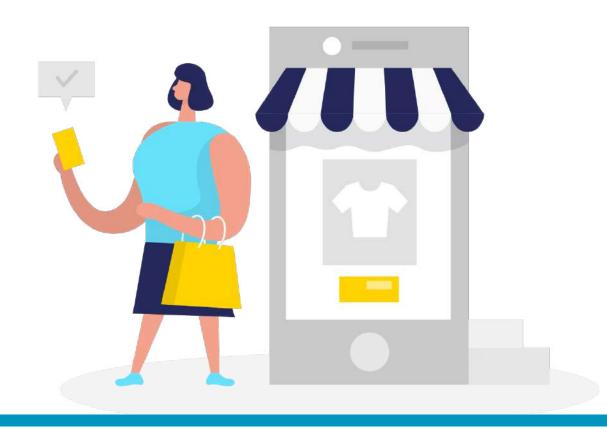


# I-DECIDE CONSUMER RIGHTS MANUAL







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// Introduction

# 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: https://www.supportgirona.cat/projectes/i-decide/



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



Support-Girona (www.supportgirona.cat)

Spain:



Finland – **KVPS** (www.kvps.fi)



Fundació Campus Arnau d'Escala (www.campusarnau.org)



Greece - **EEA Margarita** (www.eeamargarita.gr)



UK – **Social Care Training** (www.sctltd.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 181 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.

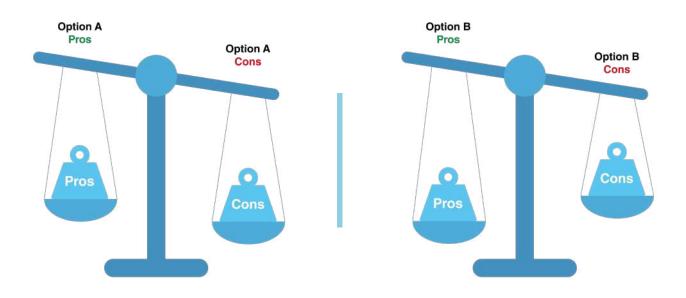


Figure 1. Comparison between different options: Pros & Cons on the Decision Making Process.

# **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**

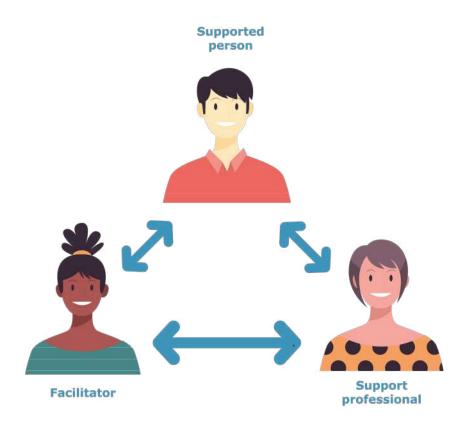
# What is an SDM Agreement?



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.

// Background

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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

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#### 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.

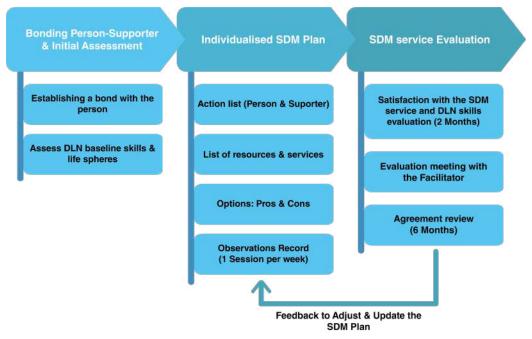


Figure 4. SDM Service & Agreement Evaluation: Working sessions

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 commons 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 month 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 Consumer Rights Manual

# **Supported Decision Making as a consumer in society**

The I-DECIDE Manual on Consumer Rights aims to provide support for persons with intellectual or learning disabilities exercising their rights as consumers. Being a consumer is tightly linked to being able to exercise choice and control over your own finances and requires a particular set of DLN Skills. Using the I-DECIDE Methodology and the tools developed by project partners ('I-DECIDE SDM Agreement', 'Individualised SDM Plan', etc.) professionals can set a framework to provide support for persons with disabilities to exercise their Rights as citizens and as consumers. This manual focuses SDM to help individuals make their own choices when purchasing products or services whilst acknowledging and reminding everyone of their rights as consumer in the EU and as equal citizens in modern societies. The I-DECIDE Manual on Consumer Rights and the support provided using the I-DECIDE SDM Methodology should not be a hit or miss process, because there is often a great deal of time and money involved as contracts formalised by the person with a disability as a consumer are a legally binding act. It is important that the support professionals and the supported person consider all potential and possible scenarios and provide adequate safeguards in order to avoid or mitigate aggressive or 'pushy' sale tactics, recognise strategies to exploit a consumer's weaknesses, or know how to take proper action when a product or a services doesn't meet basic quality standards or the person's needs.

A person with intellectual disabilities who has requested support through the I-DECIDE SDM Agreement to purchase a product or a service according to his or her own needs or desires should be able to understand the financial implications of this decision as his or her own personal budget or income may be affected. It is essential for a professional providing support to understand what stage the person with disability has reached in order to provide adequate support using different approaches, techniques or tools. For example, any request for support by a consumer, could happen at any of the different stages listed below and the support provided should be adapted accordingly. It could cover any/all of the following:

#### Planning the purchase

- Understanding the features and contents of the item or service planned to be bought;
- Understanding what they mean in relation to the person's own needs and abilities;
- Understanding the product's value in terms of, quality, warranty, safety and effectiveness amongst others.

#### Making a decision to buy

- In compiling the list of potential options;
- Getting to know the qualities of the items or products early enough to make the buying decision without feeling under pressure;
- In helping to acquire more information about the product or service e.g. from the shop or from the internet;
- In comparing products or services;
- In planning the purchase financially (e.g. having enough money, considering special offers, overall economy for example in "package offerings" and lending money)

#### Buying the product or service

- Choosing the product in the shop;
- Paying for the product at the checkout (using the chosen payment method);

- Choosing the product on the internet;
- Paying for the product in the online shop's shopping basket (using the chosen payment method).

#### Support can be provided at various levels in the decision making process:

- in making observations and coming to conclusions;
- in understanding things and relationships between them;
- in acquiring knowledge;
- in making decisions and choices;
- in solving problems;
- in learning by doing;
- in planning one's own activities;
- in weighing up the pro's and con's of the decisions to be made.

Different tools for SDM in the abovementioned areas can be used for the professional providing support to individuals with intellectual disabilities as part of the I-DECIDE Methodology and following the SDM Agreement and the Individualised SDM Plan.

It is essential that the SDM process uses communication strategies or methods which the supported person understands. The person or professional providing support through the SDM Agreement should master the particular communication method/s the supported person uses and, as their relationship is built on trust and evolves over time, their communication should improve too.

If the supported person has particular challenges in Digital, Literacy and Numeracy (DLN) skills, then the kind of materials, tools or activities scheduled in the Individualised SDM Plan should also include alternative communication styles (pictograms, figures, concepts, images, metaphors) appropriate to this person's needs. Traditional communication techniques (in a literacy sense as per the project's definition of DLN) will not be sufficient for the task.

Throughout the I-DECIDE Consumer Rights Manual, professionals will find examples of SDM applied to this specific area in different scenarios or stages.

