

# Decider

## **CASE STUDY ON SUPPORTED DECISION-MAKING (SDM)**

**Erasmus+ Project KA204-A0B8C67B DECIDER  
Enhancing life experiences for adults with special learning  
needs, trainers, and parents through supported decision-making**

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## INTRODUCTION

Material collected in this publication is based on the interviews with persons with special learning needs, their parents/guardians and supporters. Interviews were conducted by specialists representing project's partners from Greece, Lithuania, Poland, North Macedonia and Spain - Catalonia. More about project can be found on the project portal: [www.byod-project.eu](http://www.byod-project.eu)

The goal of this publication is a provision of knowledge to supporters of persons with special learning needs on supported decision making and its impact on quality of their life.

## BEST PRACTICES. DESCRIPTION OF STORIES.



### GREECE

#### **The current situation with supported decision making (SDM) in Greece**

The Convention on the Rights of Persons with Disabilities has been ratified in Greece in 2012, a hopeful sign that shows that we commit to respect the rights of persons with disabilities at all levels.

Despite this commitment, the shift from the present existing Substitute Decision Making paradigm, towards the Supported Decision-Making model has not happened yet. It appears to require more time and initiatives from all the relevant stakeholders: public authorities,

service providers, people with disabilities and their families to develop SDM services that will provide more choice and control in the lives of people with disabilities.

## The research team of the case study interviews

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### Story One

keywords: employment, self-care

#### Service User

John is a young man with Down Syndrome living in Greece. John has graduated from the Technological Educational Institute of Agriculture and Nutrition. In relation to technology, he uses a computer mainly to surf the internet and listen to music. He lives with his parents and recently found a job in the tourism industry.

Regarding his life, John believes that he always has "the first word". He has made decisions in his life for small and big issues, from the clothes he will wear and taking care of himself to finding a job. However, he considers it particularly important to receive support in decision making as he recognizes that it is not always easy for him.

Usually in the decision-making process he is supported by members of his family but also professionals. With special emphasis he refers to his psychologist and the valuable help they provide that has a "counselling character". He believes that it is important for him to trust the people who support him.

In decision making, it helps to have someone support him psychologically, "to raise his morale" and "to give him the appropriate advice".

He also made special mention to his father and the confidence he shows to him in matters of self-care. His father offers practical help in realizing his decisions. For example, when he decided to take a trip, his father helped him issue his tickets. When he decided to work, John and his family turned to a vocational training center from where he received training, support and finally mediation to find work. His vocational rehabilitation is one of his most important decisions he was able to realize because he wants to be financially independent.

He also addressed the issue of ongoing support even after finding a job. He says: "There were times when I was not consistent in my work, and I realized that the most important criterion for that is consistency and hard work. I believe that by meeting these two criteria I will meet the requirements of this job which will help me in the future." He received help in this from the social worker of the Supported Employment Service in the Vocational Training Center that found him a job and supports him at work. He generally states that most of the time he is satisfied with the support he receives in making decisions.

## Parents

John has grown up in a family of five, he has two brothers who have started their own families and he lives with his parents who are an elderly parent couple of high social status in Athens.

The parents of John, stated regarding Supported Decision Making that neither they nor their son have received any training. Nonetheless, all the years of his life, his parents have tried to always provide a supportive framework, either in terms of his education, or in terms of managing his emotions, as well as supporting him in making decisions in his life.

John, according to his parents, is quite independent and autonomous, but in general he finds it quite difficult to make decisions on his own, although they would like him to. According to his parents, John needs to discuss with them, several times, any decision he wants to make as if he needs confirmation.

The parents of John stressed that although they entrusted their son to complete his Higher Education Studies in a provincial town away from home, where every week, he went to attend classes alone for four days before returning, he still feels like he needs their approval in anything he wants to do.

The supportive circle of John consists of all the people who have been involved with him. His instructors when he was in the Vocational Training Center, the Social Worker in the service of Supported Employment and of course the Psychotherapist whom John meets privately.

His parents believe that there should be a service that will support Decision Making activities of people with disabilities because parents have a parental role towards their children, and it would not be easy for them to take on the role of a Supporter. Their biggest concern was what will happen to their child's life when they will either not be able to meet their needs due to their age, or when they will not be there anymore.

The ideal service in matters of Supported Decision Making for the parents of John, is first to have a stable staff with Psychologists and Social Workers so that parents and their children

will feel safe, confident, and stable. Parents also emphasize that in this service the staff on the one hand should not change because they need stability to build trust and on the other hand, they should have specialized knowledge of people with disabilities.

## Supporters

Kate is a Social Worker, Psychotherapist and Family Therapist and for the last 11 years has undertaken the psychological support of John.

Kate knows that decision-making acts of people with disabilities is a right recognized by UNCRPD. She has not received any specialized training in Supported Decision Making for people with disabilities, but she has extensive professional experience and knowledge in specialized education in terms of psychotherapy and family therapy.

Kate has undertaken the counselling psychotherapeutic support of John due to his initial decision to participate in an independent living program. John is a person with many skills, so Kate supports him in identifying his real needs and desires. His feelings and needs were processed and acknowledged, and in this way, requests that he had regarding his life emerged as decision-making opportunities.

According to Kate, people with disabilities want to make their own decisions and must be able to realize them. Parents need to be educated from the moment their child is born with a disability on how to help him or her be autonomous. People with disabilities from her experience understand that they try to behave in a way that will always please their parents without expressing and fulfilling their own needs.

Kate emphasizes that parents and the community are not aware of people with disabilities and therefore they are not aware that often, they act as an obstacle to Supported Decision Making for people with disabilities. SDM would be implemented more easily if parents, society, and staff working with people with disabilities were trained to listen to the needs of the person speaking to them and not to focus on disability.

In the ideal service, Kate initially considered that the employees who will take on each person should have specialized knowledge on matters relevant to disabilities but at the same time they must have the ability to acknowledge the person, to connect with him/her and to trust them to be able to unfold his/her needs and demands so the service user will be able to universally take the fate of their life into their own hands. It is important that the staff is stable. It would be good if this service could support people at all stages of their lives and maybe it could be a sectoral service and not only undertake the support of the people who attend specific Service Providing Centers.

## Story Two

keywords: employment, relationships, financial management

### Service User

Mary is a 45-year-old woman with intellectual disability working in the private sector for the last 10 years. Mary has graduated from High School and she is particularly good at using computers, she even takes classes on this subject.

Mary makes decisions in various areas of her life concerning work, shopping, financial management, travel, and leisure. What she points out is that she makes her own decisions, however she wants to have people by her side whose help is valuable. Specifically, Mary takes advice from her brother, her psychologist, and the social workers at the vocational training center where she studied, as well as another social worker from whom she receives support privately. The person who is consulted most often, however, is her mother, since, as she characteristically says, "we live together and we are closer", highlighting their trust.

As Mary characteristically says when she is called to decide, her mother urges her to see all the options available and then to choose. When she decided about her vocational rehabilitation, Mary stated with determination that "the decision was about me, it was mine to make", explaining that she chose work to be independent.

Regarding the purchases, Mary mentions that she usually consults her mother, while she describes in detail the decision-making process during which she records the list of options from her point of view, then listens to her mother's point of view and then chooses as she believes best. As she characteristically explains "I finally get what I like, and mom agrees with what I say".

Regarding the trips abroad, Mary says that she initially discusses it with her mother, who, after receiving all the necessary information, allows her to go.

In financial management, Mary explains that with her salary she makes simple, daily purchases such as, buying her everyday coffee and paying for her public transport card. As she points out, her mom and brother help her in the process of disbursing her money from the bank, and during shopping her mom helps her to understand if her money is enough for each purchase. Finally, when Mary is called to decide regarding shopping, she considers the criterion of necessity, saying that "I will get what I want and need".

In conclusion, Mary claims that she is very satisfied with the decisions but also with the support she has received so far in her life.

## Parents

According to the story Mary's mother shared during the interview, Mary grew up in the first years of her life in a family of four in a provincial town, however, due to the fact that 40 years ago in the province there were no structures for people with disabilities, her parents decided that her father should stay in the province and Mary would come to Athens with her mother and her brother in order to receive the appropriate education and to develop to her maximum potential.

Mary's mother stated that neither she nor her daughter had received any training in Supported Decision Making but had always had a supportive environment for her daughter. Mary was supported by the professionals from the Training Center where she received education and she is supported even today by the Social Worker responsible in the Supported Employment Service of the organizations as well as by a Social Worker who has undertaken her Psychosocial support privately for the last 28 years.

Mary's mother knows about the right of people with disabilities to make their own decisions and her daughter makes decisions about her daily life, taking care of herself (e.g., choosing clothes, making an appointment with the beautician, with the dentist), socialization and choice of friends, expenses, salary management. However, her mother expressed her concern to allow the daughter to become autonomous in terms of more complex decisions regarding her personal life and property management. In other words, Mary decides autonomously in low-risk decisions but not in high risk.

Mary's mother stresses that it is important for people with disabilities to be able to make decisions about their lives and to have as normal a life as possible, like that of people without disabilities; however, she considers it necessary for these people to always have support and considers it necessary to have a service that would enable Supported Decision Making for people with disabilities and their parents. The ideal service for Mary's mother would be a service that would provide Psycho-socially support to people with disabilities at all stages of their lives. Mary's mother gave great emphasis to the provision of support to people with disabilities when their parents are not alive.

## Supporters

Joana is a Social Worker, and for the last 28 years she has undertaken the psychosocial Support of Mary.

Joana knows that decision-making is a right recognized by the UNCRPD; however, she has not received any training on this topic, she is familiar with it due to her academic and professional experiences.

Joana initially supported Mary in matters of independent living using computer training. Mary was trained in managing time and finances, she was also trained on how to use public transport and how to socialize but also how to distinguish her desires.

