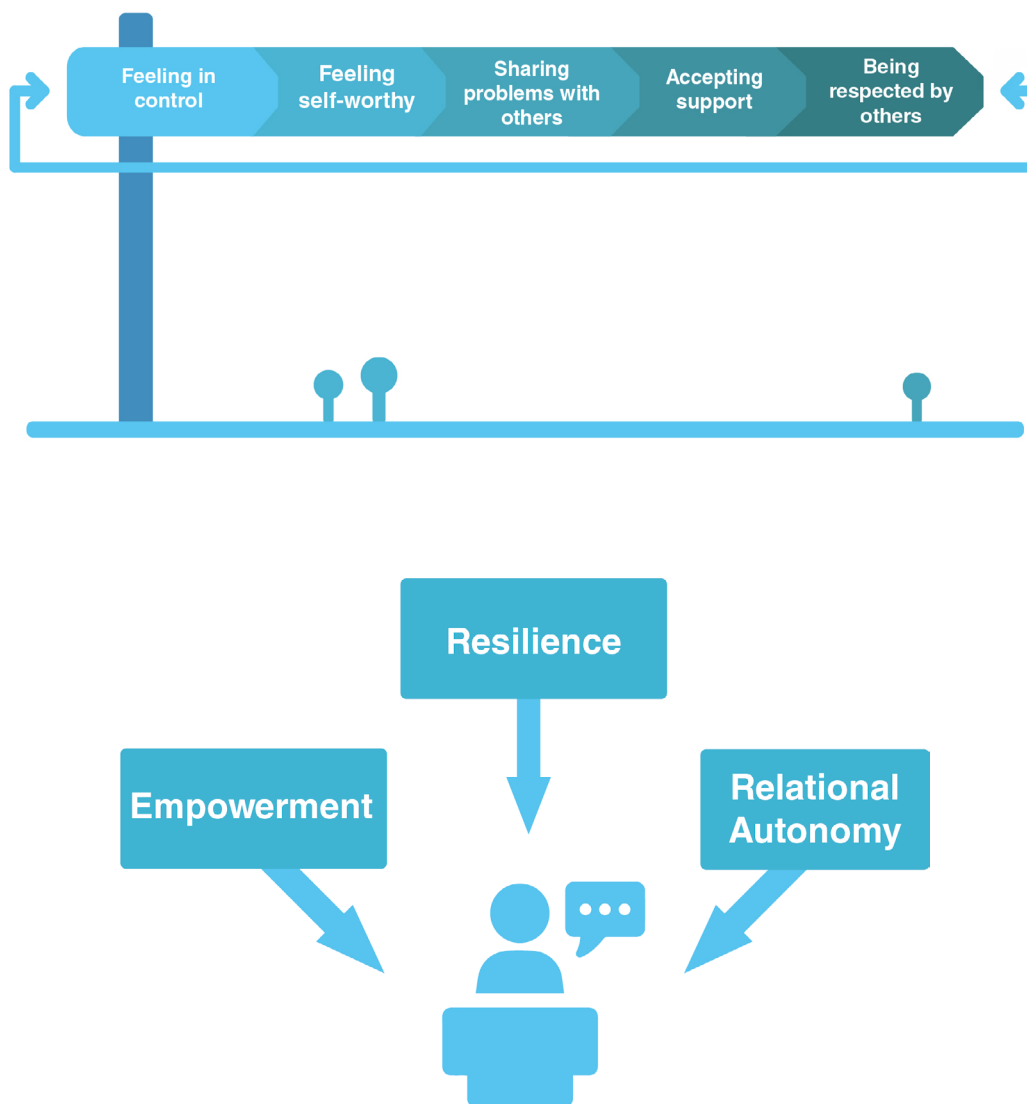


Figure 3: Family Group Conferences Theoretical Framework

**Medication Discontinuation Strategies** constitute an alternative to a sudden discontinuation of pharmacological treatments. Our practical experience suggests that many service users deliberately don't tell mental health professionals when they stop taking their medication. They do this to avoid any negative judgement and other consequences often initiated by clinical professionals, such as coercive measures including involuntary treatment or compulsory placement, or even both. Discontinuing psychiatric medication or key treatment is often a complicated and difficult process. It seems reasonable to assume that discontinuation practices, whether formally or informally, are occurring worldwide and that a certain level of resistance from the medical community exists. Proposing, jointly with medical experts, tapering strategies under supervision to reduce medicalisation levels can help improve user satisfaction and also be a possible way to improve the choice, control and safety of the users who take them and could lead them to decide in a safe manner not to take them anymore.

**Open Dialogue (OD) strategies** aim to treat disability conditions (primary conditions, secondary conditions and co-morbid conditions) in the user's home. Treatment involves the patient's social network and the responsibility for the entire treatment. Open Dialogue is a practice developed in Finland in which care decisions are made in the presence of the individual and his or her wider social networks. Psychotherapeutic approaches are taken with the aim of developing dialogue between the person and their support system as a therapeutic intervention. Service providers aim to facilitate regular 'network meetings' between the person and his/her immediate network of friends, carers and family, and several consistently attending members of the clinical team. A strong emphasis is placed on equal hearing of all voices and perspectives as both a means and an objective of treatment in itself.