# Overview of the EU Consumer Rights Legal Framework

The European Union has made significant efforts to modernise Consumer Rights Legislation in the EU.

The "New Deal for Consumers" is an EU initiative aimed at strengthening enforcement of EU consumer law in light of a growing risk of EU-wide infringements and at modernising EU consumer protection rules in view of market developments.

EU Directives are instructions to legislators in the Member States who must implement a Directive's contents in their respective national legislation within a specified period of time. A consumer cannot refer directly to an EU Directive in any legal dispute with a business or enterprise, but has to refer instead to their own national legislation implementing the EU Directive.

A minimum level of protection in various areas of consumer protection binding upon all Member States is guaranteed by EU Directives, but Member States have some leeway in national implementation. They may also enact legislation that is more stringent than the relevant EU Directive, as long as the Treaty Establishing the European Union is not violated. The Directives listed below specify the minimum level of consumer protection in Europe, but there may be some national differences between Member States.

#### EU Consumer Laws provide and ensure citizens, for example, the following rights:

- Truthful advertising: As an EU citizen, every individual has the right to have truthful advertising. "Misleading advertising" is anything which deceives or is likely to deceive the persons to whom it is addressed. Adverts should be accurate about availability of the product, and what it is made of.
- Product safety: EU rules aim to ensure that when the citizen is buying something, it is safe. Any product sold in the EU must comply with EU safety requirements (or laws), and there is an alert system to raise awareness and prompt action.
- Fair contracts: If the contract contains unfair terms, it violates the EU rights. Examples of this is are; some
  contracts may have hidden terms, or seek to limit the trader's liability, or allow the trader to cancel the
  contract without giving the consumer the same right, or demand excessive compensation from the buyer.
- Repair or replacement: It is an EU right to have a defective product fixed or replaced. A seller must repair, replace, reduce the sales price or give the person a refund if the product is faulty or doesn't work as advertised within the first two years.
- 14-day return: This is one of the basic rights of an online consumer, and there does not need to be a reason for returning it. It is enough to notify the seller within 14 days and send it back this is an EU right. There are exceptions: one you cannot return consumables like food, downloaded software or personalised products. You cannot just "borrow" and wear a piece of clothing and return it. But apart from that, the customer can return the purchase, and there are agreed legal processes to help them do this. If the seller has not informed the customer about the right and timings to withdraw of a product or a service, it is extended 12 months from the end of the initial period.

When buying goods and services anywhere in the EU everyone has the same consumer rights concerning contract information, pricing and payments, VAT (Value Added Tax), shipping and delivery and guarantees and returns.

Wherever a person buys a product or service in the EU the trader must provide the potential buyer with clear, correct and understandable information about the product or service before the transaction is completed.

When a person buys goods or services in the EU, the person has to be clearly and completely informed about the total price, including all taxes and additional charges.

For online purchases, the person has to explicitly acknowledge and understand – for example by pressing a button – that placing the order implies an obligation to pay.

As a private individual shopping in the EU, buyers should only pay VAT once, in the country where he or she makes the purchase.

An individual has the right to purchase and bring home any product he or she buys in another EU country, without stopping at the border or making a customs declaration. The only condition is that the purchases must be for his or her own use (or a family member), and not intended for resale.

If a person doesn't collect the purchase straight away or have ordered it for delivery at home, the trader should deliver it to the customer within 30 days – unless it is specifically agreed on a different delivery time.

Under EU rules, a trader must repair, replace, reduce the price or give a refund if goods bought turn out to be faulty or do not look or work as advertised.

If a person has bought a product or a service online or outside of a shop (by telephone, mail order, from a door-to-door salesperson), he or she also has the right to cancel and return the order within 14 days, for any reason and without any justification.

If someone is not sure what their particular situation about a purchase is, they can also try the consumer rights tool to help to understand their rights when shopping in the EU.



See 'Your shopping rights - an interactive tool to help to understand the rights when shopping in the EU.'

Source: https://europa.eu/youreurope/citizens/consumers/shopping/index\_en.htm

When shopping in the EU – whether online, over the phone, through a catalogue or in the local shop – the person is protected by certain consumer rights.

When buying goods anywhere in the EU – from a website, a local shop or a seller outside the persons' home country – EU law provides protection against unfair commercial practices.

When promoting, selling or supplying products, companies must give enough accurate information to enable the consumer to make an informed buying decision.

If they fail to provide this information, their actions may be considered unfair. The person has the right to seek redress if treated unfairly.

Consumers are protected against two main categories of unfair commercial practices: misleading practices, either through action (e.g. giving false information) or omission (e.g.; leaving out important information) and aggressive practices that aim to bully the person into buying.

Throughout the EU, sellers must indicate product prices clearly enough for the person to easily compare similar products and make informed choices – no matter how they are packaged or how many units are sold together.

Companies are legally obliged to be completely clear about the price the buyer has to pay when they advertise or sell something.

Every time buying a product or service from a professional trader, an individual is entering into a contract - whether it is signing up for gym membership, ordering car tyres online, getting a mortgage for the house or even just buying the weekly shopping from the supermarket.

Under EU law, standard contract terms used by traders have to be fair. This does not change if they are called "terms and conditions" or are part of a detailed contract that actually have to be signed. The contract is not allowed to create an imbalance between your rights and obligations as a consumer and the rights and obligations of sellers and suppliers.

Contract terms must be drafted in plain, understandable language. Any ambiguities will be interpreted in the consumer's favour.

Source: https://europa.eu/youreurope/citizens/consumers/unfair-treatment/index\_en.htm

# The European Accessibility Act

The European Accessibility Act aims to improve the functioning of the internal market for accessible products and services by removing barriers created by the different rules in Member States. This will facilitate the work of companies and will bring benefits for persons with disabilities and elderly people in the EU.

The European Accessibility Act covers the **products and services** listed below that have been identified as having the highest risk of being concerned with diverging accessibility requirements across the EU countries.

Moreover, these were seen as the most relevant after consulting stakeholders and experts on accessibility and taking into account the obligations deriving from the UN Convention on the Rights of Persons with Disabilities.



Computers and operating systems



ATMs, ticketing and check-in machines



**Smartphones** 



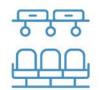
TV equipment related to digital television services



Telephony services and related equipment



Audiovisual media services such as television broadcast and related consumer equipment



Services related to air, bus, rail and waterborne passenger transport



**Banking services** 



E-books



E-commerce

Source: http://ec.europa.eu/social/main.jsp?catId=1202

# **SDM Before Purchasing**

When purchasing a product or a service (hereinafter referred as 'product'), it is important to take into account the consumer's rights.

The EU and other country specific consumer authorities, bodies or agencies, protect purchasers from misleading and aggressive business practices. The EU also ensures that country specific laws protect EU citizens from unfair business practices according to the EU consumer protection rules. For example, telemarketing is not allowed to be intrusive or confusing. Another example: a magazine subscription can no longer be advertised as 'free', if the subscription will be charged after posting the first issue.

If the purchase of a product can be planned well beforehand, it is easier to make a successful purchase decision. These are the points that the professional should explore in relation to consumer rights with the person requesting support to make a decision:

- The supported person's needs and wants;
- What kind of products are suitable to cover or satisfy the person's needs/wants
- Where to purchase the product and how those products can be compared
- What is the person's financial situation and should the person consider things like buying on credit or taking a loan?

