



# From “guardians” to “supporters”: Supported Decision Making in service provision for person with disabilities

A report on the global situation of supported  
decisionmaking and the role of support services



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## Foreword

I-DECIDE is an EU funded project addressed to help adults with intellectual disabilities to make supported decisions in the areas of personal finance, healthcare and consumer rights.

The project seeks to advance the implementation of article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) through the promotion of Supported Decision Making (SDM), a tool that allows people with disabilities to retain their decision-making capacity by choosing supporters to help them make choices. I-DECIDE wants to develop practical guidance for the supporters to be able to help the person with a disability understand, consider, and communicate decisions, fully respecting the wishes and preferences of the individual.

### The report

This document, coordinated by the European Association of Service providers for Persons with Disabilities (EASPD), is intended to serve as a State-of-Play report on the situation of SDM, with a particular focus in three EU countries (Finland, Greece and Spain).

To offer an understanding of the situation, this report analyses firstly the concept of Supported Decision Making and the relevance that this concept has gained since its first introduction on the UN CRPD in 2006. Following, a general overview on the current SDM situation is given, both at global and European level. A list of promising policies and practices is included, reflecting particularly in the support perspective and in their applicability to the areas of personal finances, healthcare and consumer rights.

To enhance the analysis on the European case and the situation at EU level, partners of the I-DECIDE project have produced country reports that picture both the current & future legal and policy framework on SDM and some promising practices in the areas of personal finances, healthcare and consumer rights. And to offer a more detailed view on supported decision-making in practice, three I-DECIDE partners (service provider organisations) have been interviewed regarding the change management process they experienced around the implementation of the SDM paradigm in their organisations. The interviews are divided in two parts, the first aiming at the organisational changes and an additional section where the manager of each organisation explains how she or he coped and managed these changes.

This report aims at serving as a reference and supporting document not only for the development and implementation of the I-DECIDE project but also for the upcoming projects committed to the promotion of the SDM principles. That is why some findings and a conclusions chapter are included, outlining a possible way forward for the real implementation of article 12 UN CRPD with a particular focus on the support perspective. Enjoy the reading!

Carmen Arroyo de Sande  
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### Supported decision making

Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) acknowledges the right of persons with disabilities to enjoy legal capacity on an equal basis with others in all aspects of life. It also affirms 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.

In line with this principle, Supported Decision Making (SDM) represents an alternative to guardianship or other types of substituted decision making. This shift in paradigm is fundamental to advancing towards the real inclusion of persons with disabilities into the society.

SDM consists of several measures designed at setting the sufficient conditions for a person with disabilities to make informed decisions on all aspects of her or his own life. The range of decisions is very broad and goes from very routine decisions such as how to dress and what to eat, through to decisions that can greatly affect the life of a person, such as where to live, who to vote for, or whether or not to accept a particular medical treatment.

It is important to highlight that SDM is a relatively new concept, mainly popularised in the framework of the UNCRPD in 2006 and it completely substitutes guardianship. 'Guardians' make decisions for the person with a disability whilst 'supporters' in SDM allow the person to make his or her own decisions. To facilitate this, the supporter will study the decisions the supported person should make and will provide him/her with all necessary information so as to give the supported person a clear view on all possibilities with their pros and cons. At this point it is up to the supported person to make her or his own decision. The decision must be respected even if it is not the best possible one from the supporter's point of view. This means the supported person has the right to make bad / unwise decisions and commit mistakes.

Supported Decision Making is key to promoting self-determination, control, and autonomy and it fosters individual independence. As a new paradigm, it can be considered as a revolutionary change in the support principles applied to persons with disabilities, and sets a firm base to advance towards de-institutionalisation and the development of community based services.

### Promising examples around the globe

There is nothing better than being inspired by others, especially when you want to move from theory to practice! That is why the I-DECIDE partnership started its journey gathering examples that could illustrate how SDM is being implemented around the globe, with a particular focus on the support perspective. Therefore, the intention was not to do a comprehensive review of all existing legal reforms and pilot projects, but to pick up some promising examples that could help I-DECIDE partners to identify the needed learning outcomes in view of the preparation of the practical guidance (manuals) for supporters.

In comparison with other areas in the UNCRPD where the main problems rely at implementation level (lack of operational frameworks or adequate funding), the legal frameworks in the vast majority of States Parties are not (yet) in line with the requirements of article 12 of the Convention. That is why the examples gathered were not only practices from the field but also policies and legal frameworks.

### Why 'promising'?

According to wikipedia.org a 'best practice' is a method or technique that has consistently shown results superior to those achieved with other means, and that is used as a benchmark. But we know that in many occasions a 'best practice' may not be able to solve a problem at all and it can be difficult to transfer it to another context. That is why some organisations, such as the Fundamental Rights Agency of the European Union (FRA), use the term 'promising practice' to refer to practices in place that are innovative yet still on an experimental level

so there is still room for some development (e.g. to be aligned closer with UN CRPD) and upscaling (showing how it may be proven to be effective in the long term and also able to be mainstreamed).

## Outlook

There are still big differences in the implementation of the UN CRPD around the world. Specifically, in terms of SDM, the present situation lies at a much earlier stage than the rest of principles of the Convention. There are currently only a few countries leading the change at international level. The situation of SDM is, in general, very under-developed.

The changes are indeed based on the principles of the UN convention but are mainly driven exclusively by private goodwill initiatives and practices, as there is so far often a clear lack of national legislation supporting SDM principles. As no national laws force the introduction of these principles, in cases such as the United States or Canada there are disparities on SDM even within the same countries.

Europe is another example of significant disparity in legislation and legal reforms regarding article 12 of the UNCRPD. Legislation on legal capacity is a competency of the Member States and so this makes it very difficult to align the implementation of article 12 of the UNCRPD at EU level. Although all EU Member States have signed and ratified the Convention, very few of them have introduced or reformed definitive laws in order to completely adapt to the SDM principles.

Most EU countries have passed laws and reforms to embed (to some extent) the principles of article 12 UNCRPD but very few of them include provisions referring specifically to the support perspective besides the provisions related to legal capacity of the individual. In addition, all of them still have some situations where total guardianship is foreseen and the procedure by which a guardian is appointed is still not consistent among countries. Nevertheless, all EU Member States show signs of progress towards the implementation of the UNCRPD and its article 12, although not being at a satisfactory pace. The new paradigm seems to be slowly but generally acknowledged, albeit comprehensive legal reforms and more practical guidance still do need to be speeded up to implement in practice the adoption of Supported Decision Making principles.

## **Policies**

Among the leading parties on Supported Decision Making some countries can be highlighted:

### Australia

The commonwealth of Australia has recently taken decisive steps towards the implementation of the UNCRPD. Namely, the National Disability Insurance Scheme (NDIS) started to be implemented in 2016 and it is expected to be fully in force by 2019. Its main objective is to provide persons with disability with greater choice and control over the disability services and support they receive. In its chapter 4, the NDIS foresees the role of the Nominee as the support person. However, the NDIS Act does not specifically require the observation of the basic SDM principles as they are only collected as a recommendation. Additionally, it foresees many cases where the nominee can act on behalf of the supported person, including the election of a nominee itself.

The reason why the Australian case is worth a mention is the large set of strong recommendations, including a full set of SDM national principles, made by the Australian Law Reform Commission with regard to the national laws and the NDIS in specific. These recommendations are completely in line with SDM principles and aim at the derogation of the Nominee role. These recommendations might be partially or totally implemented in the future

1 This section does not include examples from Finland, Greece and Spain as they are included in the respective country reports included in the next chapter.

2 For a comprehensive review, we suggest the thematic study on the right of persons with disabilities to equal recognition as a person before the law done by the Special Rapporteur on the rights of persons with disabilities, A/HRC/37/56, December 2017

3 Note that the case of Spain, which has put forward a very comprehensive reform, is not included as it is referred in the next section of this report.

## Canada

As mentioned before, Canada is one example of how the UN CRPD has been implemented unequally within the same state: Canada has a long tradition of SDM for persons with disabilities, but most of its legislation is based at regional level, resulting in a disparity of regulations. However, it is one of the worldwide leading nations on SDM. One of its best examples is the Representation Agreement Act of British Columbia region: in line with the laws in Costa Rica, a fundamental acknowledgement of this legal text is the presumption of capability (art. 3) of every adult despite any of her or his mental and physical capabilities, including their own communication means. This agreement aims at providing the supported person with all the means to elect a legal supporter and, most importantly, to avoid the need for the court to appoint someone to help adults make decisions, or someone to make decisions for adults, when they are incapable of making decisions independently. (art. 2b)

The Representation Agreement Act from British Columbia sets a step forward in an already advanced Canadian legal system that abolished public adult guardianship and that clearly states that all adults are entitled to receive the most effective but the least restrictive, least intrusive and least stigmatizing form of assistance and support or protection when they are unable to act independently.

