



SMARTS

Supporting Me About Rights to Sexuality

General Supported Decision Making (SDM)

Training Course

HANDOUTS

2020-1-ES01-KA204-08278

Co-funded by the
Erasmus+ Programme
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Learning Outcomes

On completion of this training the people on the course will be able to:

- List the main principles of the United Nations Convention on The Rights of Persons with Disabilities (UNCPRD)

- Describe what is meant by Supported Decision Making

- Explain the difference between Supported Decision Making and Substituted Decision Making

- Explain the role of the supporter and the facilitator in Supported Decision Making, and the attributes they should possess.

- Describe the process for Supported Decision Making

- Describe what is currently happening regarding Supported Decision Making in your Services.

- Explain how you will plan and implement this Supported Decision Making project in your Services.

- Plan and describe how you will pilot Supported Decision Making in your services.

Guiding Principles of United Nations Convention of the Rights of Persons with Disabilities.

There are eight guiding principles that underlie the Convention and each one of its specific articles:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
2. Non-discrimination
3. Full and effective participation and inclusion in society
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
5. Equality of opportunity
6. Accessibility
7. Equality between men and women
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Scenario Fred.

Fred is a 35 year old man with autism. He has recently moved into a shared house with 4 other people after the death of his mum, who had previously supported him living at home. There are support staff at the house most days and he has a small support package to help him settle into the house and to gain confidence in managing his money, complete his washing, shopping and other household tasks. Fred is allocated Support worker Jenny as his key worker. Fred likes Jenny and finds her easy to talk to.

Fred got some money for his birthday and has been looking forward to going shopping to spend his money. He wants to buy himself some new clothes as he really does need jumpers, t-shirts and trousers. Fred has been shopping in town previously and can easily manage to go shopping on his own. Jenny reminds him to keep his wallet safe and not to be too long, and to ring if he needs any help.

Fred goes into the shopping centre and loves wandering around the shops. He decides he is going to buy himself a couple of nice smart jumpers from an expensive known brand store. A brand that his friend wears and looks nice in. He has a look around the store and chooses the jumpers he likes. He remembers his mum always bought him medium sized clothes, so he buys 2 in a medium size and this uses up all his money. But Fred doesn't care because he loves his jumpers.

When he gets back to the house, he excitedly takes his jumpers to show his friends and Jenny. But when Jenny notices the brand, he has purchased she is shocked, for the price of two jumpers from that shop he could have bought a whole range of new clothes from a cheaper store. She explains this to Fred, but he loves his jumpers. He goes to his room to try them on. He realises that one of the jumpers is wrongly sized and is far too small for him. The other jumper has a small hole and loose thread in the middle of the back. Fred is really upset as he feels he has wasted all of his money.

When Jenny finds out what has happened, she tells him; "Don't worry you can take them back to the shop and they will exchange the one that is the wrong size and the one that is damaged. They should give you the right size and a new jumper or give you a full refund". Jenny offers to go with Fred back to the shop as he is nervous and he agrees.

When they get into to the store, Jenny immediately asks to see the supervisor or manager and demands a full refund on both items. The manager doesn't hesitate to sort out the refund. Jenny is really pleased that she knows Fred's consumer rights and is getting him his money back. She then takes Fred to the cut price store near by and encourages Fred to choose t-shirts, trousers and jumpers from the store.

- ***Fred has asked your SDM service for help with his decision making when buying items. If were supporting Fred using the Supported Decision Making process, what would you hope to include in the SDM Agreement and the Individualised Plan?***

Scenario Maria.

Maria is 55 years old and lives in a Supported Living house with two other ladies. They have 24 hour support, 7 days a week shared between them.

Maria has a good relationship with her family and sees them regularly, having tea with them most weeks and staying overnight occasionally. Maria's family took a long time to make the decision for Maria to move out of the family home and adapt to her living independently. They are very protective of Maria.

A few weeks ago, Maria returned home distressed after having an overnight stay with her parents. She refused to have any food at the evening mealtime. Eventually Maria told the staff that when she was going out to a family party, she put on one of her favourite outfits. Her mum said it was too tight and she couldn't wear it. Her mum had told her she was getting fat and she was going to get diabetes and have a heart attack or stroke if she didn't lose weight.