Joana supports Mary in decision-making issues in her life, by initially discussing with her everything that concerns her and puts her in a process of choosing what she wants by considering the possible consequences of her decision. Until now, Mary is autonomous in low and medium risk decisions, however, in decisions about her personal relationships that had a high-risk element and her mother didn't agree, Joana was more directional.

According to Joana, people with disabilities want to make their own decisions and it is important for everyone to support this. The degree of autonomy in their decisions, however, is always affected by the parents, the type of disability and the intelligence level of the individual.

Joana focused on the contribution of the professionals who first come in contact and undertake the guidance of the parents regarding the disability of their child. It is especially important that the first supporters can explain to the parents how they should manage the difficulties that their child will have but mainly how they can facilitate their child to take advantage of all his/her skills.

Joana described the ideal service of Supported Decision Making as a service consisting of Social Workers, Psychologists, Consultants and Job Coaches. It would also be great to have a community in which people with disabilities could deal with situations they are going to face in their independent lives. The biggest fear of the parents is that someone may take advantage of their child and for this reason the parents do not provide their children access to decision making opportunities. For example, for relationship decisions, they will not be able to easily distinguish when someone is taking advantage of them because most of the time, they do not have much experience on this topic.

## Story Three

keywords: employment, relationships, financial management, health

### Service User

Eve is a 40-year-old woman with Down syndrome. She is a High School graduate and uses a computer mainly for informational reasons. She has been living with her partner for the last 5 years in their own house while their relationship started 10 years ago. She works for many years in the private sector. She has made many important decisions in her life, the most important of which were about her vocational rehabilitation, choice of residence and partner as well as issues of health, financial management, leisure, etc... She characteristically said, "I decide what I will do in my life".

In these decisions she is often supported by her family, her partner, and professional supporters. She considers the Vocational Training Center she attended also offered her support in her evolution. She stated in her interview that her training in social skills was important. She also considers important the psychological support which also helped her with her self-confidence. As for her job, she states that she wanted to find a job to be more autonomous, to make her own money.

In times when she faces difficulties in deciding, she handles the situation in the following way: "I think about it a little more; I try to do it on my own; only when I can't do it on my own will I ask for help."

This help is from the people she trusts, and she asks for their help in practical matters that she cannot do alone. For example, her partner helps her by taking care of the practicalities such as booking the hotel and tickets for their vacations because he knows better how to use the computer.

In matters of health, she shows more confidence in her mother. There were some health issues, however, when she felt more pressure to make a certain decision, such as the coronavirus vaccination. In this case, they did not discuss the issue and her mother decided for her, however, they shared the same opinion on the topic. In such cases when she disagrees with her mother, she discusses the issue with her father as well.

She generally is very satisfied with the support she has received so far in her life. She also states that she is incredibly happy with the decisions she has made because she has become "more autonomous", "she has stepped on her feet".

## Parents

Eve grew up in a family of four and for the last 10 years she has been working and living with her partner. Eve's mother, who participated in the interview, stated that they had never received any training in Supported Decision Making however they always had a supportive framework for them and their daughter.

The supportive framework she had was initially the professionals of the Vocational Training Center she attended as well as the Psychologist with whom Eve and her parents did sessions privately. She currently has support in matters of management in her work environment from the Social Service Department in the company she works. Eve's partner and the supporters from the Vocational Centre help her with the management of emotions, behaviours, and decisions.

Eve's mother describes her daughter as completely independent and her role as a parent is supportive. She would be supportive towards her child even if there was no disability. The parents of Eve take a stronger stance in decision making regarding their daughter for health and property issues.

Eve, according to her mother, decided about her life from an early age. In fact, her mother says: "Eve decided and we followed her. She has a strong personality.". Her mother also emphasizes that even for decisions made by their daughter which were wrong, in the end they had a positive result because she learned from this negative experience as it happens with all people.

Eve's mother stresses the need for a Supported Decision-Making service for people with disabilities and the ideal service would be staffed by professionals who will support people with disabilities in decisions that they want to make according to their living conditions. However, it is important that these professionals do not change because the stability of the support person creates security for both parents and people with disabilities. This service would be important to provide services to people with disabilities even if they have reached a high level of autonomy because "all parents of children with disabilities are worried about what will happen when they "leave life" as Eve's mother stated.

As a parent she would like a service that will provide psychosocial support even after the death of the parents so that there are no many emotional and practical responsibilities falling on the shoulders of the siblings of people with disabilities, who may have started their own families.

## Supporters

Sarah is a social worker who supports Eve and is her reference person in her workplace. Sarah sees in Eve a woman who not only makes decisions but also sticks with them. As she states, "Eve expresses her full opinion which is indeed the right one and puts you in your place many times". Although Sarah was not aware that decision-making is a right recognized by UNCRPD, she believes that the environment plays an important role in the implementation of SDM because it provides freedom to the person to take initiatives, seek other's opinion and express. She also believes that an SDM service is necessary as people with intellectual disability are at risk of being exploited.

Sarah when she described the SDM service, she mentioned the importance of the professional to have a close collaboration with the family to encourage the person with disability to do things they can do but need support. Specifically, she stated that a service could inform the individual and their family about the rights and interests they have and how they can exercise them.

She has often had to support Eve in job matters such as which job benefits apply to her or how to understand and utilize her work leave days she is entitled. Conversely, Sarah has had to inform her about issues she needs to pay attention to in her work duties. Eve often addresses Sarah questions about health issues as well since their company provides an occupational physician and there is the possibility of performing a medical examination in a private diagnostic center.

Regarding the communication with the family, Sarah states that she has needed to talk to them and consult them on how to support their daughter better and ensure her safety. One example concerned Sarah's update on Eve's partner who was picking her up from work . In the second case, they had to work together with the family on the issue of suspending the work contract with Eve because of COVID-19 measures. The family's role was important in this case because they handled the bureaucratic work issues that arose.

Sarah confirms what Eve stated about the importance of having a job in her life because it provides her, her own income which not only relieves her parents from having to support her financially, but she also contributes as an active member to the family planning.

## COMMENTS ON THE STORIES

By Theodosia Souvalidou & Rozmari Kalogeria, psychologists

This report is an analysis of the stories collected under the DECIDER program, by two psychologists in order to highlight the support needs of people with intellectual disabilities and their families for Supported Decision Making.

Through the stories it seems that all 3 **service users** are independent when making decisions of low and medium risk, but the same does not happen in what is related to high-risk decisions. They have a close relationship with their parents and especially with their mother in all three cases. Two of the beneficiaries paid special attention to the psychological support that concerns the strengthening of their self-confidence while the third one speaks, mainly, about the importance of her education and support in decisions in her daily life. Parents hold a prominent position in supporting their children in decision making, by providing confirmation of the rightness of a decision, or provide support in the search for options and sometimes act as the person who allows or tries to impose himself/herself towards a specific decision. Despite this support, all 3 participants talk about their own decisions and their responsibility as well as the great satisfaction they are feeling when they take their life into their own hands.

**Parents** emphasize on the importance of education and lifelong psychosocial support for their children. They consider training in SDM important and one parent mentioned that SDM should be provided by a supporter who is not a parent or relative because the parental role affects the decision-making process. Parents seem to intervene and make decisions on behalf of their children when it comes to high-risk decisions, especially relevant to health, property management and relationships issues. Parents are overly concerned about the support their children will receive after their death.

**Supporters** emphasize the need for training and support of people with intellectual disabilities regarding their daily life skills, the recognition of their personal needs and desires as well as their personal feelings. They attach great importance to their ability to formulate requests about decisions which will enable the decision support process. They also stress the need for counseling parents on how to augment their children's autonomy in both daily life skills and understanding that the needs and desires of their children differentiate from those they as parents have. Early intervention and community awareness are considered important, as well for this process.

Everyone talks about the importance of SDM service as a psychosocial support service at all stages of a person's life that should:

- Have specialized and stable staff with the ability to empathize and build a relationship of trust with the service users.
- Provide support to people with disabilities to identify and express their needs and formulate specific requests.
- Provide support in the implementation of requests and their decisions.
- Provide parental counselling.
- Provide information on the rights of both people with disabilities and their families.
- Provide psychosocial support to their children for life.

## BEST PRACTICES. DESCRIPTION OF STORIES.



### LITHUANIA

#### The current situation with supported decision making (SDM) in Lithuania

The SDM service is intended for adults with intellectual and/or psychological disability. Persons permanently residing in the Republic of Lithuania from the age of 18 for whom the need for this service has been established have the right to use the SDM service. Since summer 2020 a pilot project „From Care to Opportunities: Development of Community Services“ is being implemented in Lithuania. At present the project funding of the SDM service is provided in 6 regions of Lithuania: Vilnius, Kaunas, Shiauliai, Telshiai, Marijampole and Taurage. The specification of the SDM service in Lithuania has not been approved yet; this service is not included into the Social Service Catalogue in Lithuania.

#### The research team of the case study interviews

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- Janina Butkuviene, project promoter, editor of magazine „Viltis“. Lithuanian welfare society of persons with intellectual disability „Viltis“.

#### Description of stories with service users

Key words: employment

##### Story one

Ana, a 31-year-old woman, with special learning needs, graduated from the mainstream school, studied sewing for 3 years, can use a computer and a mobile phone, and lives in a group living house in the city. Ana works at the food-store.

Ana takes the day-to-day decisions by herself. Recently she has registered with the dentists. Sometimes her social workers help her in decision-making. Ana told about the situation in

which she got help from the social worker Agne, who noticed that Ana spent a lot of money buying her much-loved TV shows programs. Agne advised Ana to plan her purchases. At first, Ana argued saying that she could spend her money as she wanted. Agne explained to her how to spend money responsibly for purchase of food, clothes, pay for the phone and cover other necessary expenses.