## Costa Rica

The Law for the promotion of the autonomy of persons with disabilities (Ley para la promoción de la autonomía personal de personas con discapacidad n. 9379 published on 30th August 2016) sets one of the first worldwide examples of national legislation clearly supporting SDM. Specifically, on its article 5 states that all persons with disabilities count with full legal rights and acknowledges their legal capacity. The same law identifies two supporting roles: firstly, a legal warrant for legal procedures that are intended to assist in decision making on the legal, financial and patrimonial matters in a proportional manner and adapted to the condition of the person (art. 11c). Secondly, a personal assistant for daily matters with the objective to support the exercise of personal autonomy and that will also be obliged to deliver her or his service respecting the preferences, interests and personal conditions of the supported person (art. 29a).

Most importantly this law establishes a state-financed programme on personal assistance (chapter III) to further support and ensure the implementation of the mentioned measures. As stated later in the present document, this key element must be highlighted, as continuity of support after a decision has been taken is crucial and not always provided or even foreseen by SDM practitioners.

## France

At the time when this report is being written, new reform proposals regarding the SDM have been announced. The aim is to find a system that effectively enshrines the principle of the legal capacity of persons with disabilities and an effective support to the exercise of their rights promoting the expression of his will and preferences. These proposals have, among others, the following general orientations: the recognition of the presumption of capacity of person with disabilities; the right to be supported in the expression of their will above all through the development of adapted means of communication; guardianship shall be removed as general rule from the French legislation. There should be a single safeguard measure based in assistance instead. However, the judge may (still) appoint a representative who would substitute the disabled person in extreme situations.

## Ireland

Although it has been the last EU Member State to ratify the UNCRPD, the Mental Health Commission in Ireland is currently initiating the operational roll-out of the Decision Support Service that will be managed in collaboration with the department of Justice. Unlike other countries, this constitutes a clear interest in investing in effective support structures aimed at complying with the SDM principles.

## United Kingdom

The UK was one of the first countries in the world to implement rules to observe the right of persons with disabilities to make their own decisions. Notably, even before the introduction of the UNCRPD, in 2005 the Mental Capacity Act was approved. In this text a few fundamental rights were, for first time, officially acknowledged. The most relevant principles introduced were:

- a. The ultimate presumption of capacity, including the condition that all practicable steps to help a person must have been applied before declaring a state of incapacity. A person must be assumed to have capacity unless it is established that he lacks capacity.
- b. The right of the persons to not be treated as unable to make a decision merely because this person makes an unwise decision – this makes clear the right to be ‘wrong’ in any decision.

## United States of America

As in Canada, each US state is responsible for SDM legislation and other disability related aspects, a system that results in big disparities between states. However, three pioneer states are worth mentioning: Texas, Delaware and, most recently, Wisconsin. Although other states have been piloting some projects on SDM, only the three above mentioned have adopted legal procedures to support a system based on SDM. However, unlike Costa Rica or Canada, and due to strong opposition from certain sectors of society, the approach on SDM is as to offer an alternative to persons with disabilities and it is not intended to replace guardianship.



## Practices

The following examples incorporate the philosophy and values shared by the partners of the I-DECIDE project; these are based on the UNCRPD and our common interest to support persons with disabilities in enjoying their right to make their own decisions in any aspect of life. Although some practices might not have been designed specifically for persons with intellectual disabilities, it is considered that they are adaptable and therefore can be used to provide support to the supported persons. All promising practices are based around discovering the will and preferences of a person and supporting their own decision-making, rather than merely acting in their 'best interests'. The practices have been selected also for their focus on the areas of personal finance, healthcare and consumer rights.

### Australia

**Name:** Pilot project on Supported Decision Making.

**Organisation:** South Australian Office of the Public Advocate (OPA).

**Type of Activity:** Multidisciplinary support as an alternative to guardianship.

**Field of Practice:** Healthcare, Consumer rights

**Skills:** Literacy, numerical, digital and others

**Main link with UNCRPD:** Article 12 Equal recognition before the law; Article 13 Access to justice; Article 19 Living independently; Article 21 Access to information; Article 25 Health.

### Description – Results:

The objective was to find people who were at risk of entry into guardianship (the 'early intervention group') and facilitate 'support agreements' with people they trust to help them make decisions over various welfare matters, including decisions about accommodation, health and lifestyle. Financial decisions were not covered. The program is described as a 'process of setting up supported decision-making agreements and supporting the participants with those agreements.'

The participants were those with intellectual and cognitive disability or brain injury. Facilitators do not provide the support themselves but help people to identify others who can support the individuals to make decisions, to set up agreements over how they will be supported and how to provide support to both parties in the supported decision-making process. Often the supporters who are chosen by the individual are friends, family or associates. The model works with the 'express will' of the individual and helps to support people to make and communicate decisions on a whole range of issues in their lives.

**Name:** Financial Decision Making and Financial Literacy Skill Development.

**Organisation:** New South Wales Government, New South Wales Trustee and Guardian.

**Type of Activity:** Training activities and workshops.

**Field of Practice:** Personal Finance

**Skills:** Literacy, numerical, digital

**Main link with UNCRPD:** Article 12 Equal recognition before the law; Article 19 Living independently; Article 21 Access to information.

### Description – Results:

The project has two parts: the training component, which is focused on enhancing sector capacity, and developed an 'Introduction to supported decision making' full day workshop for service providers. The training is free and includes the promotion of a SDM model that aims to build decision making ability. Forty training events were successfully completed, reaching 2,000 disability services staff. To complement the training a number of resources and information sheets highlighted the importance knowing the person, communication and the role of friends and family when providing support for decision making. Sessions also included a Train the Trainer component for those interested in being champions of SDM in their workplace and beyond. The financial decision-making component of the project is working with participants and their supporters to see how the principles of SDM apply to financial decision making by developing their capability through financial literacy training and looking at how they can be supported to take more of a role in their financial affairs.

## Bulgaria

**Name:** Network of support. Empowering People with Intellectual Disabilities. Example adapted from the AJuPID project.

**Organisation:** Regional Society for Support of People with Intellectual Disabilities (RSSPID).

**Type of Activity:** Support network.

**Field of Practice:** Healthcare, Consumer rights, Personal Finances

**Skills:** Literacy, numerical, digital

**Main link with UNCRPD:** Article 9 Accessibility; Article 12 Equal recognition before the law; Article 13 Access to justice; Article 19 Living independently; Article 21 Access to information; Article 25 Health.

### Description – Results:

The pilot project 'Empowering People with Intellectual Disabilities' aims at demonstrating the practical feasibility of supported decision-making and thereby advocating for a change in legislation concerning the legal capacity of people with intellectual disabilities in accordance with Article 12 of the UNCRPD.

This form of supported decision-making starts with establishing a network of support for the person. Sometimes this practice is referred to as a 'Circle of Friends' or a 'Circle of Support'. In order to identify the people who will be included in the network of support, a personal profile is made and the members of the network of support are chosen by the concerned person; a relationship of trust between the person and the members of the network is essential. The network provides the necessary support to the person concerned according to their wishes and choices. The whole process is guided and monitored by a facilitator.

The type of decisions which are covered by the supported decision-making model developed during the project covers the following areas:

- Accommodation (for example the type of accommodation, location, whether to live alone or with others);
- Relationships and lifestyle (includes choosing who to spend time with and doing what activities);
- Choices about work, education and recreation;
- Health issues (consideration of advice from health professionals including making choices about treatment options);
- Financial decisions (how to manage, spend or save money);
- Contracts (providing the necessary support to the person in order for him/her to understand the meaning of a contract).

## France

**Name:** Multidisciplinary support for people with social difficulties. Example adapted from the AJuPID project.

**Organisation:** The Association for prevention, support and orientation.

**Type of Activity:** Multidisciplinary support as an alternative to guardianship.

**Field of Practice:** Healthcare, Consumer rights, Personal Finances

**Skills:** Literacy, numerical, digital

**Main link with UNCRPD:** Article 9 Accessibility; Article 12 Equal recognition before the law; Article 13 Access to justice; Article 19 Living independently; Article 21 Access to information; Article 25 Health.

### Description – Results:

The MASP, a personalized social care measure, supports people who have trouble in managing their finances or have health problems and receive social benefits. In Paris, the local authorities exceptionally also make this service available to retired people or extremely poor people who do not receive social benefits. 30% of the persons who are using a MASP at APASO (Association pour la Prevention, l'Accueil, le Soutien et l'Orientation) are recognized as persons with disabilities by the French administration. The MASP is initiated by a contract between the local authority and the person concerned. The first contract lasts for a year, but the measure can be extended to up to four years. It is entirely up to the person to decide whether they want an extension.