The support staff at the home have a clear 'Healthy Eating Policy' where all of the ladies are supported to understand about healthy eating. The staff weighed Maria and found she had gained just four pounds since she came to live at the house, four years ago. She is still well within the average weight for her height and age. On arrival at the house, she was just a few pounds below the average weight for someone of her height. Maria has annual check-ups at her Doctors and is fit and healthy. The support staff spent a lot of time explaining to Maria about the healthy eating that they always do at the house and reassured her that she was not fat. Maria told them that her mum said she was not allowed to eat any chocolate, crisps, cakes, biscuits, bread or pasta. Maria enjoys her food and likes to have a treat occasionally and the staff include this as part of the healthy eating plan. As she cried, she said that she did not want to stop eating all of these foods, she loved having spaghetti, pasta and jacket potatoes.

The following day Maria's mum contacted the house and spoke to one of the support staff telling them that Maria must be put on a diet immediately and attend classes at a slimming club. The staff member explained that the house had a healthy eating plan in place and that Maria was well within the weight expected for someone of her height. Mum shouted and screamed at the staff member stating "You are making my daughter fat! Nothing that the staff member said could calm the mum. Mum said that the staff should only give her a mixed salad for her lunch at the day service, dictating exactly what was to be in the lunch. This was salad leaves, tomatoes, cucumber, peppers and one slice of ham, no crisps, no dessert of any kind. Maria had become so distressed that the staff decided to follow the directions regarding salad lunches. However, they found that when Maria got home, she was really hungry and was desperately gulping her evening meal very quickly and would not be slowed down. Then within a few minutes of leaving the table she would be sick.

For the remainder of the week each time her mum called she asked Maria what she had eaten during the day, and had she lost any weight? No matter what was said her mum said she had eaten too much and she was going to get fatter.

Scenario Maria

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After each call Maria became very distressed, crying, banging doors, swearing at staff and threatening everyone and shouting that she didn't want to be fat and have diabetes or a heart attack. Eventually she asked for help in making a decision about what to do.

- ***Maria has asked for help from your SDM service about decisions about her eating and her health. If we were supporting her using the Supported Decision Making process, what would you hope to include in the SDM Agreement and the Individualised Plan?***

Supported Decision Making Agreement

What is Supported Decision Making?

Supported Decision Making (SDM) is a process that helps you to make your own decisions based on your wishes and choices, supported by another person.

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

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

The SDM Agreement

- ✓ **This document allows you to appoint a person to help you with decisions. This person is called the “supporter”.**
- ✓ **In addition, you have to appoint another person, the “facilitator “. A “facilitator” is a person that helps you to check progress and ensure that the Agreement is working as you wish. If you are not happy with the supporter, you can ask the facilitator to talk about it and perhaps even to ask to replace the supporter or stop the agreement.**
- ✓ **In this document you describe the areas of your life where you need support**

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

For these reasons:

- **I agree the following person be my Supporter:**

Jenny Jones

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

How to manage my budget



In particular, I want:

Help to decide what I should spend my money on and how I could save some money for a holiday.

Rights as consumer. (e.g.: when I make purchases through the internet)



In particular, I want:

In particular, I want help to decide what to do if I change my mind about something I have bought .

My health



In particular, I want:

Help to decide if I want to lose weight and if I do, the best ways for me to do this.

My supporter is not allowed to make decisions *for* me, just to support me to help *me* make the decision.

- **To help me with my decisions, I wish my supporter to:**

- **Help me get the information relevant to the decision**



- **Help me to understand my options so I can make a decision; and/or**



- **Help me to communicate my decisions to other persons.**



- **I also appoint the following person as my Facilitator:**

Ray Rogers

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

- **to identify supporters**

- **to help me on how the Agreement works,**



- **to help me sort out any disagreement with the**

supporter



- **to the check quality and satisfaction within the**

arrangements,



- **to help me change the Agreement if needed and**



- **to confirm when the Agreement has ended.**



This agreement is effective immediately and will continue for 2 more months.

Copies of this document will be given to the person, the supporter and the facilitator.

**I consent to act as a supporter.
(signature of supporter) (printed name of supporter)**

Jenny Jones **JENNY JONES**

**I consent to act as a facilitator.
(signature of facilitator) (printed name of facilitator)**

R Rogers **RAY ROGERS**

**Signature
(signature of the person) (printed name of the person)**

S Smith **SALLY SMITH**

Signed at: (place) *My house*

Date: *20th February*

Supported Decision Making Agreement

What is supported decision-making?