Another story is about the decision-making regarding employment. Ana worked as a cleaner at the food-store. Sometimes at the request of her manager, Ana fulfilled additional work when other employees were sick. Unfortunately, Ana did not receive any bonuses. Her manager tolerated the unpaid work. When the vacation season came, Ana got a very small salary with vacation pay, although she did a lot of extra work.

Having assessed the situation, the social worker advised her to give up working in the good store because they did not value fair work and encouraged labour exploitation. Agne helped to collect all the documents for submission to the labour exchange. Ana was assigned a consultant to help her in searching for a new job. In three months, Ana has been offered a job in the same store, but under the direction of another manager. As of March 1, Ana started to work. She says that the support of the social worker and the consultant helped her to make a decision to quit the previous job and find a new one. Ana is pleased with the decision taken, she trusts her social workers and appreciates their advice.

## Story two

Sigita, a 20-year-old girl with Down syndrome, lives in a big city with her family. Sigita graduated from the main-stream school, now she attends the multifunctional center, which provides individual training under a social skills development program. Sigita knows how to use a computer and a mobile phone. Sigita does not read, therefore it is difficult for her to find complex information on the Internet. Sigita has a hobby - attending music school and a gymnastics club. Before the pandemic she went swimming and sports dancing. Sigita makes simple day-to-day decisions by herself, although sometimes she needs help. For example, every morning before going to school her mother helps Sigita to choose clothes.

Sigita finds it difficult to figure out how to dress properly depending on the weather, some occasions or place of interest. In the cafe her mother helps Sigita to choose a dish, because her daughter does not read. Sometimes it is difficult to understand the content of a dish by the title and her mother explains, then Sigita decides what dish to order.

Sometimes Sigita's mother, her teacher, and the coach help her to make decisions. During sports, Sigita's friends help her learn and do the exercises. One of Sigita's last decisions was to participate in the summer sports camp. Last year her mother suggested to her daughter to go to the camp, but Sigita flatly refused. This year, Sigita told her mother that she would like to spend summer holidays at the camp. Before taking this decision, the mother explained to her about the duration of the camp session, participants and location of the campsite. During the year Sigita trained almost every day with the coach and her sports friends via the internet, she felt safe and made this decision. Now Sigita is waiting for the summer to implement her decision.

### Story three

Karolis, a 36-year-old young man with special learning needs, studied in a special school in a small Lithuanian town and later on - in the city. At present he lives in a big city at Independent Living House. Karolis is an active computer and a mobile phone user, can find information on the Internet, he often visits the library.

Karolis is a fairly independent young man and makes every-day decisions by himself. Karolis decided to take part in the DECIDER project and give the interview by himself.

If necessary, Karolis turns to social workers, a work manager or representatives of society Viltis. When he needs to buy food, clothes or shoes, he turns to the social workers at the Independent Living House. They give him advice on purchases and help to make the budget. Karolis usually needs support in more difficult situations in order to better understand the situation and make the right decision. There is good communication and understanding between him, the social workers and the work manager. Their advice is always valuable.

Karolis tells about the case of finding the job. In the past he worked just from time to time. Two years ago, a friend of Karolis told him to get in touch with the shop manager about a job vacancy. During the talk, the manager explained to him about the job specifics, Karolis consulted with the social worker and finally agreed. His workplace is close to home. It will soon be two years since Karolis joined the ranks of workers. He is satisfied with the team, working conditions and the salary; when problems arise, the job manager and his colleagues help him. Karolis is sure that thanks to the support of other people he made the right decision.

## Description of stories with parents of service users

Key words: making decisions, responsibility

### Story one

Indre, a 58-year-old mother of a 21 years old girl with Down syndrome. Indre has higher education in economics, she is a project manager at NGO for 18 years. Indre has not participated in training on supported decision making (SDM).

Indre's daughter Sigita lives together with her. Sigita makes her own decisions in everyday life. Indre knows about the right of people with disabilities to make their own decisions, as stated in the UN Convention on the Rights of Persons with Disabilities. In Indre's opinion, at school it is impossible to learn how to make a decision with the support of other people because many things are decided without the participation of students. Independent personalities are not developed in this way. For example, students could go to the canteen by themselves, but it is more convenient for the staff to lead them because it is easier to ensure their safety.

Indre helped Sigita to start attending music and gym classes. Sometimes the help of other people in making decisions is not quite appropriate. For example, marriages. The law says that people with disabilities have the right to marry. Since they cannot take full responsibility for their actions, it is unfair to cultivate such an idea. Abroad there are positive examples of married couples with disability living with support, but Indre does not know positive examples in Lithuania.

Indre's daughter needs help in managing finances. She tells how bank accounts are managed in Estonia. People with disabilities have a manager who knows the life history of the client, helps them with necessary information and informs parents.

Recently Indre's daughter made the decision to go to the summer camp after she got to know about potential participants, duration of the camp session and coaches. Good relationship gave her daughter a sense of security. If a person is well explained about the consequences of the decision, she can really make the right decision. Unfortunately, Sigita's decisions are not always implemented. Once Sigita agreed to accept an invitation to play in the orchestra, but when the time came, she decided to participate in a gymnastics session. Sigita, like a small child, did not realize her responsibility. There is a need for an assistant or a supporter who explains consequences of the taken decision.

People with disabilities feel helpless in many situations. They need to be prepared for at least common situations, such as, getting lost in the city, getting on the wrong bus. It is necessary

to teach them simple, but necessary things. Indre says that sometimes the help of other people in making decisions is appropriate, but sometimes the advice of other people contradicts her understanding of the situation.

## Story two

Dalia, a 68-year-old woman, with a higher engineering education, the mother of a 35-year-old son. David lives in a Social Service House with full support. Dalia has not participated in supported decision-making training. She says such training would be useful both for parents and the staff. Family members of a person with intellectual disability could teach a person to make decisions with the support of other people.

Dalia's son attended the Day Occupation Center until 33. Because of deteriorated health, the family refused the services of the center. David does not speak, he needs a lot of services - personal hygiene, dressing, meals, leisure and occupation activities. As David is completely disabled, the SDM service will certainly have a positive effect on him. This would be a new stage in David's development and integration into society. Also, the qualification of specialists and the quality of the service they provide should improve.

Dalia thinks that the SDM service, especially for a person with a mild form of disability, will help them to realize their independence. Parents also must understand the need to release their children from super-care. Parents often say they know better what their children need, but they forget about the right to personal and independent life. Parents must go beyond their inner attitudes, listen to what the professionals say, though parental support is also needed in decision-making.

Dalia appreciates when someone supports her son in decision making. Even David's limited intellectual abilities allow him to choose, it makes his "gray brain cells to move."

A person with a mild intellectual form of disability can assess the situation himself. For example, Karolis lives in the House of Independent Living. During the lockdown, he complained that he was not allowed to go out of the house. Dalia advised Karolis to explain to the social worker the reasons. Sometimes the staff ask Dalia to support Karolis in decision making. After the conversation with Dalia, Karolis calms down, analyses his problem and makes a decision. Karolis appeals to the person he trusts. Dalia tries to distance herself from his personal life and gives advice only upon his request as Karolis is an adult person, who must learn to live independently.

## Story three

Veronica, 51 years old mother of a 22 years old son Arnas, who has a mild form of intellectual disability; he attends the day occupation center. Arnas lives in the family together with mother. He can make his own decisions, but sometimes he needs support.

Veronica says that a service of supported decision making (SDM) is needed, she would gladly welcome the help of a specialized service in making decisions for her son. She believes that the state should be interested in helping its citizens, especially the disabled persons. It would be nice for both parents and people with disabilities to have SDM service. Veronica thinks that there should be a manager or an assistant, who provides all types of information to people with disability and their parents. The assistant will empower them to seek and get support in making decisions.

Veronica's son had financial problems: he had to pay off his debts. When Arnas could no longer deal with the bailiffs himself, he turned to his mother for help. After a talk with his mother, Arnas realized how he could solve his financial problems. Arnas limited his needs, covered part of the debt and began to pay off the debt regularly.

Arnas consulted with his mother about the situation and felt responsible for his actions. Veronica is pleased that Arnas is asking for her advice. Other people help Arnas a lot, he consults with his sister, sometimes asks his friends for support. Arnas also helps his friends to find information, and shares his experience in decision-making with them. From the childhood of her son Veronica tried to do everything together in order to give her son a life experience. Veronica thinks that it was very helpful for Arnas. He shaped his life model in accordance with his mother's model of behaviour. Sometimes Arnas does not listen to his mother's advice, after that he regrets. In youth, everyone can make mistakes, it is important for a person to understand and be able to correct them. It's great that Arnas understands his mistakes and tries not to repeat anymore.

## Description of stories with supporters of service users

Key words: special needs, choice

### Story one

Daiva, a 54-year-old woman, a psychologist, and a social worker; Daiva works in the social field for 13 years. At present she works at the day occupation center for young people with special learning needs. Daiva organizes occupation and leisure activities for persons with intellectual disabilities, provides social and psychological assistance services at home, and

conducts training for specialists. Daiva has not participated in training on supported decision making (SDM).

Daiva believes that people with special learning needs can make their own decisions. If the level of a person's intelligence and physical abilities allow, they can make the right decision choosing from several options. About the barriers and facilitation of decision-making, Dalia says it is easier to make a decision if a person knows and understands his abilities. When it is difficult to do some things independently, other people can help; for example, a person in a wheelchair definitely needs help. People with mild disabilities can really do a lot. The SDM service strengthens their capacity. Daiva tells about a young girl with special learning needs attending the family support centre. She makes presentations for the conferences with the help of the assistant even though she has speech difficulties.