The person involved also decides for themselves what the objectives of the contract should be: those goals can be financial, health-related, finding employment, etc. A contract is always very personalised, so it may also include very practical points such as learning how to cook or engaging in a sports activity. The contract is of merely symbolic nature, as the person can terminate it at any moment. This occurs very rarely, as the person has chosen to enter the MASP and has the option to leave.

## United Kingdom

**Name:** Becoming a mother: Supported Decision Making in context.

**Organisation:** NHS Trust, Royal Holloway University of London

**Type of Activity:** Research project on personal and professional support networks.

**Field of Practice:** Health-Care, Personal Finance and fundamental rights

**Skills:** Literacy, Numerical, Social

**Main link with UNCRPD:**

Article 6 Women with disabilities; Article 8 Awareness Raising; Article 12 Equal recognition before the law; Article 23 Respect for home and family; Article 25 Health;

### Description – Results:

Social support is important for mothers with intellectual disabilities in many areas. This study explored how the support network influenced the decision-making of women with intellectual disabilities in relation to pregnancy. The study extended previous research to include the multiple perspectives of mothers and their personal and professional support networks. A model of decision-making was constructed, with implications for how services approach working with mothers with intellectual disabilities. Using a grounded theory methodology, three mothers with intellectual disabilities, two of their family members and six professionals were interviewed about their experiences of decision-making in relation to pregnancy. The results suggested that the quality of a woman's relationships was key to facilitating decision-making. The results highlighted the need for services to focus on creating supportive working relationships with mothers and other services involved in the parenting assessment process.

**Name:** The health improvement partnership project

**Organisation:** Public Health Norfolk, Equal Lives

**Type of Activity:** Access to public health services

**Field of Practice:** Healthcare

**Skills:** Literacy, numerical, digital

**Main link with UNCRPD:** Article 8 Awareness; Article 9 Accessibility; Article 12 Equal recognition before the law; Article 21 Access to information; Article 25 Health.

#### Description – Results:

This project intends to make a difference in the long term by changing the way that information about health services is designed and improving the ways that such information is delivered to people with learning disabilities. The aim of the project is to provide action-based recommendations, information and advice leaflets, good practice guides on accessibility, and recommendations for training/development.

The project is about people with learning disabilities working with professionals and others to make sure that disabled people get equal access to services. It was agreed that collecting the experiences and advice of people with learning disabilities was the best way to understand the difficulties people face. The project has been designed to use these experiences to make recommendations about how to improve access – and so improve health outcomes.

**Name:** Learning Disabilities Resource Pack for General Practitioners.

**Organisation:** South Yorkshire NHS Trust

**Type of Activity:** Access to public health services

**Field of Practice:** Healthcare

**Skills:** Literacy, numerical, digital

**Main link with UNCRPD:** Article 9 Accessibility; Article 12 Equal recognition before the law; Article 21 Access to information; Article 25 Health.

#### Description – Results:

People with learning disabilities may often have difficulty in recognising illness, communicating their needs, or generally using health and social care services. Following the success of similar packs that were introduced to support people with learning disabilities, when they go into hospital for a planned or emergency stay, the South Yorkshire NHS Trust decided to create a folder containing visual aids and tools to help GPs and primary care staff to communicate effectively with someone with a learning disability.

The packs include photo journey booklets, which have clear images and appropriate language to describe a person's journey through a variety of situations including visits to the opticians and dentist, stopping smoking, as well as breast and cervical screening for women. There are also visual aids to assist in evaluating and monitoring pain, and general health and wellbeing information in an easy read format.

#### United States of America

**Name:** Webinar Series on Financial Literacy, Capability and Employment.

**Organisation:** LEAD Centre.

**Type of Activity:** Webinars.

**Field of Practice:** Personal Finance

**Skills:** Literacy, numerical, digital

**Main link with UNCRPD:** Article 12 Equal recognition before the law; Article 19 Living independently; Article 21 Access to information.

The LEAD Centre's work focuses on promoting innovation in policy, employment and economic advancement to advance individual and systems- level change for all persons with disabilities. The LEAD Centre provides policy research and recommendations, training and technical assistance as well as demonstration projects designed to break down silos in existing systems, processes and practices, and foster wider understanding, adoption and integration of next-generation employment practices in both the public and private sector.

An important focus of the LEAD Centre's mission is to increase the financial literacy and financial capability of persons with disabilities. Participation in the workforce, which produces increased income, is a vital first step for working-age adults with disabilities to build economic self-sufficiency. Employment also serves as an important gateway for individuals to further explore tools and strategies to improve their economic stability and security. The LEAD Centre works to foster pathways to economic advancement for persons with disabilities to improve their present and long-term financial well-being, while supporting the workforce development, Home and Community Based Services, and other systems that share this mission. For this, the LEAD Centre in collaboration with other public and private organisations offers a series of webinars where persons with disabilities can acquire key knowledge and skills on relevant matters such as financial self-dependence and employment.

Tuettu päätöksenteko, Tukiliitto (2018)  
<https://www.tukiliitto.fi/tuki-ja-neuvot/itsemaaramisoikeus/tuettu-paatöksenteko/>

Oikeus osallisuuteen ja yhdenvertaisuuteen - YK:n vammaisten henkilöiden oikeuksien yleissopimuksen kansallinen toimintaohjelma 2018-2019, Sosiaali- ja terveysministeriö (2018)  
<http://urn.fi/URN:ISBN:978-952-00-3908-0>

Vammaisten oikeudet, Suomen YK-liitto (2018)  
<http://www.ykliitto.fi/yk70v/yk/ihmisoikeudet/vammaisten-oikeudet>

Vammaislainsäädännön uudistus, Sosiaali- ja terveysministeriö (2018)  
<http://stm.fi/vammaislainsaadannon-uudistus>

## Supported Decision Making in Finland

### Legal and policy framework

In Finland, Supported Decision Making is not directly mentioned in the current legal framework, so no official practices on SDM exist. SDM in Finland is defined to be “the support that someone gives to help a person to take his/her own decisions in his/her life.” This can be for example:

- Support in forming and expressing their own will
- Support in getting information
- Clarifying difficult things
- Finding out different options and consequences
- Training people with support needs on how to make decisions
- Support in the implementation of the decision
- Support in emotional handling and expression

But despite the lack of a dedicated legal framework recognising officially SDM, there are many common practices used to enable SDM to work in real life. People get a lot of support in making decisions even if it isn't an “official” form of SDM. Providing support in decision making, fully respecting the needs and wishes of the individual, is considered common practice in housing and day care services.

### Looking ahead

Finland signed the UNCRPD in 2007. Because of the UNCRPD many reforms started in disability policy in Finland. The government didn't want to ratify the convention before the legislation could support all the articles in UNCRPD. That meant that over the last 10 years there have been many reforms in the legislation.

The National Action Plan on the UN CRPD was released on 13th March 2018. It determines the measures that will be taken to promote the implementation of the Convention in different sectors during the first action plan period 2018–2019.

The Action Plan has been drawn up by VANE (Advisory Board for the Rights of Persons with Disabilities), which includes representatives from disabled people's organisations, trade unions and the key ministries regarding the rights of persons with disabilities. Disabled people's organisations and persons with disabilities have been consulted during the process of drawing up the Action Plan. Based on this information, discussions about implementation measures have been conducted with different ministries.

The Action Plan emphasises the importance of social inclusion of persons with disabilities in the changing operational environment and the importance of accessibility as a precondition for the realisation of other rights. One of the main objectives of the Action Plan is increasing awareness of the rights of persons with disabilities and mainstream these rights in different sectors and more widely in society.

The Action Plan comprises 82 measures and the different ministries have committed themselves to implement them. These measures have been divided into measures that are to be implemented during this action plan period and measures that will be implemented over a longer period. A responsible body or bodies have been indicated for each measure. The degree of achievement of these measures will be assessed at the end of the action plan period. SDM is one of those measures, number 27. To develop supported decision making and good practices on it. This seems a step in the good direction and it is expected that the SDM will be officially recognised in Finland in the coming years and indeed some elements of SDM will be included in the new legislation expected for the beginning of 2020, a law on disability and a law on self-determination:

- In the law on self-determination there will be three different steps on how to get support for decisions (always having as a main objective to give as much control as possible to the individual) :
  - a. The person selects the support person him/herself. If he/she doesn't want to make a choice the family members can support.
  - b. In decisions about housing and care, more clear regulations will provide directions on safe guards
  - c. If the authority notices that person should make decisions, but can't do it by him/her self and s/he doesn't have anyone to support them, or if there is some conflict of interest with family members, then the authority is required to appoint a support person.
- In the comprehensive revision of the legislation on disability, SDM is also mentioned when referring to Coaching and support. The purpose of Coaching and support is to support self-determination, involvement and independent management by strengthening the person's own resources and supporting his/her to be as an equal participant in the family and community.