**Peer Support Groups:** Peer support are groups in which persons with psychosocial disabilities provide support to one another. Originally conceived for people with psychosocial disabilities, peer support groups can also be used by people with intellectual disabilities and can take many forms. The composition of the groups can be informal (in homes, institutions or neutral spaces in the community) or formal (where service user consultants assist in hospitals, or in respite houses which are run by people who have experienced mental health crises of their own). The use of peer support groups has shown to have an impact by reducing admissions among participants. They have also shown associated improvements - with sufficient training, supervision and management - to drive through recovery-focused changes in health services. Peer support groups work under the idea that members can share successful strategies with each other in a mutually safe space, sharing key ingredients to succeed in reducing distress about particular health situations.

**Representation Agreements / Nominated Persons Schemes:** These types of instruments are conceptualised as advance planned mechanisms similar to Advanced Psychiatric Directives, but are not exclusively focusing on mental health related issues, but operate instead in a broader sense. Multiple forms of representation agreements exist worldwide with a different status of validity across local legislations. Most advance planning measures will include a form of representation agreement, in which a person is nominated to assist in specific areas of an individual's life, whenever specific situations happen. Powers of attorney may also provide a simple legal formula for appointing a representative on certain decisions. Others, such as Joint Crisis Planning, and informal representation agreements among users and prior users of services, are not universally implemented, but these may also work as a form of informal support alternative.

**Dialogue Group Users:** users, friends, supporters and health professionals meet regularly in an open forum that is located on neutral terrain – outside therapeutic spaces, family spaces or institutional contexts – aiming to discuss the experiences and consequences of health problems searching ways to solve them. Dialogue group discussions offer new possibilities for gaining knowledge and insights and developing new ways of communicating beyond role stereotypes.

## Daily Health-care

The I-DECIDE SDM Methodology aims to become a collaborative process allowing persons with intellectual disabilities to make health-care decisions conjointly with health and support professionals, while improving their wellbeing and their self-determination. Applying SDM principles in daily health-care implies recognising that persons with intellectual disabilities are often capable of making their own decisions and sharing them with health-care professionals, provided they get appropriate support to do this.

Daily health-care can be defined as the group of basic daily living activities that enable an individual to live a healthy independent life. These activities include eating (buying, storing and cooking food), nutritional habits (being aware of calories and following a specific diet), mobility and physical habits, bathing or toileting. Daily health-care is deeply connected with the individual's ability to perform the aforementioned above activities with or without assistance and is tightly linked with instrumental key activities of daily living (e.g.; managing money, communicating with peers, doing housework, etc.) and the concept of 'self-care'.

'Self-care' is considered a basic form care for patients with chronic conditions such as intellectual disabilities. Self-care is a process learnt throughout an individual's life and is a continuous process. Self-care maintenance behaviours can be influenced by external factors, such as access to health-care and living environments and internal factors such as the emotional state of the individual, their motivation at a given point in life, self-perception and cognitive abilities. An individual with impaired cognitive or functional abilities has a diminished ability to perform self-care maintenance behaviours.

Intellectual disability usually originates during the developmental period and is characterised by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. (Tassé et al., 2016, p. 1). In addition, people with intellectual disabilities tend to suffer more illnesses, both physical and mental, because they often have unhealthy lifestyle habits (e.g. unbalanced diets, sedentary lifestyle...), tend to suffer from illnesses associated with intellectual disabilities (e.g. epilepsy, mobility problems, diabetes, etc..) or secondary alterations associated with genetic diseases (e.g. thyroid problems specifically in individuals with Down syndrome).

Social supports may also often influence how well an individual becomes able to perform self-care maintenance. Social supports include family, friends, and support groups. Support groups can take form of peer support groups, professional experts on a specific field, a mixture of the two or community groups (usually developed in community centres), groups that manage chronic illnesses, or a community group.

### Case Scenario: Gaining Self-esteem through healthy habits

The health of individuals is determined by different factors that go beyond the purely biological and it is widely recognised that psychosocial factors have a predominant influence and impact on the health and quality of life of individuals. Individualised support also enhances the quality of life of individuals and their personal outcomes.

Marc's case illustrates the support decision-making process in the area of daily health-care (prevention strategies, nutrition habit, healthy lifestyles and daily life activities).

Marc is a person suffering from overweight and has problems establishing relations with his peers due to communication problems and because of his shyness. An initial exploratory assessment indicated that he has the desire to have more friends, since he is often alone in the afternoons when he ends his shift in the factory that employs him.

Half a year ago Marc signed an Agreement with a supporter explicitly stating that he requires support taking decisions about his health and lifestyle. In a conversation with an educator, Marc expressed his dissatisfaction at being overweight and the relation that his overweight has on his confidence in establishing new relations or maintaining them. He stated that he often fears leaving his house to attend social events and spends most of the time in the sofa playing videogames on the computer because of this. The supporter asked him directly if he wants to lose weight and obtained a clear positive answer.

The goal for Marc is to lose weight and an individualised support plan is made together with professionals and the individual to support him, reflecting his choices. At this point, it is important to be clear that the support decision-making process, the individualised support plan and the direct support that he requires are all separate elements in the process. The individualised support plan may be defined by the same professional that supports the supported individual making his/her decision (according to SDM principles), but it is not required to be done by the same professional. The support needed to implement it can also be provided by a third person.