Persons with disabilities want to do something by themselves. Here is one of the cases in the day occupation center: a girl asked for help in tidying up the kitchen. She was told to sweep the floor and she did it. Then she decided to make coffee and did it. She often needs help and she is always happy with her achievements.

Daiva says it is ideal when a person is healthy and independent. But as much assistance as possible should be provided in the case of physical and mental disabilities (setting up ramps, using easy-to-read language, applying a variety of educational methods). Daiva often consults parents of children with special needs on various issues when they need support in making decisions: managing children's anger, dealing with sexual problems of their teenagers, etc. Occupation in the Family Support Center helps children with severe disabilities to reveal their talents. Daiva emphasizes that a person with disability must show initiative in choosing an activity.

Daiva described the case of her support to a visually impaired girl, who wanted to invite a priest to the centre. The staff of the center helped to contact the priest and arranged his arrival. The priest came to the center, interacted with all the visitors and the staff. Thus, the girl's dream came true. Everyone was happy with the cordial communication and the girl's self-esteem was greatly strengthened.

## Story two

Asta, a 39-year-old woman, the manager, provides assistance to people with special learning needs in the day occupation center for one year. She has not participated in the training on the supported decision-making service.

Asta was asked whether people with special learning needs make their own decisions. She says that it is necessary to understand the meaning of the words “their own“ in this context. Even healthy people sometimes cannot make an independent decision. People get knowledge from books, from the people around, from various sources of information. The same is about people with special learning needs; they should have enough knowledge and understanding about decision making. A person with a disability must be aware that some steps should be taken to make the right decision. If tasks are given, for example, to build a house, it is necessary to explain what type of work should be done. Then a person with special learning needs can understand what type of work to fulfil. People with special learning needs often want to make decisions but, in many cases, they are unable to assess their abilities or they do not want to make any decision. It depends on the form of disability.

SDM can be influenced by the environment and parents, who sometimes take excessive care of them. At the same time the family facilitates decision-making. Their disabled child is a full-fledged person with his inspirations. Asta read the United Nations Convention on the Rights of Persons with Disabilities, but she did not delve into the provisions of the convention. She says that a person with special needs must have a choice between several possible options. Ideally, he must know and understand the consequences of the decision and, in the event of failure, should be able to understand and correct mistakes.

As for support for a person with special learning needs in decision-making, Asta says it is her every-day responsibility, even though it seems like a simple decision. It is easy for one person to ride in a wheelchair, and it is a huge feat for another one. One visitor of the center, sitting in a wheelchair, could not control the wheelchair himself due to hand spastic problems. He needed constant help. Physical therapy exercises had good results: the arm muscles strengthened, the guy began to move his arm purposefully and gradually controlled the wheelchair. Now the guy feels great pleasure riding in a wheelchair.

### Story three

Maria, a 61-year-old woman, has a higher education, 15 years of experience in providing assistance, day occupation activities and care services to people with special learning needs over 21. She has not participated in the training on the supported decision making (SDM).

Maria says that young people with special learning needs have a lot of inspiration. It is necessary to explain to each client what should be done to make a decision, to direct their inspiration to the correct direction. For example, meeting with the president is possible, but one must know what steps should be taken to achieve this goal. Among the clients of the

centre there was one young guy who took photos with the President of the Republic of Lithuania. At first the guard did not allow him to take photos, but after the President asked about his dream, the guard allowed to take pictures with the President. In the centre there are clients who dream of politics. It takes a lot of time to explain that such ambition is difficult to implement, one needs a lot of knowledge and trust of voters to become a president. Sometimes great ambition is a hindrance because young people with disabilities are not able to overcome it. It is important if the people around act favourably towards them, are eager to help, or vice versa.

Maria thinks that the ideal SDM service would be the presence of an assistant who could provide information to a person with disability and parents.

Maria tells the story about Jane, who lived in the village and did not visit any institution. Jane moved to her sister in the city after her mother's death. It was difficult for her to join the team of the day occupation centre that she started to attend. She did not want to participate in any activities, used swear words, she was "her own director". Finally, Jane had to decide whether she attends the centre or stays at home. After the girl got better acquainted with other clients and got used to social workers, she became interested in the activities and her peers. She is sure in her safety and understands that nobody would hurt her; her sister got the opportunity to work. Jane is happy about her decision.

## COMMENTS ON THE STORIES

Vida Dausgurdyte, social worker, psychologist.

- The supported decision making (SDM) service is usually a long-term process involving many people: social workers, specialists in education and employment, legal experts, family members of people with special learning needs.
- People with special learning needs are vulnerable because of the many barriers they face: attitudinal, physical, mental and financial. Sometimes dishonest individuals, especially those with opportunities to influence, exploit the needs of these people for their own selfish use.
- People with special learning needs must learn to live independently. They need constant help in making decisions. A person becomes independent only when he learns and is able to choose. The person must grow out of the position of an "eternal child", if the complexity of the disability allows. The SDM service enables him to be more independent.

- The SDM service would be very useful in complex, dangerous, situations where the disabled person has to understand and change his common behaviour.
- It is very important to combine available and incoming resources in provision of the SDM service for the benefit of the disabled person. It is necessary to ensure promotion and support of social workers and their professional development. It is necessary to seek to increase the available and received benefits in several ways.
- It is important to listen to the person with disability; a respectful relationship between the carer and the counsellor is essential.
- The society must be interested in ensuring safety and protection from any exploitation of all its members. The society must be interested in legitimizing the SDM service.

## BEST PRACTICES. DESCRIPTION OF STORIES.



### NORTH MACEDONIA

#### The current situation with supported decision making (SDM) in North Macedonia

In North Macedonia, supported decision-making as a form of support for people with intellectual disabilities has not yet been developed. Professionals working with people with intellectual disabilities (ID) don't have the appropriate training to properly guide people with intellectual disabilities in the process of SDM. Currently, some non-governmental organizations are working on self-advocacy for people with disabilities, but without adequate systemic support, everything comes down to short-term projects that don't achieve the ultimate goal. Also, a big problem is that parents of people with ID, due to exercise of certain rights from social protection and the fear of being manipulated and abused after their death, deprive them of their legal capacity, so people with ID are not legally entitled to make decisions about their life.

#### The research team of the case study interviews

- Frosina Simonovska, Special Educator, Aktivum
- Boban Popovski, IT specialist – Teacher, Aktivum
- Svetlana Dimitirevska, Social Worker, Aktivum

#### Procedure on carrying out the interviews

The interviews covered 9 people: 3 people with intellectual disabilities, 3 members of their families and 3 professionals who work with them in the services.

The interviews were conducted online due to the pandemic situation and each of the interviewees signed a consent form to participate in the interview.

The interviews covered 3 areas: education, employment and relationships.

## Description of stories

### Story One

keywords: education

#### Service user

"I am 18 years old and I was born as a person with hemiparesis. Since I know about myself, the decisions in my life were made by the people around me but not me. Where would I go see a doctor, who would be my teacher, who could be my friend and even the clothes I wore were bought by others and they decided what to wear to look decent "- this is how XX started his story. But things changed when I had to go to high school. My parents insisted that I attend a special high school, but I decided to enrol in a regular school, it was the first decision I made personally, and it concerned me and my life. And believe me, it was not easy at all to convince my parents - says XX. At school, my friends and teachers welcome me and are helping me when I have a problem and I also get support from my parents.

#### Parents

XX's mother, who is an accountant at the age of 40, thinks that she and her husband are too protective of their son. „The stereotypes and prejudices that exist about people with disabilities have led them to take a protective attitude and make decisions on behalf of their son," the mother said. She now believes that their son has made the right decision to enrol in a regular school where she is a part of the whole educational process by participating in the development of her child's individual education program (IEP). She and her husband support their son in making his own decisions, although they do not always agree with them (laughs) ... I am a parent, in the end, I just want my child to be happy and fulfilled.

#### Supporters

The professional with 9 years of experience, thinks that we unconsciously take away the legal status of the individual, knowing to say "This person is not able to make decisions on his own and we (professionals) will appoint someone else to make decisions for him. One of the most difficult decisions a family has to make is choosing the type of education for the person with disability. In most cases, the family consults with professionals on how to support

the person and after that they are making the final decision. As a barrier to the SDM process it is considered to be fear of change, inadequate support, lack of resources in schools, lack of information, fear of failure and as facilitators in the decision-making process are: the support that the family receives, information about their rights and responsibilities in the educational process, confidentiality and discretion.

## Story Two

keywords: employment

### Service user

PI is a person with an intellectual disability, he is 43 years old and lives with his family. He has completed high school and is currently studying at one of our faculties. Works in a factory as a production operator.

"I make the decisions in my life on my own, I have decided that I want to work - he says, but when a quick immediate decision is needed, sometimes I make mistakes. Therefore, in certain situations he consults with his mother and sisters but he also knows how to listen and accept opinions from friends. When it comes to work, he usually consults with his colleagues about the work process itself.

### Parents

His sister is employed as a philologist and she is 40 years old. She believes that her brother makes decisions on his own, but when needed, he mostly consults with his family because when it comes to getting support from other people, he rarely gets support due to the absence of a quality social life. "I give my support through conversation, discussion, joint consideration of all aspects of a problem or need," she said. Her brother needs constant support and encouragement from services that would help him make some decisions on his own supported by greater confidence. She is aware of the prejudices that exist towards these people in terms of employment, even when they are employed, prejudices are an obstacle for their progress in the work, as if there is no hearing about their potentials and those conditions pull her brother into the shadows, into a retreat and depression.

### Supporters

According to the professional who has many years of experience, the optimal and most ideal service of supported decision making would refer to organizing workshops, various trainings on this topic, psychosocial support from professionals, to work continuously with these people to know how to represent themselves and to make decisions independently. An

important aspect here emphasizes the need for mentoring and constant support in professional work. Giving support in a situation where there is a problem in the workplace goes in the direction of finding a compromise and considering aspects from both sides by the employee/his family and the employer.