Tuettu päätöksenteko, Tukiliitto (2018)

<https://www.tukiliitto.fi/tuki-ja-neuvot/itsemaaraamisoikeus/tuettu-paatöksenteko/>

Oikeus osallisuuteen ja yhdenvertaisuuteen - YK:n vammaisten henkilöiden oikeuksien yleissopimuksen kansallinen toimintaohjelma 2018-2019, Sosiaali- ja terveysministeriö (2018)

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Vammaislainsäädännön uudistus, Sosiaali- ja terveysministeriö (2018)

<http://stm.fi/vammaislainsaadannon-uudistus>



## Promising Practices

### General practices in Supported Decision Making

The principles of SDM are generally adopted in practice. Many supporters use easy to read and understand communication tools produced thanks to by a project developed in Eastern Finland in the years 2011 to 2015.



One good example of SDM in general is using 'talking mats' to help communication and to really help decision making and recognising that it really has an impact on how to make choices. As an example, in one-day care centre every Friday people have a morning meeting where they make plans for the next week's activities. It doesn't mean that people talk in the group and make the choices together; it means they individually make choices for each person's day time activities. All the choices are made with the 'talking mat'. Staff members ensure with pictures on the mats that each person understands what the possibilities are and that he/she can also make wishes from the other possibilities that are not already on the opportunities on display. When they make their choice(s), they can decide also with whom they want to be at each activity. Of course, there can be situations when someone's choice affects others (for example two persons want to be with the same person at the same time, but not together). In these situations, people have a discussion with the talking mats and they make the decision together. Staff members do not make the decision.



Using the talking mats in planning the day time activities. Photo: Marjaana Ropone

Tuettu päätöksenteko materiaali, Savon Vammaisasuntosäätiö (2014)  
<http://www.savas.fi/fi/materiaalipankki/oppaat/tuettu-paatöksenteko-materiaali/>

Osallisuutta ja työllistymistä tukevan toiminnan laatuksiteerit, KVANK Työn ja päivätoiminnan valiokunta (2016)  
<http://verneri.net/yleis/osallisuuden-ja-tyon-laatuksiteerit>



## Personal finances

In this area, guardianship is still the only possible legal arrangement. But the principles of SDM are generally adopted in practice and legal guardians don't make decisions by themselves but in cooperation with the person supported, after careful explanations about the financial situation and the different possibilities to spend or save the money.

People who live in group homes also get support from staff members. For example, if they are going to buy a television the staff member helps to find out from the internet what kind of televisions there is to buy, and at what price. The staff member also goes to the shop to help the supported person to understand what is included in the price and to help to them make the decision. Easy to read and understand communication materials are used many times to help with choice and shopping process so the person with disability can go shopping by her/himself.

## Healthcare

SDM in healthcare is also a common practice in group homes, day care and in individual supported living arrangements. One of the main topics is nutrition. Training about nutrition is organised for the whole group or individually. Staff members use adapted communication tools to explain the importance of having a healthy lifestyle. They can also train in practice by making informed choices at lunch time (e.g. how much of the vegetables, bread etc. to take).

## Consumer rights

In this field there are many training activities addressed to develop digital skills of persons with intellectual disabilities, as online commerce is spreading quite fast. The training activities organised by supporters are designed ad hoc, following the specific request of the persons with support needs.

## Change management

**Kehitysvammaisten Palvelusäätiön (KVPS):** The service foundation for people with intellectual disabilities.

Number of employees: 60

Number of supported persons: 620+

Surname, Name: Konola, Kirsi

Organisation: KVPS

Current position: Deputy CEO

Years of experience: 14

## Organisational aspects

- Explain why your organization is interested in promoting new strategies to support decision making.

Supported Decision Making, as well as the rest of principles of the UN CRPD, is at the foundation of the work at KVPS. In this sense, anything related to enhancing this approach at local and national level is part of the objectives of the organisation.

Furthermore, Finland is facing new legislative changes that will bring about a big reform in the public health system. These changes will also include a new approach on self-determination and disability. Supported Decision Making as such is expected to be included, but the current legal framework foresees only the role of guardianship. For all this, KVPS is willing to be part of new initiatives and projects such as I-DECIDE and benefit from an exchange of best practices and tools to lead the paradigm shift among supported persons and other relevant actors.

- What structural changes did you have to introduce in order to adapt your organisation to the principles of supported decision making? Structural changes may refer to modifications of your financial sources, relationship with the public administration and other organisations or staff size and training.

The gap in the Finnish legal framework regarding Supported Decision Making is the main reason why KVPS has never been forced to implement any major structural change as an organisation. Some changes might be needed in the mid-term future due to the afore-mentioned health system reform, but such a possibility is not yet totally clear.

- What functional changes did you introduce in your organisation? Are these related to any structural changes previously mentioned? Functional changes may refer to modifications of your organisation's role, administrative and legal procedures or participation to projects.

Even before the UN CRPD was ratified at national level, KVPS already based its activities on its principles by training staff, developing a person-centred planning approach and working on co-production with supported persons' families. The biggest change occurred in the framework of SDM is the involvement of KVPS in developing new legislation at local level (municipalities) and piloting different projects such as AJuPID: legal capacity and access to justice for persons with disabilities.

- What additional changes do you plan in the mid-term and long-term future? What other changes would you like to introduce but for any reason you are not able to?

As mentioned, depending on the upcoming legislation some changes might be needed in the mid-term future, but such possibility is not yet totally clear. This process will be implemented in different phases and it is expected to finish by 2020.

- Do you know any other organisation that went through similar changes? Please explain it briefly.

Many other organisations in Finland are facing big major changes due to the new health system reform. However, these changes started already following a de-institutionalisation reform promoted by the government along with many other changes because of the new reforms. In general, the society view on people with mental disabilities has already changed in Finland.

## Personal aspects

- What specific challenges did you face when adapting to the supported decision-making criteria? Did you require any special training?

To change the culture to be more accommodating to personal hopes and aspirations is a long haul and needs both sustained commitment and motivation. The biggest barrier is the old and traditional culture that sees persons with disabilities as objects of care and not as citizens. Services must enable and support people to enjoy their rights and all aspects of citizenship, not just meet their basic needs.

- How would you describe the dimension of the changes faced during this process?

The nature of the changes we adopted and that we promote is fundamentally cultural. It is a daily task and effort to try to influence people's views on this subject, starting with the ones of the supported persons themselves. Any change in society of this dimension requires of constant and progressive steps.

- How did you manage the change in your organisation?

We have trained our staff to use person-centred planning tools, active support and individual service design. We are supporting and investing in value-based organisational culture and management. We promote strong commitment with these principles and try to provide the space and means to discuss and reflect on these changes.

## Findings

Despite a non-compliant legal framework, SDM principles and methods are quite spread in Finland. The majority of the examples found were about communication tools.

Support persons and self-advocates are aware of the importance of applying them in the daily practice. But specific and continuous training for staff is needed to understand what the difference between SDM and general support is. The stakeholders and staff have an important role to play and it is important that they have the right set of values to appreciate the individual's self-determination. It is also important that management understands the meaning of these values and principles and support their staff in delivering them. Family members also have an important role in encouraging people to take the control of their own lives.

The announced reforms seem very promising and will hopefully pave the way for a true supported decision making system in Finland.

## Supported Decision Making in Greece

### Legal and policy framework

Although the UN Convention on the Rights of Persons with Disabilities was ratified by the Greek Parliament on April 2012, the economic crisis and the ongoing recession hit, as expected, the social policy sector that was already one of the most vulnerable of the public policy in the country. As a result, no further steps have been taken towards the implementation of the UN Convention in general as well as regarding Article 12 on matters of Supported Decision Making.

The following information presented regarding the legal capacity of persons with disabilities is based on the study developed as a final deliverable of the project “Study on Article 12 (Equality before the Law), Article 13 (Access to Justice) and other provisions of the International Convention on the Rights of Persons with Disabilities”. The project was implemented by the Centre for European Constitutional Law – Themistoklis & Dimitris Tsatsos Foundation from November 2011 to June 2012 on behalf of the National Confederation of Persons with disabilities.