#### **Individual needs**

It's important that the purchase is made based on the person's needs or preferences. Advertising usually aims to make consumers believe they need that specific product. The seller might offer the product pointing out the need for that product or its affordable price. Sometimes there is no real need for the product. Alternatively, the product might be needed, but its purchase is not economically sensible at that moment. Nevertheless, the product can still be purchased, but everyone should be aware of the consequences of their actions.

There are needs that are based on a person's desires or preferences but that are not necessarily economically sensible, but make one happy, like buying chocolate. There are also rational needs, e.g. buying a textbook for studying. From the point of view of consumer rights, both needs are equal. The consumer should get enough information to support the purchase and the product should correspond to the product information. The products should comply with international and EU standards.

The marketing of products should be factual as well. If the advert claims that "this is a healthy chocolate and helps you lose weight" and the product contains 1000 kcal/100 g, we are talking about misleading marketing. Often, however, it is difficult to file a complaint against misleading marketing or misleading product information. The process can be long, and painstaking and the result is not necessarily what was hoped for. So, it is easiest if you know how to recognise when a product description is misleading, or if the product is bad value for money, or the quality of the product is bad. It is also important to recognise misleading marketing and be able to spot when the product labelling is wrong.

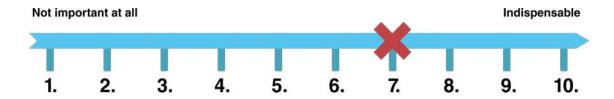
The supporter or professional can help the supported individual, if such help has been provided for in the SDM Agreement, to think about their actual need for a given product or service, with the help of support questions. These questions are associated with the situation in which the supported person already has a product or service in mind that they would like to purchase. Example questions, could be:

- Why would you like to purchase the product or the service?
- Is the product useful or does it make you feel good?
- How did you become interested in this product? How was it advertised?

# **Consumer Rights SDM Tools**



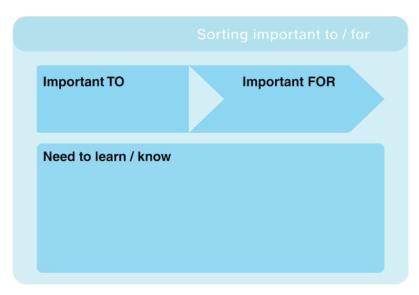
Besides these questions, supported decision making can be made easier with the help of a value line. The supported person can mark on the line the importance of the purchase between the values 1-10 and consider the purchase based on it.



**Tool: Value Line** 

Whilst the above tool helps to helps the supporter evaluate the potential purchase from the supported person's point of view, there are other tools available which produce a somewhat clearer picture of motivations and importance. One of these tools is the "Important to / Important for" sorting process devised by Helen Sanderson Associates.

For a fuller explanation of how to use this tool visit



**Tool: Important to/for** 

What kind of products or services are suitable for your own use?

If it looks like the supported person understands why he or she wants a given product and already has the relevant information about the product or the service, it is a good idea to make sure that the product is healthy, safe and enjoyable to use.

The products should be safe to use. The laws and the safety authorities of the EU and other European countries aim at ensuring all products are safe. Some products are marked with the CE marking, which guarantees that the product meets the requirement set by the EU and has been tested if required so. The CE marking is not only a guaranty of quality, but when shopping, it is worth guiding the supported person towards purchasing CE marked products.

Product descriptions are often in small print and in difficult places to read. Sometimes the descriptions are in another language, irrespective of the rules. Some product descriptions are very accurate. For example, food or fabric products might contain raw materials that the supported person is hypersensitive to. The supporter should teach the supported person how to look for given information from the product description and help them understand when a product should be avoided, for example because of an allergy. A product description might be rather vague, (e.g. "made in a factory that handles nuts") but explanations are there to alert the buyer to the possibility that the product just might have traces of nuts in it. It also helps to protect the producer in the event of any claim.

The supporter should make sure that the supported person knows how to use the purchased product. If the product is made properly and it contains clear instructions, the use of the product is the consumer's responsibility. The company cannot be held liable if a product is misused. Misusing a product might also pose a safety hazard.

The products should be pleasant to use. If the supported person wants to purchase for example an item of clothing that some other people might find uncomfortable (e.g. very tight jeans), he or she has the right to do so. However, the person should be aware of the reasons why it could turn out uncomfortable and what his or her rights are as a consumer in that case. If a consumer has purchased for example an item of clothing but in the wrong size, in some cases it can be returned, but the shop is not obliged to accept it back - unless of course the size on the label is wrong. The supporter can point out in a factual manner what the positive or negative effects of purchasing a product might have. The supported person will make the final decision.

Where to purchase a product and how products can be compared?

The supported person can search for information beforehand with the help of the support person, for instance from the web. If the product can be purchased from the web, there should be enough information provided on the handling costs, postage fees and other possible additional costs involved.

The supporter can, for example, make a simple worksheet where the advantages and disadvantages of the compared products are listed, one sheet per product. The sheet also helps highlight and keep track of extra information, such as terms of delivery, total cost and return policies. Pictures or other symbols can be added to the sheet. The sheet could look something like this:



**Tool: Comparison Chart** 

#### **Comparison Chart Instructions**

Print as many copies as needed (1 sheet per product). If the price is higher than other products, the supported person marks the price under the red smiley. If the conditions of sale (e.g. delivery conditions) are good, the support person can specify the details under the green smiley. Information, such as a product warranty or other information that can have an influence on the purchase decision, can be marked under 'Other'. In the end, the supported person can put the sheets next to each other and think together with the supporter about what the most sensible choice would be. Pictures and symbols can be used for marking.

#### What is the financial situation, and should a loan be considered?

From the point of view of the consumer, when planning a purchase, the financial aspect cannot be ignored. If the supported person does not have enough money for purchasing the product or the service, he might want to ask for a loan. From the consumer protection point of view, the so-called instant loans are problematic. Instant loan companies are trying to make getting a loan as easy as possible. For instance, often they do not demand that you should have a credit card. Instant loan services do not highlight in their adverts the disadvantages of their repayment policies. For instance, the rate of interest is often not clearly indicated. It is often difficult for the consumer to understand the importance of the repayment conditions.

It is important that the supporter points out what getting a loan means. The loan should be repaid according to the agreement. The amount of the instalments is going to be deducted from other living costs. If the loan is not paid on time, there will be other extra costs involved. Often, the instant loan agreements are complicated and are not written in easy language. The 'beneficiary' of the loan might have difficulties understanding the implications of signing the contract. At the end of the day the consumer is legally bound by the contract they signed unless it can subsequently be shown to be unfair/illegal (e.g. they did not describe the product accurately).

# **Case Scenario 1**

This example points out how versatile and comprehensive a support person can be when supporting the person with a disability or service user in making a purchase decision, and yet, the supporter must let them decide themselves about the purchase. Making a successful purchase independently with the help of the support person, in this case a personal assistant, gives the supported person the feeling of being a consumer.