## Story Three

keywords: relationships

### Service user

AK is a person with mild intellectual disability, he is 27 years old and lives with his family. He thinks that he makes the decisions in his life alone. Decision support is often sought from his family for matters and issues that he says are common and affect the whole family. Advises friends on some not-so-important decisions. AK: "I have very few real friends I can trust or ask for advice when I am making decisions." The most important decision he has made in the last period is the decision to get engaged to his girlfriend, because he thinks it is time to dedicate himself to his own family.

### Parents

His mother, who is a housewife and is about 60 years old, says that her son is very spoiled and that to some extent he has the main say in the family. Decisions are usually made by him alone, sometimes he knows to consult with her, she advises and guides him, but despite his independence, she notices a suggestibility due to which he easily falls under the influence of others. The mother says: "the environment greatly influences his decision-making and abuses his condition as a person with a disability." The family gives great support to the relationship with the fiancée and this was a decision of the family for him to be engaged and to have a life partner, as a kind of security.

### Supporters

According to the professional with 17 years of experience, in her work with people with disabilities there are situations where she provided support and consultation for decision making at the request of the other party, i.e. at the request of people with intellectual disabilities and their families. When it comes to relationships or marriage, people with disabilities are often abused in relation to this issue. And because of that there is a need for psychosocial support, workshops on the topic of reproductive health. There is still a taboo topic for relationships and there are still barriers – she says. Support in the presence of barriers consists in conversation, proper consideration of a particular situation together with

the person and his family and always strives to prevent certain deviant behaviour in a relationship.

## COMMENTS ON THE STORIES

[Lawyer comment: Snezana Sazdevska, lawyer](#)

The Republic of North Macedonia has ratified the Convention on the Rights of Persons with Disabilities, which through Articles 23, 24 and 27 guarantees the right to respect for home and family, the right to education and the right to work and employment. According to the Family Law (Article 18), persons who are classified as persons with mild or with moderate intellectual disabilities, as well as persons with severe inherited diseases in the family, can marry after obtaining an opinion about the genetic construction issued by the relevant institution. While marriage can't be concluded by persons with intellectual disability who belong to the group of persons with severe and profound intellectual disability IQ below 36. The Law on Child Protection provides an opportunity to include children with disabilities in kindergartens and according to the Law on Primary and Secondary Education, primary and secondary education is compulsory for every citizen, under equal conditions determined by these laws. A novelty in the educational process in RNM is that from September 2021 starts fully inclusive education in schools. The Constitution of RNM through Article 32 guarantees the right to work of every citizen in the country. The employment of persons with disabilities in RNM is also regulated by the Law on Employment of Disabled Persons. This law provides employment of persons with disabilities in sheltered companies and on the open labor market. The measures for improving the employment and working conditions of a disabled person according to the law refer to the granting of non-refundable funds, adaptation of the workplace as well as tax exemption for companies.

[Psychologist comment: Daniela Nedelkova master of psychology from Chamber of Psychologist of the Republic of North Macedonia](#)

From the conducted interviews it can be concluded that most people with intellectual disabilities live in a community with primary families. People with intellectual disabilities receive the greatest support in the SDM process from the members of those families. At the same time, it can be concluded that the individual model of self-advocacy is exclusively represented versus the group model of self-advocacy. Interviews indicate that people with intellectual disabilities are less likely to turn to relatives, friends or colleagues in SDM process. There is an impression that the interviewees gave socially desirable answers

because they emphasize that people with intellectual disabilities make their own decisions. In order to ensure the effective practice of independence and inclusion in the community of persons with intellectual disabilities, it is necessary for them to be informed about their rights, to be encouraged to know themselves (desires, needs, interests), to develop decision-making skills and where it is of particular importance to be allowed to make mistakes (wrong choices). In practice, SDM is no different from the usual way adults make decisions. Family life, friends or educated professionals are involved in making important life decisions. SDM will not only offer people to acquire certain skills and knowledge but can continuously have the effect of building a positive self-image, a sense of belonging to the group or community and life satisfaction.

## BEST PRACTICES. DESCRIPTION OF STORIES.



**POLAND**

### **The current situation with supported decision making (SDM) in Poland**

Poland ratified the UN Convention on the Rights of Persons with Disabilities in 2012. Since then, non-governmental organizations acting for the benefit of people with disabilities have put a great effort into disseminating the idea and implementing the provisions of the Convention. As a result of these efforts, the Convention, including Chapter 12 on assisted decision-making, is known in the relevant circles. Unfortunately, only here; this is not a widely known approach. At the same time, the practice of supported decision-making by people with intellectual disabilities is far from ideal.

The first barrier in use by these persons, the right to decide, the legal capacity and the right to support are the forms of legal acts in force in Poland. For most matters, a written form with a handwritten signature of the stakeholder is required.

The second barrier is the frequent cases of questioning such a person's statements and judging them as invalid. It is primarily about questioning a person's consciousness. It is recognized that people with intellectual disabilities are not aware of what they are doing and therefore their declaration of will is not valid.

Also, the awareness of the society about the rights of people with intellectual disabilities to decide about their lives and to be supported is still very low.

It should be noted that this topic very rarely appears as a topic of workshops or lectures. There are practically no materials and a shortage of experienced trainers. And the demand for such activities among therapists and people with intellectual disabilities is growing every year.

### **The research team of the case study interviews**

Studies' authors are:

- Katarzyna Janiszewska
- Dawid Klein
- Anna Kwiatkowska
- Katarzyna Tulik
- Urszula Wojciechowska
- Katarzyna Wrona

## Story 1

keywords: independent leaving, relationships

### Service user

Mrs X, a 37-year-old woman, with moderate significant intellectual disability, graduated from vocational school with hotelier specialization, lives with husband in Tarnow city, in another apartment, as roommates, brother tenant, is a participant of the Occupational Therapy Center (OTC).

Mrs X believes that she is an individual decision-maker. She made an important and difficult decision to put her daughter up for adoption right after giving birth. Her husband and therapists from OTC support her in making decisions. Therapists from OTC help with everyday shopping, in choosing the right technique of work, she makes constant conversations with them, can confide in them and trust them. She would like these people to help in making decisions about housing matters, matters of everyday life (cleaning, cooking, image change).

After the age of 30, Mrs X became pregnant. At first, everything was fine, but later a sensorimotor disease, polyneuropathy, appeared. She suffered from numbness in her hands, weakness in her entire body.

She had to learn to walk again. (Mrs X cries during the interview). During pregnancy, Mrs X fell into a coma, for three days it was impossible to fully wake her up. The pregnancy was at risk and a decision was made to perform a caesarean section. When she was strong enough, she was taken to her daughter to see her. When she saw her, she cried with happiness. The Municipal Social Welfare Center and the hospital staff believed that she couldn't look after the child. Mrs X lost her speech during this time. She had no influence on this decision. The decision was made by a probation officer and the child was taken away. During this time, Mrs X did not ask anyone for support. Only her husband supported her.

The decision to adopt and prohibit contact was made behind Mrs X's back. She would love to see her daughter. She is curious about what she looks like now and what she is doing, what family she is in.

She thinks it is good. She wouldn't be able to take care of the baby. She is glad her daughter is there, but she also misses her. She feels that she has relinquished responsibility for the child. She let go because she didn't want to get tired. She hopes that the child will be raised and educated.

After returning home from the hospital, Mrs X underwent severe rehabilitation. She lived with her mother and husband. Her mom passed away a few years ago. There are a lot of loans taken for Mrs X. She took these loans voluntarily and to this day she's paying them back. They are both afraid of another pregnancy. Mrs X received a new bailiff's summons for PLN 10,000 because she was unable to pay bills online.

### Family member - husband

Mr X is a 40-year-old man, 16 years the husband of Mrs X, who graduated from primary school.

Mr X believes that both spouses are independent. They live together. For financial reasons, they do not go to the cinema or go on holiday. During the week, Mr X takes his wife to the bus stop every morning when he goes to OTC and picks her up in the afternoon. During her absence, he does housekeep at home, cook's dinner and does the shopping. Sometimes he gets a part-time job. He spends weekends at home with his wife. He would like to work but is afraid of losing his benefits.

His wife receives support in making decisions from the OTC therapists he attends. Neither he nor his wife have been trained in decision-making, nor do they know the law on making independent decisions by people with disabilities.

Mr X advises his wife on cooking, cleaning and washing and believes that it is certainly positive for her. They both do not want help, advice, support in making decisions from the Municipal Social Welfare Center. Mr X describes the people representing this institution as foreign and makes it clear that they do not want them. However, they have a lot of confidence in OTC therapists. They expect the therapists to help maintain a council flat, and that they will help in everyday life, e.g., in managing money, keeping the house clean, cooking.

Mr X met his wife during a rehabilitation camp at the seaside. They moved in with the wife's mother, they did not work, the loans were enough. At the moment they have debts, they have to be paid. The wife was pregnant, she fell ill and Mr X had to tell the doctor what to do with the baby next. The hospital took the case to court, the probation officer came for an interview, asked what the conditions and income were, and he walked around the neighbourhood. A letter was sent to the court for deprivation of parental authority. And that's all. He believes that they made the right decision because they would not be able to raise her. Throughout the process, Mr X supported his wife and declared that he will continue to support her. The wife asks for help at every step, they discuss all the problems together.

## Supporter

42-year-old woman, therapist, having 16 years of experience in supporting persons with intellectual disability in the fields of occupational therapy and speech therapy, never has had any SDM training.

Making own decisions by persons with intellectual disability depends on the level of disability, on the functioning of the disabled person in the environment. Generally, people with disabilities make a decision and want it.