According to this study, Article 34 of the Civil Code provides that for a person to acquire legal capacity, he or she must be at the age of 18 while for some other cases, persons continue to be considered ‘totally incapacitated’ or ‘partially incapacitated’ to legal transactions even after the completion of the 18th year. Persons that belong in the latter category have reduced legal capacity.

Decision-making concerning persons with ‘reduced legal capacity’ is provided through the institution of judicial assistance (guardianship).

The following guardianship measures apply:

- A combination of custodial and auxiliary legal assistance (guardianship)
- Partial auxiliary judicial assistance (guardianship): The person co-decides (on certain matters) with his/her guardian.
- Total auxiliary judicial assistance (guardianship): The person co-decides (for all matters) with his/her guardian.
- Partial deprivation of judicial assistance (guardianship): The person cannot make certain decisions that are determined by the court while he/she can decide autonomously on all other matters.
- Total custodial judicial assistance (guardianship): The person cannot make decisions and is replaced by a third person.

The persons who are in full custodial judicial assistance have no legal capacity. Those that are (a) partially deprived of legal assistance and (b) those in auxiliary legal assistance have limited legal capacity.

For those subjected to limited legal capacity, the guardian must consult them in order to act in their best interests; however, their opinion is not binding on the guardian. Essentially the starting point is the best interest of the person under judicial assistance, not the effort to implement his or her will and opinion or to provide the necessary information and support to interpret his or her will as provided for by the Convention on the Rights of Persons with Disabilities.

Regarding the most recent survey conducted in Greece, and even though the data provided wasn't collected by the total Greek population with disabilities, the picture coming from the application of the judicial assistance institution reveals that a majority of respondents prefer full substitution in decision-making. The reason behind that has not been explained yet; however, the legal framework does not offer alternative solutions to guardianship, such as Supported Decision Making.

## Promising Practices

Despite a legal framework completely aligned with substituted decision making and a lack of awareness about SDM in general terms, some isolated promising practices were found in some Greek organisations. Three service provider organisations - Merimna Patras, VTC MARGARITA and ALMA – were using SDM tools in practice, as described below.

## Personal Finances

Supported Decision Making in financial management in Greece is practiced with in vivo activities such as shopping in stores or activities in which the service supported person is responsible for budget their pocket money for the week and using their cash for their primary personal needs. The organisation ALMA has a specific tool part of their “Supported Living Projects”; by which service supported persons have a monthly personal statement of income and expenditure.

Training activities regarding financial management focus on the development of the literacy and numeracy skills mainly, and in a very few cases, include the development of digital skills.

The training tools used to improve their skills and financial management are easy to read brochures, role playing activities with money transaction exercises, and videos.

**ΦΥΛΛΟ ΚΥΚΛΟΦΟΡΙΑΚΗΣ ΑΓΩΓΗΣ ΠΡΟΚΑΤΑΡΤΙΣΗ**

ΟΝΟΜΑ: .....









ΗΜΕΡΟΜΗΝΙΑ: .....

ΨΩΝΙΑ

.....

**ΠΡΙΝ ΤΑ ΨΩΝΙΑ**

Πόσα χρήματα έχω φέρει:

	ΠΟΣΑ ΚΕΡΜΑΤΑ ΕΧΩ;	ΠΟΣΑ ΧΡΗΜΑΤΑ ΕΧΩ;
	_____	$\times 2 =$ _____
	_____	$\times 1 =$ _____
	_____	$\times 0,50 =$ _____
	_____	$\times 0,20 =$ _____
	_____	$\times 0,10 =$ _____
	_____	$\times 0,05 =$ _____
	_____	$\times 0,02 =$ _____
	_____	$\times 0,01 =$ _____
	<b>ΣΥΝΟΛΟ=</b> (τα χρήματα που έχω)	_____








**ΒΗΜΑ 1) ΜΕΤΡΩ**  
ΠΟΣΑ ΕΧΩ ΑΠΟ ΤΟ ΚΑΘΕ ΚΕΡΜΑ

**ΒΗΜΑ 2)**  
ΠΟΛΛΑΠΛΑΣΙΑΣΜΟΣ Χ

**ΒΗΜΑ 3)**  
ΟΣΑ ΕΙΝΑΙ ΣΤΟ ΠΟΡΤΟΚΑΛΙ ΤΑ ΠΡΟΣΘΕΤΩ +

**ΜΕΤΑ ΤΑ ΨΩΝΙΑ**

**1. Πόσα χρήματα έχω τώρα:**

Χρήματα	ΠΟΣΑ ΚΕΡΜΑΤΑ ΕΧΩ;	ΠΟΣΑ ΧΡΗΜΑΤΑ ΕΧΩ;
	_____	$\times 1 =$ _____
	_____	$\times 0,50 =$ _____
	_____	$\times 0,20 =$ _____
	_____	$\times 0,10 =$ _____
	_____	$\times 0,05 =$ _____
	_____	$\times 0,02 =$ _____
	_____	$\times 0,01 =$ _____
	<b>ΣΥΝΟΛΟ=</b> (έχω ρέστα)	_____

**ΒΗΜΑ 1) ΜΕΤΡΩ**  
ΠΟΣΑ ΕΧΩ ΑΠΟ ΤΟ ΚΑΘΕ ΚΕΡΜΑ

**ΒΗΜΑ 2)**  
ΠΟΛΛΑΠΛΑΣΙΑΣΜΟΣ Χ

**ΒΗΜΑ 3)**  
ΟΣΑ ΕΙΝΑΙ ΣΤΟ ΠΟΡΤΟΚΑΛΙ ΤΑ ΠΡΟΣΘΕΤΩ +

**2. Πόσα χρήματα ζήτησα:**  
(Έξοδα)

ΑΠΟΔΕΙΞΕΙΣ	
1. ψώνια	_____
2. εισιτήρια	_____
3. καφετέρια	_____
4. διάφορα άλλα	_____
<b>ΣΥΝΟΛΟ=</b> (αυτά που πλήρωσα)	_____

**ΒΗΜΑ 1) ΓΡΑΦΩ**  
τα έξοδά μου

**3. Τα χρήματα που μου περισσεύουν:**

1. Είχα φέρει	_____
2. Πλήρωσα	_____
3. ΣΥΝΟΛΟ (ρέστα)	_____

**ΒΗΜΑ 2)**  
ΟΣΑ ΕΙΝΑΙ ΣΤΟ ΠΟΡΤΟΚΑΛΙ ΤΑ ΠΡΟΣΘΕΤΩ +

**ΒΗΜΑ 3)**  
ΟΣΑ ΕΙΝΑΙ ΣΤΟ ΠΡΑΣΙΝΟ ΤΑ ΑΦΑΙΡΩ -












Easy to read exercise from Margarita, on financial management – budgeting for shopping

## Healthcare

The three organisations use some educational tools that even if they do not directly involve the practice of Supported Decision Making, they can be considered as a pre-requisite for SDM.

The training activities organised for persons with support needs focus on daily life skills regarding self-care management, healthy eating, accident prevention, organising regular medical checks and taking medication. The training tools used are based on visual material, role playing games, videos and easy to read guides and brochures.

**MEDICAL**

What do I have?		Which Doctor do I need?
 Headache.	 Fever.	 <b>Pathologist</b>
 Stomachache.	 Coughing	
 I can't see well.		 <b>Ophthalmologist</b>
 Clogged nose.	 Sore throat.	 <b>Otolaryngologist</b>
 Ear Pain.		

## Consumer Rights

Contrary to financial management and healthcare activities, consumer rights is a quite undeveloped area when it comes to supporting persons with intellectual disabilities in Greece. Apart from the tools described in the Personal Finances chapter, the service providers collaborate with the service supported persons to support them in creating their own shopping list and practise SDM when visiting the local market to purchase products. These activities help them improve their literacy and numeracy skills.

The activities that are more related to the consumer rights field are mainly focused around the shopping experience, for example making a shopping list, waiting in the queue or being responsible consumers by checking the price and the quality of a product before purchasing it.



Picture: example of ease to read exercise from MARGARITA



## Change management

Margarita Vocational Training Centre

Number of employees: 35 (30 FTE)

Number of supported persons: 95 permanent + 20 sporadic (more independent).

Surname, Name: Bistas, Ioannis

Current position: Director

Years of experience: 26

## Organisational aspects

- Explain why your organization is interested in supported decision making.

Supported Decision Making has been one of the priorities since the foundation of Margarita. The focus of the organisation is on the supported persons' needs and wishes. Therefore, all students and supported persons are permanently encouraged to represent themselves in all aspects of their lives. In order to help us better implement the UN CRPD and to benefit from the exchange of best practices, Margarita joined EASPD and is permanently expanding its own inter-institutional network at a national level.