#### Supporting Mio in shopping and decision making (Adapted from the original text by Heidi Kaipio)

Mio is active in planning his life. For him it's important that he gets to make decisions about every-day things so that he feels empowered at least on some level. Because of his disability, Mio's opportunities to make important life decisions, such as choosing a profession or housing, is limited, and because of this the importance of making small decisions is emphasised. Because of his disability, Mio's way of conveying his thoughts, wishes and decisions is restricted. Mio's assistant is not able to understand his communication without proper introduction and training. This is because Mio expresses himself by the first and last syllable of the words, gestures, pictures and facial expressions. Supported writing is not always successful. Days are structured with pictures in the weekly calendar. Long-term plans are written in the yearly calendar. In his free time Mio expresses his wishes in many aspects of his life, but he needs help to write his wishes down and inform others about them. He needs a supporter to write his decisions down, and to help him accomplish them.

The cooperation between Mio and the assistant is so sensitive that it cannot be fulfilled satisfactorily unless both parties feel good about each other. Therefore, it is important that both parties express their opinion on their collaboration. Sometimes Mio has clearly communicated that he didn't want a (particular) new assistant and his wish was listened to. On the other hand, if Mio likes a new assistant, he tries his best to help the new person in his life to understand his thoughts and wishes.

When writing the shopping list, the assistant has challenged Mio to consider if he really needs more of a given

item. Mio and the assistant checked the cabinet for coffee. Mio needs a concrete idea whether there's enough of an item, he is not necessarily satisfied by simply being told "yes, there's some left." Mio and the assistant check together for instance for how many days the coffee is enough, and they discuss whether Mio will buy the coffee now or in a week. Of course, Mio can decide to buy the coffee, even if there's plenty left.

In many aspects Mio is quite strong-minded, but sometimes decision-making is quite difficult in apparently trivial situations. Such a situation can happen at the sweet shop where Mio can get stuck when he can't decide between two options. To get round this dilemma, the assistant needs to suggest that Mio could decide on one option and then perhaps next week he can buy the other one.

For Mio it's difficult to have a clear idea of time. Sometimes the assistant must help Mio to stick to the original plan, so they can stay on track, or, for instance, that they still have time to go to the shop as planned. Plans need to be changed sometimes if the planned timetable is side abandoned for some reason. In such situations the communication skills are very important because Mio needs to understand the reasoning behind the decision.

Whilst predictability in Mio's life is paramount, however, not everything can be decided beforehand and unexpected situations can and do emerge. For example it might be that a particular restaurant was closed or that the bus didn't come, or it deviated from its original/normal route. On another occasion Mio happened to be in the same space as some crying children, and the stress of this was too much for Mio.

Mio does not cope with unexpected situations consistently. In such cases he needs another person who can come up with creative solutions and unexpected decisions when the situation demands it.

The role of the supporter is often to be a kind of mentor and interpreter between Mio, who is trying to get ahead in his unique life, and the peculiar world that is often so unpredictable and complicated. This role is ethically quite a responsible one. It requires sensitivity and strength, so that the assisted person's interests and rights of self-determination are realised as much as possible, considering the level of disability.



Photo 2:Tiiu Kaitalo

# **SDM During Shopping**



The actual shopping situation and the support in decision making concerning consumer rights, differs depending on the method of shopping.

- Buying from a shop
- Buying from the web
- Buying from a telemarketer or sales agent
- Buying from a private person



# **Buying from a shop**

If the features of the product to be purchased are known in advance, buying from a shop is usually straightforward, if the product is available at the price on display. Buying directly from the shop can be sensible because the product can be often viewed, or even tried before the purchase. The consumer also has the right to try a product in the shop and order it from the web if the price is better. If needed, the supporter could point out issues concerning the final price or trying the product.

If the purchase was not planned beforehand, it's possible to use the tips from "Before buying." In practice it's difficult to make a realistic comparison within one shop if it's not possible to compare the same item in different shops before the actual purchase.

Some shops offer different package deals. For example, a company can sell packages of TV channels and offer a game console, or one-year free Internet connection on top. The comparison of such packages and their content can be laborious. On the internet (see below) there are many price comparison websites which make this job easier.

It is often the least risky to buy products or services without a package deal, but on the other hand those 'special offers' might have clear advantages, too. If the support person has the opportunity to find out about the advantages and disadvantages of the package deals, as well as explain them clearly, it helps the supported person make a decision. On the other hand, this kind of procedure is time consuming and raises the responsibility of the supporter in preparing the information to help the person make a decision. If possible, the professional will prepare the information in written and simplified language or using the communication method that the person understands best.



# **Buying from the web**

Consumer protection works also when buying from web shops. The variety of products is wider, but on the other hand there are many that have different operating principles. Many of them operate according to the consumer protection principles, but some companies try to avoid these because of the costs they involve. The supporter should point out to the supported person how to make sure in advance that the products are ordered from a trustworthy source. Many web shops have started to use the publishing of reviews on their pages. These reviews can be read together with the supported person. Assessing if the web shop is trustworthy can also be based on clear product description and reasonable terms of delivery. Sometimes a low price can indicate that there are hidden 'extras' behind the terms of packaging and delivery.

When buying from the web the usual payment method is credit card or PayPal account. Some web shops offer the possibility to pay with debit from your bank account. The supporter should be able to guide the supported person in using the different payment methods. Unconditional impartiality and good ethics are required from the supporter when guiding someone in using money. When paying with a credit card, bank account or with a PayPal account, the supporter should make sure that the web page is secured (https). At the moment of payment be sure that no outsiders area able to see personal information such as user names or passwords, if possible not even the supporter.

Often, web shops offer their services in the languages of the country they are based in and often in English as well. If the language skills of the supported person are not good enough for him to understand the terms of service in the language offered by the web shop, it's often better to buy from a web shop that offers its services in the language the supported person speaks. If the supported person uses alternative communication methods (AAC communication method), the supporter should find out whether the supported person is able to get enough information to support their decision-making. If this is not possible, the supporter should find an alternative way of transmitting the necessary information. If needed, the help of a communication expert should be used. The aim of the supporter should be that the supported person only takes a decision when he is familiar with what kind of product he is buying and what the conditions are. These instructions also apply to purchases made over the phone, from a sales agent or from another consumer.

Web shops usually have applications where the products to be purchased are put in a basket. The supporter should guide the supported person in using the application. With the application, the customer might end up ordering, by accident, more products than needed. Often, products can't be returned if the order was higher than intended.



# Buying from a telemarketer or sales agent

Telemarketers and sales agents are trained to promote and emphasise the current special offer. The offer, for example, is valid only at the moment of the sale. Sometimes it is claimed that the product is free of charge, without mentioning that, at the same time, the customer is committing to a contract that will later charge for ongoing products. Many such practices are against consumer protection law in the EU. In such cases the consumer has the right to a cancellation period, for example 14 days, during which the consumer has the right to cancel an agreement made on an impulse, or often because of a misleading advertisement. Unfortunately, telemarketers and sales agents exploit people with special needs. Aggressive methods of sale are illegal in the EU. It is not allowed to try to sell too aggressively or too many times. At-risk groups are young people, the elderly and people with special needs who have limited or impaired comprehension. The supporter should tell the supported person about telemarketing and sales agents and what they can sometimes do or say to try to make a sale. The supported person should be aware that he also has the right to consider buying a product after the telemarketer hangs up the phone or the sales agent has left. Often, the offers that are advertised are said to be available only at that given moment, but you discover they are also available later. If the marketer or agent represents a company, the consumer has the right to cancel the agreement in accordance with the consumer protection legislation, if the product is not as described. If the product is purchased from a door-todoor salesman, the salesman should provide a receipt, the contact details of the company and the product description in print.