Supported decision-making in daily health-care encompasses the resources and strategies available to promote the development, education, and personal wellbeing of Marc in relation to his overweight and his decreased personal skills, with the aim of enhancing his personal functioning. The supporter must present Marc with individualised support strategies related to choices and decision-making to increase his quality of life in his chosen area (i.e. losing weight), but at the same time the supporter must respect Marc's self-determination on this. Success may well come from appealing to Marc's sense of personal responsibility.

The process followed by a supporter in this case is exemplified below:

- I. Firstly, he must assess and compare the skills and abilities that the person (Marc) already has with the skills and abilities needed, in relation to understanding the several sources of information available on this issue: e.g. internet forums and videos, books, face to face peer testimonials, professional assessment, nutritionists and dietitians, sport advisors, etc. If the supporter thinks that Marc is unable to interpret the information available, s/he must then suggest to Marc a plan to improve his skills so that he can understand the information, or alternatively, think of a way to present that information to Marc in such a way so that he can understand it.
- II. The intention is make Marc aware of what self-care management means, (this involves following healthy habits and involving him in physical activity and acquiring good nutritional habits) and the consequences of not doing so. S/he must explain to Marc about different diets and how some poor diets are a health risk and who the professionals are that he can get advice on this from. At this point the supporter explains to Marc all the different alternatives to achieve this goal.
- III. It may be necessary to involve other professionals and experts in the field or to make an appointment with a nutritionist or general practitioner. The supporter will need to explain the visit to Marc and possibly suggest going with him to be sure he understands the information he is given.
- IV. The supporter will then have to create an individualised support plan made jointly between professionals and the individual to support him achieving his declared goal of losing weight.
- V. There also needs to be some control and monitoring mechanisms. The individual must be aware from early stages that following a diet or joining an educational group about nutrition implies establishing mechanisms to monitor its effectiveness. At the same time, the supporter must state clearly to the individual (Marc) that success depends on how well he follows all the recommendations (e.g. diet, regime, nutritional habits, physical exercise, etc.) made by the professionals. For example, he could use weight scales to record the progress made to see if the diet is going well (or not) and if more help is needed. This monitoring phase can be complemented with different visits to relevant professionals (in this case different professionals involved could be a nutritionist, a general practitioner, or experts on weight loss). Overall, the monitoring phase of monitoring enables the supporter and Marc to check if the intervention made after the assessment is actually achieving his wish to lose weight. This can be seen as a three way evaluation, looking firstly at the user's satisfaction, secondly at the supporter's evaluation of progress and finally, if previously agreed, at any evidence of progression relating to the user's DLN skills.
- VI. The individualised support plan should make use of any SDM tools available. Some examples of SDM tools available in Marc's case (in Spain) are:
  - a. Health Education Programme: Health Education is a specific type of programme addressed to people with intellectual disabilities that complements the recommendations given by the General Practitioner or a specialist doctor. These are explained to Marc in different thematic sessions about specific topics (e.g. in Marc's case, the topics would be nutrition habits and healthy lifestyles). The group is the ideal way of addressing the psychosocial aspects that influence the lifestyles of individuals and of comparing them, as it enables participants to learn by interaction with other participants. This promotes peer education, reinforces motivation and facilitates mutual support and help for decision-making and the maintenance of healthy lifestyles. Note: specific group education might not always be possible at a given time and the availability or the location of such a support group might make it difficult for some people to use.



- b. Self-maintenance recommendations: if the individual tends to avoid socialisation but may be able to use new technologies, then the use of video materials is highly recommended. In Marc's case for example, he will need the supporter's help to increase some specific IT / digital skills by showing him how to use some new programmes on his computer / tablet.
- c. Online courses aimed to train individuals in healthy lifestyles and good nutrition habits. The supporter can find a list of such courses for the individual to follow. These will increase Marc's understanding of healthy lifestyles, nutrition habits and increasing self-care management.
- d. Plan for some form of physical activity: This will require some coordination with the physiotherapist and an assessment of all the relevant physical-sporting activities offered by the local leisure and sports centre(s). Of course, like all other people, this will depend on Marc's reality and commitment (in line with the wishes and preferences of the person) to see this through. These could include sessions of physical exercise carried out in the community or through a personal trainer, depending on the income of the individual.
- e. Nutrition plan: this will require coordination with the nutritionist doctor and could include mini training sessions on different topics of food and healthy habits organised through games or visual and interactive tools such as pictograms.

## DLN Focused SDM Tools

Digital, literacy and numeracy skills can be increased in this specific scenario in different areas.

- Digital Skills can be increased if the appointment with the doctor is made by Marc using technological tools such a computer (it may vary from country to country). Also ask or help Marc to search for a new diet using the internet and compare the kind and quantity of food with the previous a previous diet he tried or with what he eats now.
- Literacy Skills can be increased if the supporters enable the individual to understand the type of documentation provided by the physician, nutritionist or general practitioner. In this case, the 'teach-back' methodology is recommended in order to be clear how much of the information given by the nutritionist or GP is retained by the user. The teach-back methodology consists of making the person with a disability explain back what has already been explained to them, checking for gaps in the user's responses, reinforcing the messages with a collaborative conversation with the supported individual. A practical example of how to initiate teach-back is by asking, "I want to make sure that I explained everything, if you have to explain what I told you to your friends, what would you say to them?"
- Numeracy Skills can be increased if the supporter enables the individual understand calories, the way they are measured, etc. Ask Marc for his preferences about the kind of food and quantities he likes to eat regularly and (together) compare the answers. Finally, ask Marc to build a diet for a full week. Use simple images (e.g. see below) to illustrate the kind of food, the differences between healthy and unhealthy habits, which ones are related with obesity, etc. and compare them with the current preferences of the person.