A good example of Margarita's interest in SDM is the Margarita's Student: an organisation of students that practise self-advocacy and represent themselves and other students with intellectual disabilities.

- What structural changes did you have to introduce to adapt your organisation to the principles of supported decision making? Structural changes may refer to modifications of your financial sources, relationship with the public administration and other organisations or staff size and training.

Since Supported Decision Making has always been a key objective of the foundation, there has never been a need for significant structural changes. These principles were already observed during the creation and mission of the organisation.

However, due to the financial situation of the country, Margarita faced several difficulties to adapt to the challenging circumstances and finally decided to establish a European projects unit to access new international funds and sustain its work. This also changed the relationship between Margarita and the local authorities; together with other NGOs and through specific pressure activities, a new access line to national funds has been established.

- What functional changes did you introduce in your organisation? Are these related to any structural changes previously mentioned? Functional changes may refer to modifications of your organisation's role, administrative and legal procedures or participation to projects.

The financial crisis has played a major role a national level, specially producing an important negative impact in the social sector. Consequently, the relationship between Margarita and the local Greek authorities suffered some changes. For this, a group of Margarita supported persons met with the Finance Minister with the objective to raise awareness of the need to increase public funding in the social care sector. New ways of accessing national funding have been granted to Margarita. This was, at the same time, a change in Margarita's functioning since it was the first time that service supported persons represented themselves to the public administration and on behalf of Margarita.

In parallel, the trainers and psychologists at Margarita have been trained to help supported persons and their relatives approach the principles of Supported Decision Making. This highlights that even though the Foundation and its employees are well in line with this paradigm, there is still a predominant element of stigmatisation among the supported persons and their families that still hampers the pursuit of their own self-representing rights. In this sense we can say that Margarita had to shift slightly the focus from supported persons to their

relatives to help boost the confidence in their own capabilities.

- What additional changes do you plan in the mid-term and long-term future? What other changes would you like to introduce but for any reason you are not able to?

To approach its main objectives, Margarita plans an increase in frequency and interaction with supported person's families. For this, an increase in the number of professionals involved will be necessary. In addition to this, new training activities are planned for Margarita's staff and specialists to boost their knowledge and skills. Another one of the big changes planned is to involve supported persons in Margarita's work, projects and strategic decisions.

In parallel, there are already plans to enlarge and empower Margarita's Student Committee.

- Do you know any other organisation that went through similar changes? Please explain it briefly.

There are similar organizations in Greece that work in this subject but due to a lack of strategy at national level they are forced to work alone. To improve this situation, Margarita will implement a program from our local authority titled "Child Protection and Rights", which focuses on the collection of good practices and their presentation in a charter that will make the information available to people in the special education field. This programme also aims at collecting the needs of persons with disabilities and their families.

## Personal aspects

- What specific challenges did you face when adapting to the supported decision-making criteria? Did you require any special training?

The main challenge has been changing society's mentality on intellectual disability and specifically the mentality of our staff and the families of our supported persons. It has been a daily effort to bring the change from small things to the big changes. To achieve this, it is necessary to provide a lot of information regarding the legal framework and be open to new educational activities and projects like I-DECIDE. If the personnel themselves don't believe in the power and the skills of their service supported persons, then it is even harder for the rest of society to change.

- How would you describe the dimension of the changes faced during this process?

From a manager's point of view, the challenges are faced daily, making it a very progressive and dynamic process. These changes involve three main areas including the relationship with the service supported persons, the relationship with the supported person's families and a change in Margarita's staff philosophy and methodological approach.

- How did you manage the change in your organisation?

The main requirement identified is the one of time and patience. A useful tool to apply the changes is the forms that supported persons fill to evaluate the quality of the service provided. This helps Margarita's staff understand better their own performance and aspects that need to be improved.

In parallel, Margarita encourages its members to take part in projects at European level and learn the good practices from other organisations.



## Findings

Based on the historical review of the legal framework, it is clear that very few decisions have been made which enable people with intellectual disabilities to improve their quality of life by providing more autonomy. No substantial changes have been made to adopt UN CRPD or to promote Supported Decision Making based on article 12 of the Convention.

However, both the Greek universities with a background in special education and social sciences as well as service providers have adopted methodologies that develop and increase the self-determination and self-advocacy of people with intellectual disabilities.

According to the interviews done with support service organisations in the framework of the I-DECIDE project, service providers have a supported person-centred approach which responds to the needs, wishes and requests of the service supported persons. Service providers, apart from the training they offer, support the service supported persons by providing counselling to their families and informing the local community and the society regarding intellectual disability and inclusion. However, this needs to be further developed in order for Supported Decision Making to evolve and be implemented in real life and not only be practised in protected environments. By focusing more in counselling families, the service providers should encourage their participation as well. Their participation would be quite paradoxical since they should be advised to withdraw to a small degree so as to give opportunities to their children to gain control of their lives instead of being so totally protected. As it is right now, Supported Decision Making is applied in very few cases during training activities regarding financial management (budgeting, using cash), consumer rights (shopping list and shopping) and health management (self-care). The Greek Legal system of guardianship and the mentality of the families themselves needs to change completely in order to adopt and support Supported Decision-Making practices. For this to be achieved, policy frameworks need to allow for the creation services that encourage appropriate Supported Decision Making from childhood and on into adulthood and after, in all types of educational organisations.

Service providers also need to update their training, so they focus more on activities that develop digital skills for people with intellectual disabilities to have access in web platforms and to use applications that simplify decision making in financial management, health and consumer rights. However, the development of digital skills should not reduce the opportunities for socialisation by participating in daily activities in the community. Finally, another next step to achieve Supported Decision Making is the formation of a structure that will represent the population with intellectual disability which consists of people with intellectual disabilities (and their supporters). A self-advocacy movement may be able to more effectively bring the needs of people with intellectual disabilities to the attention of the decision makers and so lead to the appropriate changes in the legal framework regarding their social inclusion and autonomy.

## Supported Decision Making in Spain and Catalonia

### Legal and policy framework

In the Spanish legislation we can find mechanisms such as Full Guardianship, Partial Guardianship (or Curatorship), de facto guardianship (or physical custody) and a judicial defender to support individuals in court proceedings. In the case of the Catalan legal framework, the aforementioned mechanism is expanded or complemented by introducing the Assistance Mechanism and the Protected Heritage (real estate and financial assets). The latter (pioneering in the Catalan legal framework) constitutes a supported decision-making mechanism since the individual retains full legal capacity to decide and to act.

Notwithstanding numerous efforts in the last decade, persons with disabilities are facing numerous obstacles that impede the adaptation of the social, physical and cultural environment to meet their support needs. The existing policy framework is still not fully adapted to the principles of the UNCRPD, people still suffer from negative attitudes based on prejudices and there's insufficient provision of services due to lack of adequate funding.

In terms of the availability of supported decision-making arrangements, numerous efforts are being made to individualise the assessment of capacity, not only from a clinical and legal perspective and with a restrictive finality, but also from a social and ethical point of view to advocate for non-restrictive measures aligned with the principles and values enshrined in article 12 of the UNCRPD. Support providers are in need of practical guidance and some reference documents for professionals do exist in Catalonia. The most relevant ones are the "Screening protocol before starting a process Modification of capacity, and criteria and recommendations for the promotion of the autonomy in the taking of decisions" and the "Guide on protection and support for the exercise of capacity. Beyond incapacitation".

Those documents are particularly interesting since the first defines a range of capacity scales to assess individual capacity prior to modifying its legal capacity with a substituted decision-making court mechanism and it defines, in form of algorithms or flow charts, mechanisms to prevent it. Briefly, this document makes a compendium of different models of capacity assessment, namely "The Catalan model to assess capacity to take advanced decisions in time –PDA", "The Ottawa Decision Support Framework", "The Drane's model on decision-making" and "The MacArthur Scale MacCAT-T", "DMC", "D-SAT 10". The second document, although interesting per se, doesn't develop supported mechanisms in practice and limits itself to providing guidelines and recommendations from an ethical perspective.

### Looking ahead

At the moment when this report is being written, the Council of Ministers of Spain has already taken the first step towards a comprehensive reform of the civil law that will remove terms such as 'incapable' or 'incapacitation' from the Spanish legal system. This reform has as its main goal respecting of the will of persons with support needs. The text replaces the role of the guardian, who now governs the decisions of the vast majority of people with intellectual disabilities, with other roles that, depending on the degree of disability, can have a supporting role to guide the person in making of their own decisions. The attribution of representative functions will only be done in extreme cases. The new law was promoted by the Ministry of Justice and negotiated with the Committee of Representatives of Persons with Disabilities (Cermi). The reform also takes into account the availability of support measures, designed and provided following the specific needs of each individual.