If the sale was made over the phone, the company has to send the customer a written copy of the agreement that also includes the terms of cancellation.

If the supported person finds that he gets too many disturbing telemarketing calls, the supporter can guide his client to ask the company in question to stop such calls, or alternatively, help him register to the telemarketing blocking service that is available in several European countries.



Consumer protection law does not cover buying from a private person. When buying from a private person, the responsibility for the product is shifted to the buyer after the purchase. Therefore, it's particularly important that, when making a purchase, especially of bigger value, the buyer has the possibility to think and try the product before making the decision. It would be good if the supporter could be present when the supported person is trying and buying the product and guide the supported person to pay attention to the quality, safety and value for money of the product. The supporter should be present at the moment of the purchase to make sure that everything is going according to the agreement.

#### **Case Scenario 2**

The following example shows how a person with intense support needs can make purchase decisions for herself if the situation is planned carefully beforehand.

#### Supporting Sirpa with shopping

Everyone, even the most challenged person, can make choices and decisions if he or she gets enough support from his / her environment.

Decision-making ability is not something that a person either has or does not have, but it is rather a continuum that moves from reactive / almost random decision-making to an increasingly specific expression of opinion. When a person with support needs is not involved in decision-making about how to use his / her own funds, their chances to choose things for themselves are considerably limited. Under the provisions of different legal frameworks, professionals might be required to safeguard and protect other needs and interests as well as promoting the well-being, health and safety of the person. If other needs require the use of the person's own resources, professionals must help with budgeting and balance the needs and preferences of the individual.

At the level of active and self-motivated decision-making, it may be that, over time, the person is able is able to become more capable of making their own decisions and so be more independent, requiring diminishing levels of support.

A person can often tell what he or she considers important and what he / she wants to do or change in his / her own life. Even so, situations may still arise where s/he needs support from his/her support person to understand the matter fully, or to think about different options, to implement the decision, and to manage funds safely.

An example is 51-year-old Sirpa. She lives in a residential home in Tampere. Three times a week she goes to a daytime activity centre for special needs people.

Sirpa expresses herself with the help of sign language and pictures in the communication book. She understands speech, but does not say anything other than 'yes' and 'no'.

Sirpa has been diagnosed as having and intellectual disability and ataxia. She is a happy and loving woman who likes beauty-care and delicacies and spending her money all the time. Once a month, she is provided with a fund of 150 euros to buy all the hygiene supplies, extra delicacies, taxis, coffees and other expenses.

Sirpa manages short trips with a rolling walker and long journeys in a wheelchair. Helpers push the wheelchair. The helper visits her once a week to assist her with shopping, to go to the cafe or a library and once a week she attends the Stylish Girls' Club. On Saturdays there is usually a disco day. At the beginning of the month, the residential unit's staff plan an accurate weekly budget together with Sirpa. If there was no plan, Sirpa would spend all her money at once.

So, with the help of the staff, she has enough money for the whole month by spreading her spending evenly. Sirpa regards this decision-making as a good thing.

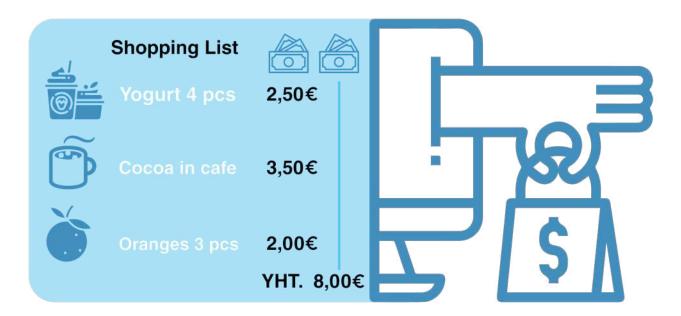
Sirpa plans to negotiate in advance with the staff. They discuss through communication pictures and sign language what Sirpa is missing and what to buy from the store. The staff reserve a time slot during the day when they can discuss in peace with Sirpa about her health and what she needs from the shop. This way she will not end up buying unnecessary items.

Sirpa shows what she wants to eat and where she wants to go. They check the budget and together calculate what she can buy for that money.

A shopping list containing the pictures of the products is printed so that Sirpa can take it along with her to the shop. This also facilitates the work of the assistants: the shopping list is ready, and there is no need to negotiate again in the shop. This also shortens the time spent in the shop, leaving more time to be spent outdoors or in the library.

#### **DOING SHOPPING LISTS**

In these pictures, Sirpa plans with the staff member a shopping list for a shopping trip. A communication book and sign language help their communication.



In these pictures, Sirpa plans with the staff a shopping list for a commercial deal. A communication folder and supportive signs help their communication.



# **After Purchasing**

Sometimes, after the purchase, the product turns out to be faulty or is not working according to the product description. Nonetheless, in some cases, the supported person might be satisfied with the product. It is his/her legal right to think this way. However, if the product is dangerous to use, it is important that the supporter points that out and agrees together with the supported person about no longer using the product and about making a complaint. If the supported person is simply not satisfied with the product in general, but it is not a faulty product, it's a good idea to see if the shop selling it offers an option to return the product under those circumstances.

Sometimes the supported person might be unhappy with the purchase, but will not admit it, or doesn't know if there is anything that can be done about it. To help express satisfaction, a simple feeling chart can be used. With the help of it the supporter can ask the supported person what kind of feeling does he have with respect to the product? If the supported person wants to, the supporter can find out the root of the dissatisfaction with the so-called "5 Why's technique." For instance: "You are not satisfied with the product, why?" "Why does the sound bother you?" "It's not nice, why is it not nice?" "Why does it annoy you when you use it?" "Why does its sound bother you?" So, does the loud sound bother you?" In this example it turns out that the sound of the vacuum cleaner (or another similar product) bothers the supported person. After this they can investigate together whether the product has a quieter mode, or what noise level the manufacturer has put into the description of the product.



**Tool: The Feeling Chart** 



Tool: The 5 Why's Technique

If the supported person is not satisfied with the product because of a fault or poor product description, the supporter can encourage/enable the supported person to make a complaint to the seller and help him make the complaint. The consumer protection authorities of different countries can offer help and different aid tools for making the complaint. The supported person might find it intimidating to file a complaint if s/he is not familiar with what it involves. Maybe s/he is used to trying not to upset other people. The support person can encourage him/her by telling him/her that s/he has consumer rights and asking for those should not offend the seller. The support person can also point out that the supported person will not have to face any repercussions from asking for their rights.

The customer also has his/her own responsibilities. If the product is bought using a loan, and the buyer is not able to pay the instalments, the seller has the right, in some conditions, to cancel the deal. The customer is also responsible to use the product according to the intended use so that the warranty remains valid. If needed, the support person should make this clear to the supported person.

# **Complaints & Compensation**

When complaining about a product or service (after you have had the service), you must make sure you complain to the right service provider. Before making a complaint, it is also necessary to evaluate the error in the prduct/service as to whether the content of the service corresponds to the content, the performance and the result of what has been agreed. The error assessment is based on general expectations and the most important is how the company has acted in the consumer's advice and information.