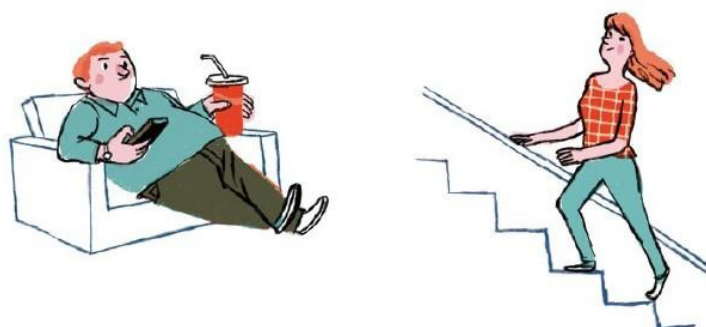
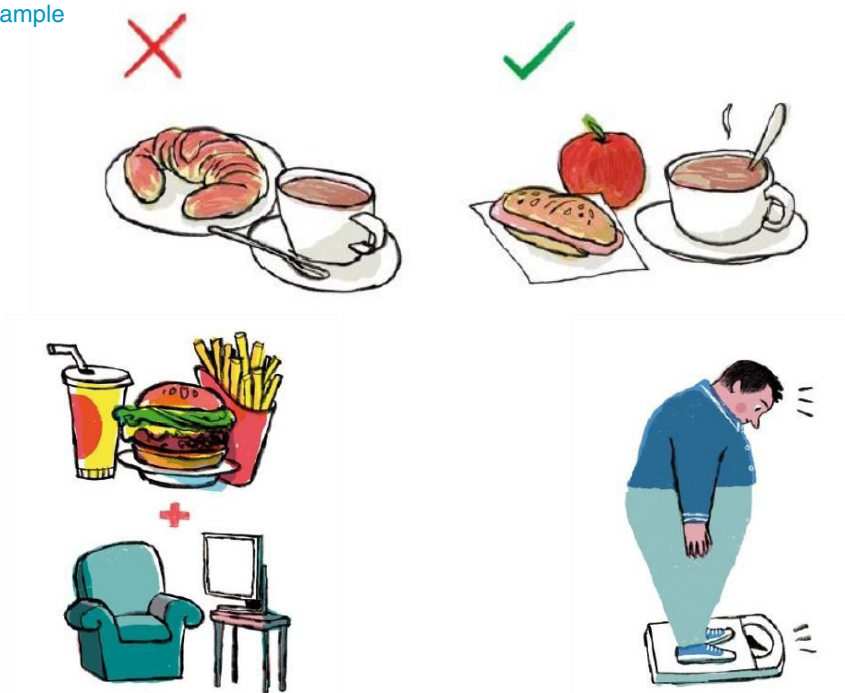


Figure 4: Pictograms Example



Illustrations by Martín Tognola, (2017, Hábitos alimentarios).

## General Health-care

General health for individuals with a disability is frequently associated with a very wide range of primary health conditions that may result in poor health and generate high health-care needs and consequently require even more resources to be allocated to achieve a good standard of health. Many common health conditions should normally not prevent people with disabilities from achieving a normal standard of health, but the fact is that the World Health Organisation (WHO), specifically addressing health-care related issues for PWD's, categorises their health-care conditions into three broad categories and provides guidance on how to address these categories.

Firstly, 'Primary health conditions' are defined as a possible starting point for future impairment, activity limitation or restricted participation in society. As examples of primary health conditions these could include depression, arthritis, chronic obstructive pulmonary disease, ischaemic heart disease, cerebral palsy, bipolar disorder, glaucoma, cerebrovascular disease, and Down syndrome. A primary health condition can lead to a wide range of impairments, including mobility, sensory, mental, and communication impairments.

Then 'Secondary health conditions' are additional conditions, assuming the existence of a primary condition, and are distinguished from other similar health conditions by the lapse in time since the primary condition is diagnosed and the appearance of the secondary condition. Examples include pressure ulcers, urinary tract infections, and depression. Secondary conditions can reduce functioning, lower the quality of life, increase health-care costs, and potentially lead to premature death. Many such conditions are preventable and can be anticipated from primary health conditions.

Thirdly, in addition, 'co-morbid conditions' are additional conditions independent of and unrelated to the primary condition. Co-morbid conditions are often not well managed in terms of early detection and treatment for people with disabilities and have the potential to create an adverse effect on their health. For example, people with intellectual disabilities and psychosocial disabilities commonly experience 'diagnostic overshadowing', that is, attributing a person's symptoms to their mental condition or disability. Examples of co-morbid conditions include cancer or hypertension for a person with an intellectual disabilities.

People with disabilities require the full range of normal health services just like the rest of the population. General health needs include health promotion, preventive care (immunisation, general health monitoring and screening), treatment of acute and chronic illness, and appropriate treatment for more specialised needs if required. These needs should all be met through primary health-care or through the specialised health circuit.