Spanish Civil Code Articles 199 to 313

Catalan Civil Code Articles 221-1 a 227-9

Screening protocol before starting a process Modification of capacity, and criteria and recommendations for the promotion of the autonomy in the taking of decisions GENCAT, Department of work, social affairs and families

Guide on protection and support for the exercise of capacity. Beyond incapacitation Ethics Committee on Catalan Social Services

## Promising Practices

SDM arrangements & methodologies are not systematized, meaning that there's not usually a standard procedure to develop them inside organisations providing support and so they are not equally or consistently used by all professionals. The tools described below are selected by professionals after an initial needs assessment with the final supported person.

### General practices in Supported Decision Making

**Individualised Support Team** - This is an internal management approach to provide the best available professional support to fit with the required support needs of the supported persons. After a personalised needs assessment, the service provider organisation set up a team of specialized professionals (social workers, educational workers) who support individuals (under guardianship, curatorship, assistance or advanced powers of attorney). The support team is always the same, enabling positive bonding with the supported person; this also facilitates the knowledge and understanding of the will and preferences of the individual. The team also develop customised communication tools which allows for a positive and collaborative vision focusing on the capabilities of the person. This deep interaction supported person-professional also helps persons with disabilities to acquire digital, literacy and numeracy skills. Last but not least, this model facilitates the interaction of all actors involved and the integration of the care & support services.

**Education Groups** – These are conceptualised as training courses for persons with disabilities aimed to increase, enhance and boost personal abilities in daily-life activities (eg: cooking, hygiene, cleaning, taking care of financial affairs, social interaction, etc...). These Education Groups take place when an individual is transitioning from an institutional facility to a community-based environment (group home, supported home...). These groups are being developed in settings such as mental health mid-term units (semi-closed units) and also there are specific modules being developed in primary care mental-health centres, residential or day care centres and associations like Associació de Familiars de Salut Mental Club Social El Cercle (a peer support organisation). There are specific and dynamic modules that the supported person can try to sign up based on an assessment made between the supported person and the professional supporter.

### Healthcare

Three of the main practices found can be defined within the area of healthcare. Namely, they are based on:

- a Blister system for storage, dispensing and monitoring medication,
- a physical activity plan,
- nutrition plans and education groups on lifestyle models and daily-life activities:

The **blister system** used to compartmentalise prescriptions is a tool used transversally across different service providers (Health-Care Centres, long-term residential centres, day-care centres, small group homes, et al.) or even in the individual's own home and by a diverse range of professionals (Social Workers, Educational Workers, Family Workers, Nurses, etc.). This tool is often linked with an easy to read prescription system which uses pictograms to indicate visually the time of administration and the correct dose. This provides a clear advantage when communicating with an individual on the need to follow complex prescriptions and it opens a window of opportunity to work on health-related aspects of an individual's life. This good practice allows working on the co-responsibility of the supported person and the support person, increases the supported person's knowledge of the medication and the side effects of taking it and not taking it and at the same time increasing the supported person's decision-making skills and the supporter person's abilities around communication. It also increases co-production skills, since it is usually developed in practice co-operatively.

**Physical Activity Plans-** These are plans elaborated jointly with the supported person and the professional or supporter person based on an individual's needs assessment and ultimately taking into consideration the supported person's own will and preferences. The professionals coordinating physical activity plans are:

- physiotherapists - who assess the physical abilities of the supported person,
- physicians - who assess organic health and monitor the impact and evolution of the physical activity plan,
- social workers - who usually provide the supported person point of view on the typology of activity they want to practise (a concrete sport or activity, the intensity of the routine, changes on its will and preferences)
- and the supporter (usually an educational worker or family worker) who executes the final activity plan with the supported person.

The current trend is to develop activities in the community such as trekking, football championships, etc, so the supported person's ability to interact with other individuals is increased, as well as the ability to follow routines and communication skills. Physical Activity Plans are flexible and revisable over time. In some instances, the supported person's digital skills are increased, since technology allows the use of mobile phones, smartphones, tablets and computers - e.g. when planning an activity, viewing a tutorial, following GPS directions - but that is variable depending the activity and the professional involvement and technical means available.

**Nutrition Plans** – These are used by a diverse range of professionals and with different formats, usually recommended by a nutritionist, physician or nurse. Professionals working in day-care centres, residential facilities, group homes and support professionals (in-home educational workers or family workers) use easy to read communication tools to teach persons with disabilities healthy lifestyle habits both in terms of diversity, quantity and quality. At the same time, elaborating together weekly menus according to their nutrition plan improves their literacy (receipts and procedures), numeracy (quantity wise) and digital skills (if for example the family workers use videos to show how to make a specific dish). Dedicated training sessions (like workshops) on different topics of food and healthy habits are organised through games or visual and interactive tools are being conducted in different centres.

## Change management

FTCG Tutelar de les Comarques Gironines – Support (FTCG)

Number of employees: 78

Number of supported persons: 800+

Surname, Name: Solé i Chavero, Josep Maria

Current position: Director

Years of experience: 15

## Organisational aspects

- Explain why your organization is interested in supported decision making.

FTCG is currently the biggest NGO in Catalunya providing guardianship services. Since its foundation, FT CG has been pursuing the principles of the UN CRDP at local level but following the de-institutionalisation process initiated by the Catalan government, FT CG w forced to take up guardianship services that involve substituted decision making. Now, FT CG aims at shifting this role into the Supported Decision-Making paradigm. In addition, new legislation more in line with the UN CRPD might be implemented in the mid-term future. This means that the framework in which FT CG operates will change drastically and so it will do its internal functioning. To adapt better to these circumstances, the organisation is looking for the means, tools and good practices not only to adapt to this situation, but also to lead these changes at local and national level.

- What structural changes did you have to introduce in order to adapt your organisation to the principles of supported decision making? Structural changes may refer to modifications of your financial sources, relationship with the public administration and other organisations or staff size and training.

During the last years, FT CG has been awarded progressively more confidence from the legal authorities, facilitating a big expansion mainly in the number of supported persons and a much smaller (but still significant) increase in staff. However, it is very important to highlight that the public funds awarded for each supported person (using supported decision making arrangements) are much lower than the amount awarded in cases that still require guardianship. This means that with a new shift in paradigm FT CG will receive much less public funds for the same number of supported persons. That is why the new legal framework needs to reflect the support perspective and resource it accordingly.

In line with these changes, FT CG recently adopted a new name and brand: SUPPORT, that clearly show a shift from guardianship intervention towards a supporting role.

- What functional changes did you introduce in your organisation? Are these related to any structural changes previously mentioned? Functional changes may refer to modifications of your organisation's role, administrative and legal procedures or participation to projects.

Since the public quality control is still based on pre- UN CRPD practices, it has not been considered as fit for our purpose and therefore FT CG has been looking for new ways of improving its own service delivery. Specifically, the organisation is working in collaboration with an external consultant to create a quality system and reduce substituted decision making to a minimum (according to the current legal framework). It is very relevant to highlight how one of its main tools is the principle of agreement: supporters must avoid giving negative answers to those supported person requests (or decisions) that might seem negative at first. Instead, the supporter and the supported person are encouraged to find an agreement on an alternative that meets the needs and wishes of the supported person but that also brings added value to the his or her life.

- What additional changes do you plan in the mid-term and long-term future? What other changes would you like to introduce but for any reason you are not able to?

We are aiming for a new supported person approach style. This means to provide support services only when clearly requested by the supported person.

We want to provide more training services to all health professionals involved (psychologists, psychiatrists, nurses and social workers) in Girona province on the new SDM paradigm.

The goal in the service delivery is to achieve a more flexible and adaptable assistance. This includes not only supporting the decision-making process, but also helping supported persons to manage their decisions once they are taken.

- Do you know any other organisation that went through similar changes? Please explain it briefly.

There are many other organisations in the same situation as FT CG that are also looking at the new paradigm of SDM. However, their level of progress is lower, and they often request support from FT CG, especially on training activities for their staff.

## Personal aspects

- What specific challenges did you face when adapting to the supported decision-making principles? Did you require any special training?

The main challenge comes with the debate around how to act in front of a supported person who is clearly taking a decision against his or her own interest and that is clearly negative. In this sense, it is always difficult to balance the freedom they must have to do this alongside the amount of help that must be applied for each case. This means that on one hand providing too much help might lead back to substituted decision making and, on the other hand, leaving too much freedom to the supported person might lead to abandonment or harm.

In addition, due to the key role that FTCCG has at local level, pressure from society and public authorities is often received to insist on or even require the provision of assistance to certain difficult cases (especially when there is a homelessness or violence element) even when they refuse it.