There was an error in the service when:

- Work is not done professionally and carefully
- The consumer's interest has not been sufficiently considered
- Work or materials are not of good quality in terms of durability and other characteristics
- Work does not meet the requirements of law, regulation or authority
- The work does not match the information given in advance
- The service provider has not given enough information on the rational way of commissioning the work or any other important matter

To make it easier to resolve conflicting situations, it is best to make your complaint in writing, so there is clear evidence of the discussions that have taken place. The sender of the complaint must be able to prove that the recipient has been informed of the complaint. A complaint sent by e-mail should ask the recipient to acknowledge the e-mail on his own and to acknowledge receipt of the complaint.

The website of many service providers can provide feedback by using of a form. The laws in many countries also help consumers.

Please note the following items in your complaint:

- backgrounds
- the agreement and the parties
- what performance has been agreed upon
- the cause of the complaint, ie. how the performance deviates from the agreement (identifying the deficiencies, errors, breach of contract)
- Identify the penalties imposed on the advertiser for the violation
- presenting the requirements and identifying them as well as possible at this stage (e.g. the amount of damage to be compensated)
- reserve the right to submit specified requirements later (e.g. the amount of damage is not necessarily known at this stage)
- Date and Signatures

# **Compensation methods**

The methods of making a mistake in the service are:

- partial repayment of the purchase price,
- correction of the error and doing the job again (but properly this time!),
- termination of the contract.

Generally, the service subscriber has the right not to pay part of the service until the error has been corrected or otherwise credited. The consumer is also entitled to require the service provider to correct his mistake or to renew the defective work. If the service is not repaired within a reasonable time or cannot be renewed, the consumer is entitled to a discount. The service provider's contract may be terminated if the damage has been high or the error cannot be replaced by other means.

The nature of the contract depends on which party handles complaints and disputes about, for example, service housing services or payments.

The provisions and principles of consumer law and contract law apply to agreements between the consumer using the consumer rights and contract law.

The consumer who carries out the service concludes an agreement with the private service premise and pays for all the services he receives, whereby service and payment contracts fall within the scope of the consumer protection legislation.

#### An example of the reclamation of a service:

In many countries the 'state' in some form (e.g. the regional or local authority or the local municipality), must provide personal assistance in addition to day-to-day activities, work and study, as well as 'other activities'. These 'other activities' include hobbies, social participation and maintaining interaction. They are referred here using the collective term 'leisure activities'. Such services may be directly provided by the relevant state body or (as is increasingly the case) provided by other agencies after a competitive tendering process. Personal support for leisure activities can be provided for an individual with complex needs due to his or her disability. Complex needs means in this context that a person necessarily and repeatedly needs the assistance of another person to perform basic everyday activities, and the need for assistance is mainly due to age related illnesses and disabilities.

In this example the resident has booked for himself (within the agreed time) a personal help to assist him with his leisure activities. On this occasion the purpose of booking the assistant is to take the resident in a taxi to a concert, to act as his support at the concert and to deliver him back after the concert to the housing unit.

The resident is all prepared by the unit staff, and is waiting for the assistant to go to the concert where tickets have already been purchased.

The pre-booked taxi waits in the yard, but the assistant does not arrive. The taxi announces that the waiting time is over and as it can wait no longer, the taxi will be sent off. Assistant Service is called and told that the assistant has not arrived, even though the order has been made and confirmed.

The resident is, of course, disappointed, but understands the fact that this time there was no trip. The service provider has no other explanation than the fact that the order did not get to the assistant and so there has just been a human error.

The concert tickets were bought in vain and the taxi had to be paid even if no ride was needed.

So the resident lost a nice night at the concert, listening to his favourite songs and there was a financial loss.

The directors make a written complaint on behalf of the resident by email to Assistant Service.

At first Assistant Service said "Just tell us what has happened and what requirements the resident had for the event. We don't pay for financial losses but can allow this resident to have his unused staff hours again." On behalf of and with the agreement of the resident the directors said this was not a good enough response and, after threatening to take the matter up with the municipality contract department eventually got back the cost of the concert tickets and an apology for the disappointment resident had suffered.

## **Consumer Rights in Social Services?**

During the past few years, services for persons with disabilities have seen many positive changes from the point of view of its beneficiaries. These changes are due to the UN Convention on the Rights of Persons with Disabilities, deinstitutionalisation processes and the increasing freedom of choice.

Services are more and more planned and developed on a personal basis, with the beneficiary being part of the planning process. Possibilities for greater freedom of choice, as well as new ways to deliver this are being developed. Service users are more often active development partners rather than just the objects of the service system. By putting the emphasis on freedom of choice, service users are beginning to be regarded, to some degree, as 'consumers'. This is mainly a positive step.

Different countries are developing different freedom of choice models. The main principle is that the clients of social services can choose for themselves the services that suit them best. Various freedom of choice mechanisms are, among others, service vouchers and personal budgeting. In these situations, the social services client is not only a client, but also a consumer in a supposedly 'free market'.

When freedom of choice is growing, and the consumer status gets stronger, it is important to take into account the relation between the services promised, the rights of a customer as well as the need for supported decision making.

We can consider it a good goal that beneficiaries of social services are considered, above all:

- as a human who has human rights;
- as a citizen who has citizen rights;
- as customer of the social welfare system who has social welfare customer rights;
- as consumer who has consumer rights.

If the development of social welfare is based on human rights, it pays attention to the implementation of rights and treats people as subjects instead of objects.

#### Problems and challenges arising:

- Many services are arranged through a competitive tendering processes where the customers of social services are not normally part of the process or contract. Consequently, they are not a party to any agreed contract and so often don't necessarily have any legal protection if the quality of the services does not meet the personal needs of the service user;
- if the system being purchased/commissioned by the authority does not include or specify the need for supported decision-making; the freedom of choice might be difficult to access if support for decision-making is not offered;
- if people are considered solely as consumers without the rights for the supported decision making. This
  approach can end up isolating the person, without giving them the chance to benefit from the services,
  especially if there are not enough quality service providers on the market, or if the service price is set in
  a way that it is either too low to support someone properly, or doesn't adequately answer the individual's
  (perhaps quite complex) needs.

#### Consumerism in the social services can be successful if:

If the development of social welfare is based on human rights, it pays attention to the implementation of rights and treats people as subjects instead of objects.

Problems and challenges arising:

- the system is developed with the basic human rights in mind and respects the individual rights;
- individual client plans actively guide the planning of services and support and the system is flexible enough
  to meet the needs of each customer;
- the customers get the amount of support they each need for supported decision making;
- there is a wide range of quality service providers to choose from;

- freedom of choice is not limited (i.e. resource constraints or restrictions on what someone can spend his/her own budget on for example; you must 'buy' your hours/ days of support from a list of 'approved' providers);
- the customers of social welfare have access to legal protection, if the services or their quality do not meet their needs or if they feel their rights have been breached;
- the services also consider the customer's life as a whole, support networks and involvement in society.