Some people with disabilities may have a greater need for specialist health-care than the general population, since they may have multiple health conditions. For this very specific reason, it is necessary to provide persons with disabilities with person-centred care, focusing on identifying, respecting and caring about individuals’ differences, values, preferences, and expressed needs; relieve pain and suffering; coordinate continuous care; listen to, clearly inform, communicate with, and share decision-making.

Conventional ambulatory medical care in clinics or outpatient departments	Disease control programmes	People-centred primary care
Focus on illness and cure	Focus on priority diseases	Focus on health needs
Relationship limited to the moment of consultation	Relationship limited to programme implementation	Enduring personal relationship
Episodic curative care	Programme-defined disease control interventions	Comprehensive, continuous and person-centred care
Responsibility limited to effective and safe advice to the patient at the moment of consultation	Responsibility for disease-control targets among the target population	Responsibility for the health of all in the community along the life cycle; responsibility for tackling determinants of ill-health
Users are consumers of the care they purchase	Population groups are targets of disease-control interventions	People are partners in managing their own health and that of their community

Figure 5: WHO Aspects of care that distinguish conventional health-care from person-centred health-care (Source: World Health Report 2008 – Primary health-care: now more than ever)

### Case Scenario: Primary Factors, Secondary Factors & Co-morbidity

A common issue when providing support to an individual with an intellectual disability is how to enable the individual to be fully aware of their own health problems and the impact these problems may have on their health on a short, mid and long term basis. More often than not, the person is unaware of the implications of specific issues and may also not understand the importance of taking care of general health-care issues. Also they might additionally face other obstacles and barriers to treatment. Health-care workers and supporters often lack adequate knowledge and skills around many primary, secondary and co-morbid conditions associated with disability and how to effectively manage the health-care needs of people with disabilities or where to find help to tackle them. Service providers and supporters may be unsure how to address health needs directly related to a disability and how to distinguish between health problems related to a disability and those which are unrelated. They may also not understand the need for comprehensive health-care services. Support workers should ideally have a general idea about the causes, consequences, and treatment of disabling conditions, and of the incorrect assumptions about disabilities that may result from prejudice about people with disabilities.

Common barriers include health-service providers’ attitudes, knowledge and skills, and ensuring that health practices do not conflict with the rights of persons with disabilities. People with disabilities may be reluctant to seek health-care because of prejudice and discrimination. People with disabilities may have experienced institutionalisation or other involuntary treatment, abuse, neglect and persistent devaluation. Negative experiences in the health system, including instances of insensitivity or disrespect, may result in a distrust of health providers, a failure to seek care, and a reliance upon self-diagnosis and treatment. Therefore, respectful, knowledgeable and supportive responses to people with disabilities from health-care providers are vital. However, attitudes and misconceptions among many health-care providers are still barriers to good health-care for people with disabilities and some clinical decision-making may be influenced by negative attitudes and assumptions.

The **case of Charles** illustrates the process of choosing between two alternatives for a treatment.

Charles is an individual of 46 years old with learning disabilities, with a high level of functioning in society. He works in a part-time job in the protected labour market and the earnings from his job are a little below the minimum wage, but he supplements his total income with state benefits. He is very happy in his job because he is doing very well and he has made great friends in the job, including befriending a woman younger than him. He always enjoyed having a cigarette from time to time, but in the last three years he has been smoking more than he should. Nowadays he smokes two packs of cigarettes a day. One day, Charles was not feeling well and went to the doctor and he had a series of tests. Charles has been diagnosed with chronic obstructive pulmonary disease, a condition that affects his lungs. After several visits to the doctor the professional has been able to prescribe a specific treatment that reduces the effects of his condition (i.e., breathing difficulties, constant mucus, etc.) and since then his condition has been improving. On several visits to the doctor, he advised Charles that his health situation is not helped by his heavy smoking. Smoking is the principle cause of his condition and particularly because he is still suffering from chronic obstructive pulmonary disease and this is now affecting his life, causing absence from his work from time to time. His manager has spoken to him a couple times about this. Consequently, the doctor advised him to undertake a specific treatment to quit smoking, so he did. After one month, Charles, is experiencing a series of side effects from the treatment, particularly after he takes the pill every day in the morning. In this particular situation, Charles is asking for support, since he wants to keep his job and his friends at work, but he doesn't know if it is wise to stop the treatment or how he might better cope with the side effects.

The process followed by his supporter in this case is described below:

- I. Firstly, the supporter has to assess the skills and abilities that Charles already has in relation to following previously prescribed treatments by the doctor (such as preparing the medication by himself, taking the prescribed medication on a timely schedule and routine). Then he needs to compare those abilities with the new skills and abilities Charles needs to understand his new current health situation (the consequences of his condition, the consequences of the side effects of the prescribed treatment). The role of the professional supporter is important at this point, since it can help Charles to rationalise what side effects he has been experiencing and to see the potential ability to increase his knowledge about this using different sources of information available. These could include visual materials about strategies to quit smoking, videos from YouTube or interviews with his doctor or nurse. All of these could help Charles increase his own knowledge about the problem he faces before creating a support plan and before using tools he is willing to accept.
- II. The intention for Charles is to learn about quitting smoking; how to improve his health situation in the long term (since the chronic obstructive pulmonary disease is still present); how to increase his personal strategies to follow the prescribed treatment, coping with side effects and, ultimately, to avoid the risk of being fired since the manager has already warned him a couple of times. However, during this phase Charles's stated wish to follow (or leave) the prescribed treatment should be clarified (preferably in writing) since taking one path or another will influence the individualised support plan created by the supporter in later phases. At this point the supporter should explain to Charles the different alternatives or tools that can be used to achieve his stated objectives. The supporter must make sure that Charles understands the consequences of following one path or another.
- III. The supporter must involve relevant professionals and experts. For example, s/he must show Charles how to make an appointment with the doctor or nurse to help Charles understand the information given earlier by the supporter. The supporter must explain to Charles the objectives of the visit and suggest going with him to be sure he understands any clinical information he is given. During this step it is important to include information about what the treatment implies and the consequences related to following to it or not following it. The role of the supporter in this phase is to help Charles understand the consequences of the different paths, tools and strategies explained in the previous phase. Information should be presented in an accessible and understandable way to Charles.

- IV.** The supporter must then create an individualised support plan made jointly between professionals (health professionals and the supporter) to support Charles in achieving his goals in relation to (in this example):
- a.** Following the prescribed treatment to quit smoking
  - b.** Looking for an alternative form of treatment with fewer/no side effects on Charles
  - c.** Abandoning the treatment prescribed by his doctor.

Some practical tools that should be carefully explained to Charles and that can be used here are things like peer support groups and medication discontinuation strategies, depending on what Charles decides to do.

- V.** The supporter must also create monitoring mechanisms. The individual must be aware from early stages that each strategy has its own limitations and that there needs to be some way of monitoring progress and assessing effectiveness. At the same time, the monitoring phase can be complemented with follow-up visits or calls from the supporter if a physical meeting is not feasible due to Charles' work schedule.
- VI.** The supporter must also use all the available SDM tools to help Charles. In this case (giving up smoking) there are different SDM tools that can be used depending on which direction Charles decides to go in. It is important to note that the individualised support plan must be created with Charles' understanding and agreement and in consensus with other relevant professionals involved.
- a.** Peer Support Groups: this kind support method can be used if Charles decides to follow the treatment prescribed by the doctor. Peer Support Groups facilitate sharing experiences between individuals who are (or were in the past) in a similar situation, The intention of peer support groups is to share strategies between peers, to integrate the group's own experience into that of Charles' health and social situation so as to increase the chances of Charles sticking to his treatment.
  - b.** Medication Discontinuation Strategies: this tool can be used if Charles decides to abandon the treatment prescribed by the doctor. Medication discontinuation strategies must always be operationalised with health professionals. The role of the supporter is to enable Charles to understand how such discontinuation strategies work and check that Charles does follow the procedure explained by the doctor. If Charles experiences problems with this strategy of stopping the medication (if it is contemplated in the individualised support plan) they must be shared with health professionals.

## DLN Focused SDM Tools

If so required, evidence of increased digital, literacy and numeracy skills can be collected in this specific scenario in different areas.

- Digital Skills can be increased if technological tools are used in any of the following: during teleconferences with his doctor; using the health system application online to schedule a meeting with the doctor; or using internet resources for assistance when finding out about giving up smoking.
- Literacy Skills can be increased if the supporter enables the individual to understand the type/content of documentation provided by the general practitioner in relation of the side effects of a specific treatment. In this case, the 'teach-back' methodology is also recommended to check on the amount of information that is retained by the user after it has been given by the professionals.
- Numeracy Skills can be increased if the supporter enables the individual to understand prescriptions and the timing of dosages, how many pills to administer and so on. The use of simple images in relation to pill administration (if available) and easy-to-read versions of prescription schedules is highly encouraged.

## Cross-sectional Issues in Health-care

Cross-sectional issues in Health-care cover a wide range of topics, transversal issues in social support and health-care situations (communication strategies between the supported person, the health professionals and the supporter's role; the issue of informed consent; involuntary placement and hospitalisation, pharmaceutical treatment, birth control planning, etc.).

### Case Scenario: Tackling Complexity

Carol is a 31 year old woman diagnosed long ago with epilepsy. At the same time, she has been diagnosed as having an Intellectual Disability. Three years ago, she started be depressed and since then she has been experiencing episodes of nervous breakdowns that lead to episodes of self-harm and have frequently escalated to suicide attempts, leading to involuntary hospitalisation and involuntary treatment in psychiatric hospital settings.

On the other hand, Carol likes to go out, meet people and to start new relationships. Carol has been dating Rob for a year and since then her episodes of nervous breakdowns have diminished in frequency and intensity alongside the episodes of self-harm, but when they do happen, they often lead to hospitalisation. Rob has been a great help to her and they have made plans to live together. She is happy and wants Rob and her to strengthen their relationship, maybe even starting a family. Carol asks her supporter in the Agreement for orientation and support to help her make wishes to come true.