- How would you describe the dimension of the changes faced during this process?

The changes that FTCCG is facing are fundamental for the future of the organisation and for the quality and principles applied to the provision of services.

- How did you manage the change in your organisation?

To manage the change in the organisation a leading role has been adapted. The director himself has taken initiative in the most difficult cases, especially when deciding about the hospitalisation or not of a person. This carries an assumption of risks (including legal and economic) but serves as a role model not only for FTCCG's staff but also for the rest of stakeholders to perceive supported decision making as the new mainstream approach.

## Findings

In the research that FTCCG Tutelar de les Comarques Gironines has done in the framework of the I-DECIDE project, it was clear that organisations don't systematically define their qualitative methods of delivering support in practice, even though they often develop tools and strategies aimed to develop supported person abilities and capabilities to effectively provide opportunities to individualise the support they offer.

It is remarkable that in the Spanish Disability Strategy 2012-2020, a document establishing guidelines with a length of 42 pages, there's not a single reference to support perspective in SDM and in the same regard, the recommendations lack sufficient detail to enable them to be put into practice.

Persons with disabilities, particularly people with intellectual disabilities, experience a mismatch between their personal competence and the demands of the social environment. This creates the need for individualised support aimed at improving personal results in relation to their independence, better personal relationships, greater opportunities to contribute to society, an increase their participation in community contexts and activities and a greater sense of personal well-being or life satisfaction. It is of the utmost importance to provide support in three fundamental aspects to develop an adaptive behaviour: conceptual & logical skills, social skills and better experience with the use of technology.

The support needs of people with intellectual disabilities differ both quantitatively and qualitatively. No individual will need all the potentially available support at the same time. Therefore, this means always selecting and implementing the appropriate support for an individual and involves identifying the person's support needs and then adjusting them to the available resources and the appropriate strategies to address those needs. This is a team effort that requires support organizations to dedicate time and resources to this task, including the training of personnel to ensure their competence in the development, implementation, control and evaluation of an individualised plan of support.



## Conclusions

It is clear that the general situation of Supported Decision Making suffers from significant disparities in many aspects, both globally and at the European level.

Firstly, the most advanced practices and pilot projects in SDM often come from civil society organisations and initiatives and not from public administration or statutory bodies. In many places lawmakers still have an outdated vision on persons with disabilities and their decision-making capacities, hampering the advancement of the new paradigm in national legislation. In this sense, there is a lack of recognition of the principle of equal recognition before the law and a need to include it as one of the fundamental principles in any legal system as recognised by the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights and the Convention on the Rights of Persons with Disabilities.

The UN CRPD General Comment on Article 12 clearly states that “States parties must holistically examine all areas of law to ensure that the right of persons with disabilities to legal capacity is not restricted on an unequal basis with others.”

Even though some countries have achieved significant advances in this field, a clear majority of changes are focused exclusively on the more complex legal decisions such as marital status or place of residence. There is a clear gap between the protective measures for these decisions and those related to daily routines that affect greatly a person’s life and the work of support services. In this context, **five fundamental aspects must be strongly considered when adapting the legal frameworks** - with a special focus on the daily reality that supported persons and service providers routinely experience:

- **1. Supported Decision Making is fundamental to people’s quality of life:** making your own decisions contributes directly to personal independence, self-perception and boosts the development of new social and mental skills. The adoption of a SDM based system is a fundamental and complete change in a person’s daily routine contributing directly and decisively to a much better quality of life, making it the most relevant aspect to be considered when working for the implementation of the SDM principles.
- **2. The right to be wrong:** at the time in which this report was drafted it has been observed that only in very few cases is this right acknowledged. Supported Decision Making consists mainly of a set of procedures to properly support the supported person when he/she has to take a decision. The possibility of making a wrong or non-optimal decision must also be respected as part of the free will of the supported person and as part of her or his own learning process.
- **3. The right to not be medically treated or institutionalised:** if a person can make a conscious decision or has formerly stated her or his will on this matter, she or he has the right to decide to not be given a certain treatment or be institutionalised. This principle, although inherent in SDM, is not explicitly provided for most of legal systems consulted. Many cases have been identified where service providers report strong pressures from local society and authorities to act for them and make a particular decision for a supported person, even when the person has clearly expressed a strong will against it.
- **4. Continued support after a decision has been taken:** this aspect is not included in any legal system but is a fundamental principle that must be part of any support scheme. Once the supported person has taken a decision, it should also be part of the support plan to assist him/her with the execution of what has been decided. Otherwise, any efforts to reach a conscious decision are in vain since such decision often cannot be effectively implemented by the supported person.

- **5. The role of service providers in a co-productive way:** any organisation in charge of coordinating or advising on SDM plays a key and direct role on the success of the related activities. Of course, even having the supported person in the steering seat and following a co-production approach in service delivery, it is still nevertheless necessary to involve service provider's organisations and other social actors in the development not only of new legislation but also in the design and implementation of national strategies. To contribute to changes in the life of individuals, the introduction of SDM should be developed from a practical point of view and in full cooperation with all stakeholders, including the full involvement of supported persons and service providers.

#### The way forward: I-DECIDE Decalogue

SDM proves to be an effective and valid option to support individuals in the enjoyment of their equal recognition before the law. It is one of the most relevant and innovative practices in the area of social care and human rights and its actual and potential impact justify any efforts towards its full implementation. That is why the I-DECIDE partners have produced a set of 10 recommendations to tackle the main issues described in this report:

- 1 **Person centred planning:** the approach on service planning must shift towards a person based one where the supported person him or herself is the main factor when shaping the strategy and not his or her disability.
- 2 **Experiential learning:** to better adapt to the new paradigm and, in general, to adapt to the changing lives of the supported persons, special attention must be put on learning through reflection on doing from each one of the cases and from each one of the occasions where the supported person has taken a decision alone. The acquisition of digital, literacy and numeracy skills should be a core component of the learning framework.
- 3 **SDM as a lifelong process:** it is very important to introduce the SDM principles in parallel to the personal development of each supported person, this means from the early stages of their childhood. A supported person who has been well trained in independent decision-making from his/her childhood will always find it much less challenging to live independently and will require much less support in doing so, directly improving the quality of life. The acquisition of digital, literacy and numeracy skills should be also considered as a lifelong learning process.
- 4 **Train the supported person's relatives into the new paradigm:** to simplify and synchronise the support strategies, supported persons' relatives must also be introduced to and trained in the new SDM paradigm.
- 5 **Personal budgets:** the improvements that supported decision making bring to a supported person's life are also based on the financial capacity and independence of the supported person. It is not possible to fully implement the SDM if the supported person has no means to implement his or her own decisions alone.
- 6 **Sustainable funding for service providers:** based on the experience of some service providers, the less intrusive their support is, the smaller the budget they receive from public funds, since it is considered that fewer resources are needed. This could endanger the sustainability and quality of the provision of services in the mid-term future and constitute a perverse incentive to retain substitute decision making. SDM does not imply a reduction in resources needed by service providers. On the contrary, better training and exchange of practices are needed to ensure the quality in provision of support services. If the funding of these organisations is drastically reduced, they run the risk of becoming too small to be sustainable.
- 7 **Informal networks of support:** to ensure the success of the new strategies, all networks related to a supported person must be aware of and involved in the same support plan. In this sense, it is important to introduce the whole society into the new paradigm.



8 Specialisation of support: service providers, social workers and other related professionals such as medical personnel must be trained accordingly at different levels (technical, legal, and ethical) to successfully comply with the new principles and be able to offer an effective and coordinated support. In this framework, there is strong need of developing ICT-based solutions to facilitate the implementation of SDM mechanisms. In certain cases, a new and more specialised type of professional profile can be created in order to fill the gap and improve the coordination between institutions, service providers, supported persons and their personal networks.

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

10 Support network for the supporters: to promote exchange of good practices, share knowledge and in general provide a framework of reference, it is essential to establish a support network for all persons who have a relevant role in SDM. This support network is especially needed in cases where ethical or legal issues come up when advising a supported person about his or her own decisions and goals.

There is of course a fundamental pre-requisite to all those recommendations, which is to have adequate legal frameworks: the introduction and development of the Supported Decision Making principles must be supported by adjusting the laws to promote (first) and establish this approach as the only one legally valid. And those legal frameworks need to strongly consider the continuum of support. The I-DECIDE project will continue raising awareness on the need of making the shift towards empowering and supportive decision-making mechanisms for person with disabilities and their families.

I-DECIDE partnership  
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Inclusió social i suport en la presa de decisions  
Social inclusion and supported decision making



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