The level of disability is of great importance, but also the lack of support from a person who would help make the right decision. Often, other various diseases prevent a disabled person from making a decision. There is also a problem with the consequences. These people are often unaware of the consequences. For example, they are not aware that what they are doing will result in debt and financial consequences. They don't come for help at the right time.

Sometimes the incredible spontaneity of these people causes making decisions easier. There is no reflection, no logical thinking, it is spontaneous. It is certainly easier when there is someone who will give you good advice and support. Then the decision is definitely better.

I know that making your own decisions is a right recognized by the United Nations in the UN Convention on the Rights of Persons with Disabilities. Somewhere in one of the training sessions, it was mentioned. And also, I know that SDM is a service that favours the performance of legal activities of disabled persons, because in our OTC there was a girl who applied for the inheritance and was supported in it.

In my opinion, the ideal decision support system would have to be multifaceted from every angle. This person should be supported by a psychologist, lawyer, occupational therapist,

and in some cases a psychiatrist. If there is a family, then the decision-making person in the family should also be included. I believe it is important to discuss the problem as a team.

I had and every day I have the opportunity to support a decision made by a person with special needs. We are trying to get the apartment in which the interviewed couple lives out of debt. We're trying to get the husband a job. We support them all the time. These people are asking for help themselves. But if there is something uncomfortable, they decline the offer. This may be the case with a job offer.

At every step I consult decisions with family or supporters. I will not do anything with the OTC participant until the family agrees to it, regardless of whether they are incapacitated or not.

## Story 2

keywords: IT, accessibility to services

### Service user

Mr Y is 27-year-old man with significant intellectual disability, graduated from vocational school, has good IT skills, lives in a big city in a flat with parents, is a participant of a multimedia workshop.

Mr Y admits that he is unlikely to make his own decisions. Recently, however, he managed to decide to pay the bills himself. Usually, he is helped by his parents and his brother. According to Mr Y, he prefers their advice because they have taught him it from childhood. Mr Y emphasised that they do it like good friends. He is satisfied with the way the support is provided but would like to start taking care of his own money.

Mr Y once posted a video online when he was in a band. Hateful comments about his image appeared under the video. As he admits, he fell victim to hate. He decided not to leave the situation like that. First, he showed his father, then his brother, the comments under the video. At first, he did not know what to do with it, so he asked for the support of his father and brother from whom he had received it. He consulted his dad, who warned the persecutors. Then his brother took care of it. He explained not to upload material himself. He then himself took care of the next steps involving drawing the consequences of the persecutors. Andrzej was pleased with the support provided. The persecutor was held responsible for their actions.

### Family member - mother

66-year-old woman, with no professional experience in supporting persons with intellectual disability but supporting son for 27 years

According to the respondent, her son does not make his own decisions. In making decisions, he is supported by his family (parents and brothers) and only them.

No one has ever attended any decision-making training. The mother does not know the law on making independent decisions by people with disabilities. She had the Convention in her hands, but she hadn't read it.

According to her, independent decision-making has a negative impact on Mr Y. You have to undo everything after him.

In the future, when the parents are gone, decision support services will be good for the son. The mother would like it to take the form of meetings where it will be calmly explained to her son what consequences he may suffer. Mr Y must have time to understand. Maybe some workshops would be a good idea.

The son reports his problems most often when the mother notices something and asks. The son considers himself an adult. According to the mother, however, he must be controlled due to various situations. For example, he reveals details of trips to strangers or provides personal data on social networks. Because of that, the family controls his actions.

The decision to help with online harassment came from his son. The siblings were in control of their brother's social media at all times. When he asked for help, they had already known something was happening. However, they waited until the son himself asked for help in this situation. The comments hurt him, and then he confided. Her husband and her second son with his wife supported him. They tracked down the perpetrator and communicated with him. It was fit for reporting to the police. Mr Y was not involved in the course of events. The family took care of everything themselves. They reminded him afterwards not to do such stupid things. Now they don't go back to that situation anymore.

## Supporter

32-year-old man, therapist, has been working as therapist in Occupational Therapy Workshop for 7 years, no SDM training.

Persons with special needs make their own decisions at a basic level. If they are to decide on things that really affect their lives, they are often blocked by their overprotective parents. After the death of their parents, these people are very often transferred to nursing homes or retirement centres, where they have no influence on their lives. They want to make decisions, but in my opinion, their parents tell them that the consequences of making decisions will be so great that they will not be able to bear them. In my opinion, they should try the

consequences of decisions several times, because if they are told all the time that they will not be able to handle the consequences, they will never take the risk. So, parents are kind of an obstacle, because they leave no room for mistakes. And it is facilitated by situations when these people are temporarily separated from their parents, for example, trips lasting several days. Parents lose some control in favour of therapists who are prepared to let disabled people make their own decisions.

They allow that person to make a decision and face the consequences. I know the UN conventions and the right of people with disabilities to make their own decisions. Following I'm convinced this service is also conducive to the performance of legal actions. I think that especially if siblings fail to fulfil their obligations to their parents, such a service would be very valuable, could solve many problems. It may be that they will not have any formal right to stay in this apartment and that they will find themselves in the institution.

An ideal service of supported decision making should be a place where there will be a psychologist supporting the activities. I think that it is also worth including people who work with people with disabilities daily so that these people feel that this is not an official situation, but an extension of what they do in workshops daily.

I had some situations where I supported decisions made by persons with disabilities.

These were 2 cases of people who for a long, long time were asking their parents to open an account. The parents believed that since they had a card for their account, they had a joint account, there was no need for that. These people asked me for help in the realization of their decisions.

I spoke to the parents and told them what decisions the participants had made. There was resistance, especially from one of the mothers. In the second case, the mother was happy. Now she even transfers this person some amount. So, we went to the bank together and now they are happy users of their bank accounts and they can pay by contactless card or fast online transfers. And I can see a chain reaction - suddenly other people from the workshop also want their own accounts. Because there is resistance to telling parents that they want to be independent. Concerning the story described above I learned it later on another occasion. I got to know the brother's perspective, and the parents gave just this example when this person had similar problems again. At one point he was cut off from this situation, although I do not know what the motivations for this decision were.

## Story 3

keywords: independent living

Service user

Ms Z. is 38-year-old woman with medium intellectual disability, graduated from college, using IT tools with a help from supporters, lives on her own in a big city, employed as a cleaning staff at the swimming pool

Ms Z. claims that it is different with her decision-making - as for the scale. She believes that she makes her own decisions, although it is sometimes difficult. In everyday life, for example, she does the shopping herself. Sometimes she cannot decide what to buy. But she doesn't give up easily. She does not call her mom. Mom is the last lifebuoy. Sometimes, although she is afraid, she asks the staff in the store. If she wants to buy a piece of clothing - then her niece goes with her and she advises. She recently made a decision about the cat. She took him to the vet. With the cat it was the hardest case, she was afraid that she may harm her during the visit.

Sometimes she looks for information on the internet when she wants to know something. If she cannot do it, her nephew or brother-in-law helps her. When it comes to deciding what to buy online, she doesn't trust the sizes. She benefits from the support of her niece (12 years old).

The sister, and more often the mother, helps in making decisions. Nephew too.

The decision of an independent apartment was partially Ms. Z. and partially her mother's. Ms. Z. was not afraid. She thinks her sister was more afraid that she would cry. Now sometimes she cannot be pulled out of the house. She is pleased with this decision. She's a home-bird. She is also satisfied with the decision to work.

She also decides how to spend the weekends off. She goes alone to the Old Town in Warsaw. She loves this place.

Sometimes she doesn't want to go to club meetings, but the girls envy her that she goes to various interesting places with clubs for free. So she tries to go.

### Family member – mother

Mother is 63-year-old woman, supporting daughter for 38 years, with no professional experience in the field and with no trainings on SDM

It had already started before the divorce. Division of assets. The purchase of an apartment was considered. Mom was sure that she would live with her daughter, but it was the daughter who started to whim that maybe she could live alone. It was something abstract for the mother. But the daughter, after training in sheltered flats, said that she could do everything

herself: cook, clean and everything! In the beginning, the mother used to visit Ms Z. every day to check. In 2021, it will be 7 years for her to live there.

After these experiences, the mother feels that the child should live alone if only given the opportunity. It is known that there will be no parents one day and these persons have to cope on their own. And in the beginning, it might be a hardship, but... this is the best solution.

Ms Z. can make bank transfers, she pays the bills herself. She makes appointments with doctors, informs the employer when she is on sick leave. Mom believes that she should also file a tax return herself and remember the deadlines.

There are problems with the cat now. The cat is adopted and has been abused by its last owner. Now it honours only Ms Z. Ms Z. noticed that the cat was behaving strangely and took it to the vet. At the vet, she took great care of it, kept it on her lap, even though her mother was next to her.

Does she make her own decisions? Sometimes mother and daughter do not agree, but the mother doesn't make her do anything, just advises, says that she would do something differently. That was the case with the apartment. The daughter pushed with this so that it would be as she wants. Her mother supports her all the time. The immediate family also helps - her sister, her husband, niece, nephew. Ms Z. asks for support, discusses the problems. Work Clubs are also helpful, in which many topics are talked about, as support.

Decision-making sometimes had negative consequences. Of course, there are sometimes wrong decisions. But the decisions taken by Ms Z. have a positive effect on her because even if they are bad, it still is a lesson.

The optimal service of supported decision-making helps the respondent to achieve her intended goal. But first, this goal must be reasonably defined.

## Supporter

35-year-old man, job coach with 10 years of experience in the field of professional activation, no SDM training.

I think that people with intellectual disability do make their own decisions, although they often have concerns and try to consult their decisions with family and friends because they think that the decision may be wrong and harmful. They want to, but are not quite sure if they're acting right, what will be the consequences of their decisions.