Carol's case shows how the supporter needs to help her to design advanced planned directives about particular issues with specific strategies and recommendations during the supported decision-making process to avoid over-reliance on medicalisation. They must also cover possible scenarios in which alternatives to coercive practices in medical intervention are able to recognise and accommodate Carol's wishes and preferences and acknowledge current trends in disability policy and practice. Of course, these available resources will be different in each country. In Carol's case, there are three potential factors to be considered which may require support and/ or intervention. They are:

- ▶ **A** – Her depression and suicide attempts that lead to involuntary placement
- ▶ **B** – Any epilepsy crisis and the specific medication she may need
- ▶ **C** – Family planning and post-natal support (if the situation occurs)

Best practice strategies would be designed to help minimise involuntary measures and increase voluntary and consensus-based measures, recognising that people with intellectual disability experience higher rates of major mental disorders than their non- intellectually disabled peers. (Evans, E. et al.; 2012). According to the Committee on the Rights of Persons with Disabilities, forced treatment is a particular problem for persons with psychosocial, intellectual and other cognitive disabilities, as this type of coercive intervention is also used on persons with intellectual and/or developmental disabilities and older persons. Subsequently, during the SDM process a comprehensive analysis of the best practices available should lead to a decrease in the use of coercive tactics (first factor) by professionals, help people with intellectual disabilities cope with the side-effects of medication (second factor) and emphasise the role of their family and social network involvement in post-natal support (third factor).

The process followed by a supporter in this case is exemplified below:

- I. The supporter must assess and compare the skills that Carol already has from her past experience in the field of mental health-crisis situations (**depressions leading** to suicide attempts, periods of compulsory detention in secure mental health facilities etc.) with the skills she might need in future with any baby.

Sources of information are available on this issue: professional assessment from her main psychiatrist on the reasons that lead to involuntary placement (since it may not be entirely clear to Carol why this happens to her). Similarly, peer support groups of people with intellectual disabilities who have experienced similar situations in the past could be helpful to build a rationale of facts to Carol and help her to acquire some perspective about her potential skills. The role of the professional supporter is important at this point since it can help contextualise or focus on the reality of the situation and not only on just one part of the experience.

- II. The intention is for Carol to understand about what particular events and risks trigger her psychiatric hospitalisation and, at the same time, think about foreseeable scenarios that could lead to another compulsory placement in the future. This phase also can include information about what treatments exist, what they involve and the consequences of sticking to (or failing to stick to) the prescribed medication. Translating general problems into precise goals for Carol and searching for means to achieve these is a challenge both for the supporter and for the other professionals who offer support to Carol. Practical tools that can be used in this scenario are open dialogue scenarios and Trialogue techniques involving related professionals (from clinical settings, social workers et al.)
- III. At this point the supporter must explain to Carol some of the different practical tools and alternatives to achieve her goal (e.g. advanced Psychiatric Directives, Crisis Cards, Family Group Conferences, Peer Support Networks, Medication Discontinuation Strategies, Open Dialogue Schemes, Representation Agreements / Nominated Person Schemes, Trialogue Group Users). If any of those tools has already been used by professionals, remind Carol about its use and purpose so as to help her have a clear picture of what is currently being considered. The supporter needs to involve professionals and experts in the field using a multidisciplinary approach, and also involve – if the user consents – family members, peer supporters or experts by experience, who can help Carol understand the underlying consequences of the various strategies. Information should be presented to Carol in an accessible and understandable way.
- IV. The supporter must create an individualised support plan made jointly between professionals and the individual to support her achieving her clearly stated desires, wishes and preferences in relation to possible future events and her decisions on one or more strategies to be put in place. Clear examples of practical tools in this phase could be Crisis Cards, Advance Psychiatric Mechanisms, Representation Agreements / Nominated Person Schemes. Deliberately choosing between one and another depends on the networks of support available to the individual (i.e. formal or informal / natural networks of support), the level of cooperation available from the medical authorities and the practicality/ acceptability of those mechanisms within the country's legal, social or medical system.
- V. The supporter must create monitoring mechanisms. The individual must be aware from early stages that each strategy has its own limitations and that there needs to be some way of monitoring progress and assessing effectiveness. At the same time, the supporter must explain clearly to the individual that success is variable and depends on several factors, including the level of cooperation the professionals show in each particular case. The monitoring phase can be complemented with follow-up visits from the supporter.
- VI. The supporter must also use available SDM tools. In the case of Carol the tool chosen by consensus with her in phase IV is the Advanced Psychiatric Directive. The Advance Psychiatric Directive is fulfilled by Carol and her supporter and she explicitly states that Rob is appointed as her direct supporter in crisis situations, since she discussed with him aspects of previous hospitalisations that she does not want to be repeated again. The advanced psychiatric directive explicitly states that:
  - Carol doesn't want to be mechanically restrained.
  - Any pharmacological treatment should be exclusively taken orally since she doesn't like injections.
  - Any hospitalisation should be limited to containing the immediate and sudden effects of any depression.
  - Carol doesn't want her mother to be informed about her situation since she previously stated that Carol should be institutionalised.



The Advanced Psychiatric Directive deals with the fact of Carol's specific health context, but Carol also has a diagnosis of epilepsy where the prescribed pharmacological treatment has led to an improvement in the reduction of epileptic seizures in terms of frequency, duration and intensity. Carol has been diagnosed with epilepsy for most of her life and she is conscious of having it and is able to recognise when an epileptic seizure is imminent.