#### It is essential that:

- the beneficiaries have enough information and support for decision making;
- service providers have a genuine will and desire to provide quality services that are tailored to the individual and respect human rights;
- information sharing between service organisers, service providers and the clients is transparent;
- service delivery relies on an individualised customer plan that is made together with the customer;
- the service provider has vision and directorship of developing a service system together with the customers;
- the activities of the service providers are monitored so that the quality is as promised, and the service provider is not able to limit the customer's freedom of choice;
- digital services offer equal opportunity and are easy to use;
- the customer's information security is guaranteed, but does not limit the overall support and service;
- integration between different services is working well and, from the customer's point of view, the one-stop
  principle is being used, so choices are easy to make;
- consumerism genuinely benefits the customers, it does not impair their rights protection, their services, their support or influence;
- the service provider has vision and directorship of developing a service system together with the customers;
- the activities of the service providers are monitored so that the quality is as promised, and the service provider is not able to limit the customer's freedom of choice;
- digital services offer equal opportunity and are easy to use;
- the customer's information security is guaranteed, but does not limit the overall support and service;
- integration between different services is working well and, from the customer's point of view, the one-stop
  principle is being used, so choices are easy to make
- consumerism genuinely benefits the customers, it does not impair their rights protection, their services, their support or influence.

### Self-Directed Support & Service Vouchers: An overview

#### Personal Budgets, **Public Traditional Self-Directed Service Vouchers Procurement &** Services Support **Tendering** Role of a service Role of a citizen. Role of a ser-Role of a sera service user user. vice user and a vice user, as an and a consumer. consumer, as a object without People can People have subject. People power. often say yes/ rights to use recan choose beno to offered sources flexibly tween different Some people, Individual role of services, but when designed options. especially in ina person with a cannot control in the right way. stitutions, do not details of their have consumer rights or influservices or they can have some ence on their influence on own services or the designs of support. services. To arrange To give more To increase To arrange serservices. control for the the customer's vices and public person and for freedom of procurement the service user. To promote choice, improve procedures that and maintain the availability Goals & are carried out the functional To increase of services and objectives in accordance capacity, social persons customdiversify service with national wellbeing, safety er's freedom of production. procurement and inclusion of choice, improve legislation and individuals, famithe availability To improve serthe procurement lies and commuof services and vice availability, directives of the diversify service shorten queues, nities. European Union. production. diversify service provision and Efficient Customers can promote cooptendering and eration between influence the non-discriminacontent of their municipalities tory treatment of own care and and private sertenderers. services, revice providers. tain their inde-Save costs. pendence and continue as full members of the society throughout the different phases of their lives.

	Traditional Services	Personal Budgets, Self-Directed Support	Service Vouchers	Public Procurement & Tendering
Contract or legal agreements	Contract is concluded between the authority and the service provider.	The legal relationships between the authority, the service provider and the customer.	The legal re- lationships between the authority, the service provider and the custom- er.	<ul> <li>Contract is concluded between the authority and the service provider.</li> <li>Service user is not a party to the contract.</li> </ul>
Individual rights of a person with a disability	Rights of a service user.	<ul> <li>Based on human rights and active citizenship.</li> <li>Care and support should be designed and delivered in a way that promotes choice and control.</li> </ul>	<ul> <li>Rights of a consumer. Way of choosing and using social and healthcare services. It may be used for procuring a given item or service.</li> <li>The customer may choose the service provider based on his or her own preferences and needs.</li> </ul>	Some obligations for authorities that person with disabilities should be heard during the process, but individual does not have the right to complain about the tendering process.
What kind of services?	<ul><li>For example:</li><li>Housing services</li></ul>	<ul> <li>Services that support citizenship</li> </ul>	<ul> <li>For example:</li> <li>Housing</li> <li>services</li> <li>Personal</li> <li>assistance</li> </ul>	<ul> <li>For example:</li> <li>Housing</li> <li>services</li> <li>Personal</li> <li>assistance</li> <li>Rehabilitation</li> </ul>
Questions to be asked – things to be considered.	What is the role of traditional services in the future?	<ul> <li>Cultural and system changes required to support successful implementation.</li> <li>The supported person should receive the assistance they need to help them to make an informed choice.</li> </ul>	<ul> <li>Is the value of the service voucher enough to meet the individual needs of a person?</li> <li>Are there enough service providers to choose from?</li> </ul>	<ul> <li>Many bad         experiences in         many countries         – people are         not involved in         the decisions         concerning their         lives and servic-         es, they don't         have legal remedies. Not in line         with UNCRPD.</li> </ul>

#### References

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

United Nations General Assembly. (2006). Convention on the Rights of Persons with Disabilities and Optional Protocol. Available at:

https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Palacios, A. (2008). El modelo social de la discapacidad: orígenes, caracterización y plasmación en la Convención Internacional sobre los Derechos de las Personas con Discapacidad. Madrid: Cinca. Available at: https://www.cermi.es/sites/default/files/docs/colecciones/Elmodelosocialdediscapacidad.pdf

Loeffler, E., & Bovaird, T. (2017). From participation to co-production: Widening and Deepening the Contributions of Citizens to Public Services and Outcomes. In E. Ongaro, & S. Van Thiel (Eds.), The Palgrave Handbook of Public Administration and Management in Europe (pp. 403-423). London.

Bach, M., Kerzner, L. (2010). A New Paradigm for Protecting Autonomy and the Right to Legal Capacity Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice. Toronto: Law Commission of Ontario. Available at:

http://supporteddecisionmaking.org/sites/default/files/paradigm\_protecting\_autonomy.pdf

Giertz, L., 2018. Guardianship for Adults with Intellectual Disabilities: Accountant, Advocate or 'Family' Member?. Scandinavian Journal of Disability Research, 20(1), pp.256–265. https://doi.org/10.16993/sjdr.40

Gooding P. (2013). Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health. Psychiatry, psychology and law, 20:3, p. 431-451. https://doi.org/10.1080/13218719.2012.711683

Inclusion International. (2014). Independent But Not Alone: A Global Report On The Right To Decide. Available at:

https://inclusion-international.org/wp-content/uploads/2014/06/Independent-But-Not-Alone.pdf

Millar, D. (2013). Guardianship Alternatives: Their Use Affirms Self-Determination of Individuals with Intellectual Disabilities. Education and training in autism and developmental disabilities, 48(3), 291-305.

Arstein-Kerslake, A. (2016). Legal capacity and supported decision-making: Respecting rights and empowering people. SSRN Electronic Journal.

https://doi.org/10.2139/ssrn.2818153

Arstein-Kerslake, A. (2016). An empowering dependency: Exploring support for the exercise of legal capacity. Scandinavian Journal of Disability Research, 18 (1), 77–92.

https://doi.org/10.1080/15017419.2014.941926

Bigby, C., Whiteside, M., & Douglas, J. (2019). Providing support for decision making to adults with intellectual disabilities: Perspectives of family members and workers in disability support services. Journal of Intellectual and Developmental Disabilities, 44 (4), 396–409.