These are the main concerns: will the decision be right and will they manage afterwards. Just like people with no disability.

I encouraged Ms Z. to not be afraid to make a decision. I gave her examples from my own life that I also have this type of fear.

As a job trainer, I have been supporting Ms Z. for a year. She was not immediately convinced of me, it had to be a month before we started working on our decision to take up a job.

SDM is something intuitive. When I am in a relationship with a participant, they naturally turn to me for advice. Certainly, support and understanding from the loved ones makes it easier. In the case of Mrs Z's mother, who gave her a feeling that she is an adult and that it is her decision. Ms Z. was helped by the awareness that her mother would not criticize her. She also struggles with self-confidence. Ms Z. emphasized that the relationship with her father was her serious problem, that his alcoholism influenced her self-insecurity. So, family relationships have a big impact.

Another difficulty can be the fear of negative consequences.

I know that making your own decisions is a right recognized by the United Nations in the United Nations Convention on the Rights of Persons with Disabilities. Every adult person has the right to make decisions.

I often have the opportunity to support a decision made by a person with special needs. The most important thing is to talk. The question of what you need, what you know, what you like - their preferences, interests, skills, or what they would like to learn. I'm talking about decision-making about work, but not only.

At work Ms Z. was very happy but only scared of a new machine. I said that nobody at the beginning can do something, they have to get familiar with it. I try to build self-confidence in people. She was very bothered when she made mistakes. I supported her saying that it was normal at first.

The idea of an independent apartment for Ms Z. came up through her sister, who told their mother that she will not live forever, and then what will happen to Ms Z. Her sister believed in her, and her mother initially had concerns. However, they are incredibly open-minded people. I remember that Ms Z. was very scared at first, she had many doubts like organizing time and life.

They agreed with mother that the mother will be doing fees because Ms Z. said she has concerns someone can deceive her because she doesn't know the value of coins and banknotes. But she does the shopping. I showed her where and how to do it.

When she was concerned that she would come home and be alone, we made a list of things to do at the time. Due to the conversations, she came up with the idea that she could have a cat for her loneliness.

There was a lot of maturity in these decisions. Currently, Ms Z. said that she would never like to return to her mother and that it was a very good decision.

## COMMENTS ON THE STORIES

[Katarzyna Janiszewska, psychologist](#)

Based on the interviews, I can state how important it is to implement the SDM (Supported Decision Making) program for people with intellectual disability, which should cover not only these people, but also their families. I estimate that the change of mentality will be a long-term and individually effective process. Although these are undoubtedly difficult activities, they are possible and necessary if we care about the good of these people. Contemporary psychological knowledge emphasizes the importance of the need to influence as one of the key human needs conditioning his development and happiness.

Here are the conclusions of the interviews:

Person X reports the need for WPD. She made decisions with dramatic consequences, including taking the child away and having to pay back gigantic amounts of loans. This is an example of how the lack of preparation to apply the right to make independent decisions can have irreversible consequences for the existence of the person with intellectual disability and his/her relatives.

The attitude in Mr. Y's family is an example of the lack of awareness and, consequently, of the lack of respect for the Convention law on making independent decisions by relatives. I observe camouflaged incapacitation of the person with intellectual disability by assuming that his decisions will only bring problems in the future. The attitude of lack of faith in his abilities and reluctance to educate him towards his rights stems from overprotection and personal comfort.

Person Z is an example of an opportunity that gives respect to close family members for the right to make independent decisions while systematically becoming independent and cooperating with occupational therapy workshop's instructors. The correlation of such an attitude of supporters with the personal development and level of life satisfaction of Person Z (independent living, independent work, own pet, independent spending of free time, social relations) may prove the value of all activities related to SDM.

## **BEST PRACTICES. DESCRIPTION OF STORIES.**



**SPAIN**



**CATALONIA**

### **The current situation with supported decision making (SDM) in Spain & Catalonia**

In Spain and Catalonia, supported decision-making services are not strictly regulated in the legal framework until recently. In May 2021, Spain approved a Civil Code reform abolishing guardianship and representation mechanisms, paving the way to incorporate informal supported decision-making services aside from formal support if the situation requires it. Catalonia, with its own Civil Code, has a voluntary figure called 'Assistance' in which the

person with support needs can designate the person he or she chooses to support him or her in different spheres and that person always has to respect the will and preferences of the individual and never decide on behalf of the person. This figure has been active since 2010 and has an increasing number of users since it entered into force.

## The research team of the case study interviews

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## Description of cases on provision of SDM

Here we describe the state of the art of SDM in Spain and Catalonia through six case-stories. Each story involves the person with disability, his/her parent and his/her direct supporter from a support or assistance service. To show an integrated point of view, the three interviews of every case have been analysed to build a unique narrative story.

### Story 1

**Keywords:** independent living, health, personal finances, social inclusion

#### Mr. Oriol

Mr. Oriol is a 31 years old man. He is a geologist and lives with his parents after he was diagnosed with a psychosocial disability.

Mr. Oriol always wanted to live independently. After finishing his geology degree, he went to Chile, where he contracted various diseases and had to return to Catalonia. After returning, he had no more control over money and his wills, which made it very difficult to find stable work.

Eventually, he was admitted to a specialised centre to receive appropriate treatment to take care of his health needs. He was aware that he needed support and he wanted the personnel of the centre to help him. His goal is to live again independently and learn how to manage his

finances. He would also like to find a job as a geologist, but if this is not possible in the current situation, he is willing to start working at something else.

Mr. Oriol's mother has always been by his side and has tried to help him and support him to rebuild his life track many times, but it has been very difficult for her because her son lied to her and the family many times. Also because of this, she proposed to be supported by the Support-Girona ('assistance') and he accepted.

The social worker – his assistant – who supports him, believes that he is doing giant steps to get back on track, but still far from achieving full independence.

At the moment, the two areas in which Mr. Oriol has more difficulties are finances and social inclusion. In relation to finances Oriol has it very clear, as "for anything I want to do, I first need to have control over my money responsibly". In relation to social inclusion, an area that encompasses having effective relationships, being included as a citizen with your own identity or being aware of your own rights, Oriol highlights that "the problem is that people like me feel excluded from society and it is difficult to change this situation".

On the other hand, the supporter highlights that in health-related issues, the decisions of Oriol are not always respected. As Oriol pointed out, "when health professionals intervene it is often difficult for them to take my decisions into account and accept them. Sometimes I experienced very difficult situations when I was not able to decide things about my health".

## **Story 2**

**Keywords:** mental health; personal finances

### **Ms. Rosa**

Ms. Rosa is a 64 years old lady suffering from epilepsy, depression and a very bad hip problem due to a degenerative disease. She worked as an actress and later on in life she looked after her parents until they died.

Ms. Rosa lives alone in a small flat in the countryside very near to one of her four brothers, who visit her very often. When her parents died, she didn't have enough money to afford an apartment in the city centre, so she asked her brothers to live in an apartment property of the family. They accepted and supported her by lending her money to renew and adapt it.

She is very close to her brothers and for a long period she had to rely on them for taking decisions concerning all the aspects of her life. She is conscious that it was a heavy burden

for them that consumed a lot of their time and energies. In retrospect, when their brothers asked a judge to have professional supervision from her sister, she rationalises that “it was the right decision”. The professional support received at the beginning was focusing on her finances since she had – and still has – just a small pension, and her brothers thought that she was not very good at managing her limited benefits. For instance, “some years ago she bought a very expensive bed, which had to be paid in instalments for years”. Some years ago she suffered from cancer and the surgeon had to remove a breast. Her brothers suggested she visit a surgeon to rebuild it, but she refused and decided not to.

Nowadays, their professional supporters help her in very different situations but always taking into account her will and preferences so the support she receives is very diverse, from taking her to the local market, going to listen to the sea or taking a swim in the beach.

In addition, since the COVID-19 pandemic, she is getting depressed and her motivation to take any kind of decisions about her life is very low. Her brothers are concerned because of that; they would like her sister to do more physical exercise, improve her diet, but she decides to spend all day laying on the bed or on the sofa.

### **Story 3**

**Keywords:** Personal finances

#### **Mr. Antonio**

Mr. Antonio is a 42 years old adult man with a learning disability. He lives in an apartment together with his partner and her two children. He is currently unemployed and is looking for a job in the gardening sector.

Since last year he has been living with his partner. It was a very important decision that he took autonomously, despite his father not really being happy with it. Since then, he is really satisfied and he thinks that it was a very good decision. Mr. Antonio explains that he makes many decisions together with his girlfriend, for instance, they sit together in the kitchen room and they agree on the shopping list before going to the supermarket.

The local court decided that his money had to be managed by a professional supporter. Since then, every time he needs to buy something, especially when shopping online or spending a big chunk of money, he has to ask for their permission. As an example of last month's requests, he asked to subscribe to a streaming service to watch wrestling fights from his mobile phone or to buy a new mountain bike, but in both cases, he was not allowed to buy those things since his personal economy was not at the best moment and he could not

afford it. Instead, his supporters suggested buying a cheaper bike, but he didn't accept because he wanted exactly the one, he asked for. These situations stress Mr. Antonio a lot and he cannot accept that others decide what he can or cannot do with his money. The professional who supports him suggested having a meeting with the accountant to run his finances and look at his savings, but he refused.

When he finds himself in this situation, he receives a call from his father and helps him to calm down. Actually, he suspects that the professionals will get in touch with his father and explain the situation. His father is very satisfied with the organisation who offers support to his son because they help him make decisions with a very transparent process and consider him at all times.

Besides these difficult moments, Mr. Antonio usually has a very good relation with professionals, "even if they should just support me with financial issues, during a quite long period, I also asked to be accompanied to the doctor to not miss a comma and understand my health problems".