Carol also knows that such seizures affect her negatively in different situations in her life (i.e. developing daily routines, attending to her place of work, developing leisure activities, attending cultural events or having a normal relationship with her family, friends or partners) and has said clearly that she doesn't like having such seizures any more. She sometimes forgets to self-administer the correct pharmacological treatment. So, Carol's vulnerability, arising from her failure to reliably self-medicate (see factor B above), means the supporter should seek SDM strategies to ensure that positive steps are made by Carol about this. SDM Tools in that regard can be implemented and, as agreed in the individual support plan, a Peer Group Session will be scheduled every time Carol experiences an epilepsy seizure to emphasise the importance of following the prescribed drug treatment related to this issue.

### Peer Group Session Objectives

If it is impossible in practice to fully eliminate or mitigate the concurring factors that lead to Carol having an epilepsy seizure, (e.g.; changes in the family and friends relationships, labour stress, stigma perception, drug abuse, new drug treatment introduced in her rehabilitation plan, etc.) then it is absolutely vital that Carol can recognise the symptoms of an imminent epileptic seizure. This will allow Carol to have a plan to help herself or to seek the help from a supporter or someone else if the symptoms appear.

### Peer Group Session Structure

1. The first step of the group meeting is to contextualise every participant and explain clearly to them that the role of the group conductor is that of a facilitator of communication between peers. After the presentations, role definition and objective clarification the supporter asks Carol to explain with her own words how she feels during her epileptic episodes to the supporter and to other peers. It is important that others share their own vision of similarly experienced situations. If it is possible, use writing techniques and or images/graphics/drawings to show the impact on her life.
2. Share with other peers strategies on how to detect symptoms and self-diagnosis strategies with the help of the group conductor (e.g. mood changes, difficulties in carrying out regular daily tasks, any increase in agitation, losing interest in leisure activities, any physical sensations in the body, etc.)
3. List the strategies and, with the use of plain and simple language and with image reinforcement, establish pathways of care to identify and manage crisis situations in daily-life environments.

## **DLN Focused SDM Tools**

If so desired digital, literacy and numeracy skills can be developed in this specific scenario in different areas.

- ✓ Digital Skills can be increased if technological tools are used during Peer Group Sessions to show examples of how she feels (searching for images, or using presentation software like Powerpoint for example).
- ✓ Literacy Skills can be increased if the supporters enable the individual to understand the type/content of documentation provided by the general practitioner, psychiatrist and/or social worker when talking about hospitalisation, bureaucratic procedures or topics related with medication. In this case, the 'teach-back' methodology is also recommended to check on the amount of information that is retained by the user after it has been given by the professionals.
- ✓ Numeracy Skills can be increased if the supporter enables the individual to understand prescription schedules, how many pills to administer and so on. The use of images in relation to pill administration (if available) and an easy-to-read version of prescription schedules is highly encouraged.

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# SUPPORTED DECISION-MAKING AGREEMENT

## What is supported decision-making?

Supported Decision-Making (SDM) is a process that helps the person to make his/her own decisions based on his/her wishes and choices, supported by another person.

Decisions can be about different things, for example, deciding to buy something, using the internet, how to manage your savings, or how to decide between two medical treatments offered by the doctor.

In the supported decision-making agreement you choose someone you trust (called a "supporter") to help you get information you need to make the best decision, think about the different choices you have, understand the good things and the bad things about them and tell other people about your decisions.

## The Agreement

- ✓ This document allows you to choose a person who will help you make decisions. This person is called the "supporter".
- ✓ You will also have to choose another person, the "facilitator". A "facilitator" is a person who helps you to check that the Agreement is working as you wish and supports you to make decisions. If you are not happy with the supporter, you can ask the facilitator to talk about it with you. Together you can make things better and perhaps even replace the supporter or stop the agreement.
- ✓ In this document you describe the things in your life where you need support to make decisions.

- I understand what supported decision-making is and what the Agreement to provide this support service to me is about.
- I say here that I need and I want this kind of support to be provided in some areas of my life

For these reasons:

- I agree the following person will be my Supporter:



- I want to allow my Supporter to help me with decisions about e.g. :

HOW TO MANAGE MY MONEY

In particular, I want:



\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

MY RIGHTS AS A CONSUMER. (e.g. : when I buy things from a shop or through the internet).

In particular, I want:



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MY HEALTH

In particular, I want:



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- My supporter is not allowed to make decisions for me, just to support me to help me make the decisions.
- To help me with my decisions, I want my supporter to:
  - Help me get the information I need to make good decisions
  - Help me to understand my choices so I can make a decision
  - Help me to tell other people about my decisions.
- I also choose the following person as my *Facilitator*:

- In particular, I want to allow the facilitator to help me with the following:

to find a supporter who I like



to help me understand how the Agreement works,



to help me if I don't get on with the supporter



to check if the arrangements are good and if I am happy with them



to help me change the Agreement if needed



to confirm when the Agreement has ended





- This agreement starts today and will continue for X more months.
- Copies of this document will be given to the supported person, the supporter and the facilitator.
- I agree to act as a supporter.  
(signature of supporter) (printed name of supporter)



- I agree to act as a facilitator.  
(signature of facilitator) (printed name of facilitator)



- Signature  
(signature of the supported person) (printed name of the supported person)

Signed at:

(place)

Date:

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Inclusió social i suport en la presa de decisions  
Social inclusion and supported decision making



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