Gooding, P. (2015). Navigating the 'flashing amber lights' of the right to legal capacity in the United Nations convention of the rights of persons with disabilities: Responding to major concerns. Human Rights Law Review, 15 (1), 45–71.

https://doi.org/10.1093/hrlr/ngu045

// References

Stainton, T. (2016). Supported decision-making in Canada: principles, policy, and practice. Research and Practice in Intellectual and Developmental Disabilities, 3(1), 1-11.

https://doi.org/10.1080/23297018.2015.1063447

Special Rapporteur on the rights of persons with disabilities. (2017). Report on legal capacity and supported decision-making, A/HRC/37/56 (Adopted 17 December 2017). Available at: https://undocs.org/en/A/HRC/37/56

Special Rapporteur on the rights of persons with disabilities (2016). Report of the Special Rapporteur on the rights of persons with disabilities, A/HRC/34/58 (Adopted 20 December 2016). Available at: https://undocs.org/en/A/HRC/34/58

Committee on the Rights of Persons with Disabilities (2011). Concluding observations on the initial report of Spain, CRPD/C/ESP/CO/1. Available at:

https://undocs.org/en/CRPD/C/ESP/CO/1

Committee on the Rights of Persons with Disabilities (2014). Concluding observations on the initial report of Belgium, CRPD/C/BEL/CO/1. Available at:

https://undocs.org/en/CRPD/C/BEL/CO/1

Committee on the Rights of Persons with Disabilities (2017). Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland, CRPD/C/GBR/CO/1. Available at: <a href="https://undocs.org/en/CRPD/C/GBR/CO/1">https://undocs.org/en/CRPD/C/GBR/CO/1</a>

Committee on the Rights of Persons with Disabilities (2019). Concluding observations on the combined second and third periodic reports of Spain, CRPD/C/ESP/CO/2-3. Available at:

https://undocs.org/en/CRPD/C/ESP/CO/2-3

Committee on the Rights of Persons with Disabilities (2019). Concluding observations on the initial report of Greece, CRPD/C/GRC/CO/1. Available at:

https://undocs.org/en/CRPD/C/GRC/CO/1

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

Canadian Association for Community Living (2014). A statutory framework for the right to legal capacity and supported decision making for Application in Provincial/Territorial Jurisdictions in Canada. The Working Group on Legal Capacity and Supported Decision Making. Available at:

https://cacl.ca/wp-content/uploads/2018/05/Draft-Statutory-Fmwk-Legal-Capacity-June-9.pdf

Martínez de Aguirre, C. (2014). El tratamiento jurídico de la discapacidad psíquica: reflexiones para una reforma legal (1ª ed.). Pamplona: Thomson Reuters Aranzadi

Mental Health Europe & European Network of National Human Rights Institutions. (2020). Implementing supported decisions-making: Developments across Europe and the role of National Human Rights Institutions. ENNHRI & MHE. Available at:

https://www.mhe-sme.org/wp-content/uploads/2020/06/Report-ENNHRI-and-MHE-Implementing-supported-decision-making.pdf

Navas Macho, P., Gómez Sánchez, L. E., Verdugo M.A., Schalock, R.L. (2012). Derechos de las personas con discapacidad intelectual: implicaciones de la convención de naciones unidas, Revista Española sobre Discapacidad Intelectual, Vol. 43(3) Núm. 243, 7-28.

// References

Porxas, M. A., (2020), De la incapacitació al suport a la presa de decisions: Anàlisi de l'estat de la qüestió i proposta per un ordenament civil català respectuós amb els drets humans en el context de la reforma estatal, Barcelona, Espanya: Generalitat de Catalunya, Centre d'Estudis Jurídics i Formació Especialitzada. Available at:

http://cejfe.gencat.cat/ca/recerca/cataleg/crono/2020/incapacitacio-decisions/

Ribot Igualada, J. (2012). L'assistència: abast i limitacions de la nova institució. Dins Qüestions actuals del dret català de la persona i de la família (1ª Ed., p.49-105). Girona: Documenta Universitària.

Seoane Rodríguez, J.A., Álvarez Lata, N. (2010). El proceso de toma de decisiones de la persona con discapacidad: una revisión de los modelos de representación y guarda a la luz de la Convención sobre los derechos de las personas con discapacidad. Derecho privado y Constitución, 4, 11-66.

The National Safeguarding Committee. (2017). Review of current practice in the use of wardship for adults in Ireland. Available at:

https://www.lenus.ie/handle/10147/624083

European Centre for the Development of vocational Training (CEDEFOP). Common European Framework of Reference: Self-assessment grids. Download Available at:

https://www.cedefop.europa.eu/files/europass\_-\_european\_language\_levels\_-\_self\_assessment\_grid.pdf

Turnpenny, A., Petri, G., Finn, A., Beadle-Brown, J., Nyman, M. (2017). Mapping And Understanding Exclusion: Institutional, Coercive And Community-Based Services And Practices Across Europe. Mental Health Europe. Available at:

https://www.mhe-sme.org/mapping-exclusion/

Hordacre, A.L. (2016). Understanding everyday money skills for young people with disabilities. Flinders University Australian Industrial Transformation Institute. Available at:

https://doi.org/10.13140/RG.2.2.25721.47206

Beadle-Brown, J., Mansell, J., Cambridge, P., Milne, A. and Whelton, B. (2010), Adult Protection of People with Intellectual Disabilities: Incidence, Nature and Responses. Journal of Applied Research in Intellectual Disabilities, 23: 573-584. Available at:

https://doi.org/10.1111/j.1468-3148.2010.00561.x

Craft, A. ACTing against abuse, (Leaflet). Available at:

https://www.surreycc.gov.uk/\_\_data/assets/pdf\_file/0017/19700/Keeping-you-safe-easy-read-booklet-part-1.pdf

Mithaug, D.E., Mithaug, D.K., Agran, M., Martin, J.E., Wehmeyer, M.L. (Eds). (2003). Self-Determined Learning Theory: Construction, Verification and Evaluation. Lawrence Erlbaum Associates Publishers: New Jersey. Raley, S. K., Shogren, K. A., & McDonald, A. (2018). How to Implement the Self-Determined Learning Model of Instruction in Inclusive General Education Classrooms. TEACHING Exceptional Children, 51(1), 62–71. https://doi.org/10.1177/0040059918790236

Shogren, K. A., Wehmeyer, M. L., Burke, K. M., & Palmer, S. B. (2017). The Self-Determination Learning Model of Instruction: Teacher's Guide. Lawrence, KS: Kansas University Center on Developmental Disabilities.

Diamond, A. (2013). Executive Functions. Annual Review of Psychology, 64, 135–168. Available at: http://doi.org/10.1146/annurev-psych-113011-143750

// References

Dalley, G., Gilhooly, M., Gilhooly, K., Harries, P., Levi, M. (2017). Financial abuse of people lacking mental capacity, Institute of environment, Health Societies, Brunel University London. Available at: <a href="http://www.mentalcapacitylawandpolicy.org.uk/wp-content/uploads/2017/10/Financial-Abuse-of-People-lacking-mental-capacity.pdf">http://www.mentalcapacitylawandpolicy.org.uk/wp-content/uploads/2017/10/Financial-Abuse-of-People-lacking-mental-capacity.pdf</a>

Dalley, G., Gilhooly, M.L., Gilhooly, K., Levi, M. and Harries, P. (2017). Researching the financial abuse of individuals lacking mental capacity, The Journal of Adult Protection, Vol. 19 No. 6, pp. 394-405. Available at: https://doi.org/10.1108/JAP-05-2017-0022

// Annexes



# 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. shop or through the internet).	(e.g.: when I buy things from a
In particular, I want:	
My HEALTH In particular, I want:	
O	

- 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 the 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:







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











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