## Story 4

Keywords: Social relations

### Mr. Ramon

Mr. Ramon is an adult man of 41 years old with a learning disability, experiencing an obsessive-compulsive disorder. He lives in a residence and a large part of his decisions are taken together with staff from the residence.

He lives in a single room in a residence in the city of Girona and has a part-time job at the laundry of the residence, where he helps sorting out the clothes. Because of the COVID-19 pandemic, he has spent a lot of time in his room, watching TV and playing video games. He decided to buy them before the pandemic after a long time saving and he recognizes that the professionals at the residence are very supportive and always try to find solutions to his demands, for instance, they recently accepted and supported him subscribing to Netflix.

When he needs to buy something, he always relies on professionals at the residence. This situation also applies to online shopping, as he receives support to choose and manage his money. One of his wishes is to buy things without support from professionals or from third persons. They support Mr. Ramon in the process of checking if he really needs something and if he can afford it. Because this process is also done with him, he is very happy to live

there as he makes his own decisions because “in other places where I lived, I was not able to have a say in those things”.

Ramon’s father is not really sure that this is the way to go, for instance when his son doesn’t take care of his appearance, he asks him to wear better clothes or to shave, instead of listening to why his son “wants to wear the clothes he wears”. Ramon gets very nervous when his father does that or when his father doesn’t let him do something but they always get to an agreement since his father buys comics and adventure books for him to compensate and help him relax. Mr. Ramon is very obsessive about some things and one of them is coffee but doctors have limited his intake to only one cup per day instead of the twelve or more cups that he used to drink. He receives a lot of supervision to ensure that this obsession with coffee does not interfere with his daily life, instead he occupies his days reading books, playing games or doing physical activity.

Some years ago, Mr. Ramon had a girlfriend who lived in another residence and the personnel of his residence and his father helped him to visit her. Unfortunately, she moved to another city and later on she died. Ramon suffered a lot for this event, but now is actively looking for another partner, even if it is very difficult to find a girl that loves him and love back.

Professionals say that he is very insistent in his relations with women, and usually, they have to go with Mr. Ramon when he walks in the street to prevent him from stopping all the women who come across on the street to chat and try to seduce them. He receives a lot of support from professionals in order to make him respect women and to increase his awareness of what is appropriate to do or say to women and what is not.

Related to Mr. Ramon’s health, he always attends visits accompanied by professionals from the residence and he is satisfied with this fact. During the pandemic, he went to the hospital quite often but luckily, he didn’t get the virus.

## **Story 5**

**Keywords:** family relations; personal finances; independent living, use of technology.

### **Mr. Pere**

Mr. Pere is a 29 years old man experiencing a psychosocial disability, and more concretely a schizophrenic disorder. He lives independently in a rental flat with two mates. Mr. Pere receives almost daily support from professionals who help us do tasks and household activities.

Mr. Pere has been living in the City of Girona for about 9 years. Previously he had been living in a hostel and in the psychiatric hospital, where he was living for a long period of time. After that, his doctor released him from the acute unit since the “voices he hears were not affecting him as much as in the beginning”. Prior to his hospitalization, Mr. Pere was living with his grandmother, as her mother also is a person with a psychosocial disability, and the relationship between them was toxic, causing him to drop out early from college. Her mother was not able to support and take care of him.

Mr. Pere receives support from professionals who help him manage his finances and to supervise his health. In the beginning, the professionals had to accompany him to visit the psychiatrist, but now he is more skilled and is able to do it by himself; supporters just have to remind him about the appointments.

Professionals have been very supportive and empathetic with his situation. For example, when Mr. Pere wants to visit his mother, despite knowing that when he visits her, the chances of “hearing voices again” increase on his return. His supporters help him with the logistics of organizing his visits and supervise if his mother is a good influence for him and situations that are not positive for Mr. Pere don’t come again.

Mr. Pere is able to make decisions on his own in a lot of aspects. For example, deciding what to do in his leisure time and the activities he wants to do. Usually, he likes to watch TV and play videogames but now as he is getting older, he decided to try to get a job and in the last months he has been doing interviews with an organization that works in employment inclusion and he hopes to get hired by them so he can earn money to increase his quality of life as he lives independently and things are expensive.

Mr. Pere frequently asks his supporters for help using his smartphone as he is afraid of getting scammed over the phone, particularly when using the internet and downloading applications. He is very cautious about the use of social media too.

## Story 6

Keywords: finances

### Mr. Joan

Joan is an adult man of 53 years old with a learning disability living independently in his own rented flat. He has a good relationship with his flatmates and he is a very active man.

Joan likes living independently in his own flat. It's been a long time since he was living with his sister, a time he remembers fondly. Despite that, he doesn't hesitate to say he's better now. They have a good relationship, but they live independent lives, and he doesn't ask her or his family for any advice. His sister used to support him for nine years, but she realized he listens better to someone from outside the family environment. He likes living with a flatmate, who has become his 'little brother' as he usually helps him make decisions when in need.

Joan is very proud of having decided by himself the person with whom he shares his flat. Also, Joan is passionate about cycling, an activity he likes to practice almost daily. He likes repairing his own bicycle as he's a very handy man, despite needing support from time to time. He's very happy about the support he receives from his supporters as they support him in making decisions about his personal finances, something that he recognizes that he needs as he's not very educated about.

He likes going every day to work, where aside from having an important role in a manufacturing workshop he learns how to use computers, the internet, and new technologies. Mr. Joan has been confident lately using new technologies and he has learned how to use mobile applications in order to buy second-hand products, mainly related to the fact that he decides almost every month to buy new components to upgrade his bike. He's very proud of that learning and he refers that at the beginning he received support as he was not as confident to exchange money with strangers face to face alone, so he was always doing deals accompanied by his supporters. Now he is able to do it independently, and he requires minimal support.

He has received support from professionals for a long time, but it's him know who asks for this support in the parts of his life in which he needs it: finances, healthcare, informatics, and relationships. When it comes to making decisions, Joan is the one who takes them, he does ask supporters to help him, but they respect his decisions, such as buying new components for his bike. He has a strong bond with the professionals he's supported by and he is confident to tell them the things that are important to him when he needs them. He says he will be always grateful to them as they supported him when one of his best friends suddenly left this world.

## **COMMENTS ON THE STORIES**

[Mrs. Mariona Alonso Ibañez - Psychologist](#)

As a general observation, the persons with disabilities participating in the interviews perceive a high degree of autonomy in decision-making and were able to exemplify when and in which topics they can and cannot make decisions. Whilst taking decisions on their own contributes to their empowerment and leads to improved levels of satisfaction it is noteworthy that in the area of financial management there are barriers that make it difficult for persons with disabilities making their own decisions and exercising autonomy. Persons with disabilities want to govern their purchasing decisions but they often lack the skills for “proper management of their income”, as professionals and family members usually state. Hence, situations where the person cannot decide and where they perceive excessive guidance, supervision or control from support professionals or family members provoke stressful episodes that need to be adequately addressed. The use of technologies, whether to consult, to purchase or to consume products such as subscription services, is perceived as a facilitator that contributes to the empowerment of the person with a disability but also can lead to experience situations where support is needed, for example in returning online purchased goods or unsubscribing from unwanted services. It seems appropriate to ensure that persons with disabilities receive support in the use of new technologies when needed but also to increase the digital skills and abilities of the person in that matter.

On the side of the families, a certain degree of paternalism can be sensed in the relationship. Although families strive to allow the person to make their own choices, they feel a certain fear or discomfort when the choices of their relatives do not coincide with their way of thinking. The “right to be wrong” has not been integrated yet into the family's view and perception of the person with a disability. This is normal considering that we come from a deeply rooted paternalistic culture that focuses on protecting persons from making mistakes and encourages avoiding all potential risks. If we want to contribute to the improvement of the subjective well-being of these family units, significant efforts will be necessary to raise awareness that the person with a disability has the right to make decisions and exercise choice and control over all spheres of life.

Awareness-raising is the key, as well as information campaigns and services, which should be managed by public administrations and be universal in scope.

Support professionals perceive that person with disabilities want to decide on their own and make a lot of efforts to do it. They are aware of the importance of the support they offer to the person with a disability and they are increasingly committed to improving the decision-making process to improve the quality of life of the person with a disability as well as the skills of the person to make their own decisions. This leads to professional satisfaction and pride in their

work. In general, they tend to modulate the support they offer to the person, for example acting only in certain areas or spheres of the life of the individual when and where the person really needs it or asks for it. In some cases, especially in the area of personal finances, professionals limit the autonomy of the person as they are still required to act on the “best interest of the person” by law when a court order restricting the legal capacity of the person is in place, especially in the most restrictive measures. The paradigm of the “best interests” has been abolished in Spain in May 2021 by the recently approved legislative reform in the Civil Code, procedural law and related legislation that represents a comprehensive upshift in guaranteeing the rights of persons with disabilities as the United Nations Convention on the Rights of Persons with Disabilities intends. Whilst the recognition of full legal capacity of all individuals with a disability represents a step forward, how the services providing support to persons with disabilities adapt to this new legislation remains to be seen.

## CONCLUSIONS

The supported decision making (SDM) service is an important part of psychosocial support service at all stages of a person's life.

- The SDM service is usually a long-term process involving many people: social workers, specialists in education and employment, legal experts, family members of people with special learning needs.
- The SDM service will not only offer people to acquire certain skills and knowledge but can continuously have the effect of building a positive self-image, a sense of belonging to the group or community and life satisfaction.
- It is very important to combine available and incoming resources in provision of the SDM service for the benefit of the disabled person.
- The society must be interested in ensuring safety and protection from any exploitation of all its members. The society must be interested in legitimizing the SDM service.



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