Supported Decision Making (SDM) is a process that helps you to make your own decisions based on your wishes and choices, supported by another person.

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

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

The Agreement

- ✓ **This document allows you to appoint a person helping with decisions. This person is called the “supporter”.**
- ✓ **In addition, you have to appoint another person, the “facilitator “. A “facilitator” is a person that helps you to check progress and ensure that the Agreement is working as you wish. If you are not happy with the supporter, you can ask the facilitator to talk about it and perhaps even to ask to replace the supporter or stop the agreement.**
- ✓ **In this document you describe the areas of your life where you need support**

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

For these reasons:

- **I agree the following person be my Supporter:**
-

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

In particular, I want:

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- **To help me with my decisions, I wish my supporter to:**

- **Help me get the information relevant to the decision**



- **Help me to understand my options so I can make a decision; and/or**



- **Help me to communicate my decisions to other persons.**



- **I also appoint the following person as my Facilitator:**

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

- **to identify supporters.**



- **to help me on how the Agreement works,**

- **to assist me to sort out any disagreements with the supporter.**



- **to the check quality and satisfaction within the arrangements,**



- **to help me change the Agreement if needed and**



- **to confirm when the Agreement has ended.**



This agreement is effective immediately and will continue for _____ more months.

**Copies of this document will be given to the person,
the supporter and the facilitator.**

**I consent to act as a supporter.
(signature of supporter) (printed name of supporter)**

**I consent to act as a facilitator.
(signature of facilitator) (printed name of facilitator)**

**Signature
(signature of the person) (printed name of the person)**

Signed at: (place)

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Form for Individualised Supported Decision Making Plan Example. Page 1 of 2

HANDOUT 6

Name of Supported Person	Name of the Supporter	Name of the Facilitator
<i>Simon</i>	<i>Chris</i>	<i>Erica</i>
SDM topic(s)	<i>Health. Simon (the supported person) would like help in deciding how he can lose weight</i>	
Plan of Activities	<p><i>We (Simon & Chris) agreed that:</i></p> <ul style="list-style-type: none"> <i>we need to find and understand information about what a healthy weight is for Simon's height.</i> <i>Find and understand information about diets and physical exercise as two main ways to lose weight. Think about seeing a person who knows all about food and losing weight (a dietician) for help with how Simon can understand a diet (eg. calories, what is in different foods, things that make you fatter, etc).</i> <p><i>Find out what kind(s) of sport / physical exercise would help him lose weight. Discuss ways of doing this (if possible eg available resources & personal abilities & likes/dislikes). Agree to have a trial period for following an exercise plan and to follow a diet, so the supported person can see what this would look like and if they would like to do it.</i></p>	
New Skills involved	<p><i>What extra help does Simon need on the computer to be able to search for information through the internet?</i></p> <p><i>How to monitor and record Simon's weight loss/gain</i></p>	
Start date: <i>10/03/2019</i>	Predicted End date: <i>01/05/2019</i>	Actual end date: <i>30/05/2019</i>
How have the activities progressed?	<p><i>It has been easy for Simon to understand the dietician and what following a diet means.</i></p> <p><i>We improved (using tables and pictures) Simon's understanding about what is in different foods and their calorific value. Actually counting and recording the calories is causing a few problems for Simon</i></p> <p><i>Simon likes individual sports (like swimming) and low intensity activities (walking). He has been searching the internet to find a local swimming pool near his house. This required some support to learn how to search such for this. Simon has made a table to record his weight every week, but sometimes he forgets to do this. Simon knows he could choose to visit the dietician regularly if he decided to follow a diet.</i></p>	

Form for Individualised Supported Decision Making Plan. Blank Page 1 of 1

Name of Supported Person	Name of the Supporter	Name of the Facilitator

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SDM topic(s)			
Plan of Activities			
New Skills involved			
Start date:	Predicted End date:	Actual end date:	
How have the activities progressed?			
What to do next? (if not enough SDM improvement achieved)			

HANDOUT 7

SUPPORTED PERSON SELF-ASSESSMENT - An Introduction for supporters

Assessment – who does what?

Assessment is a complex and progressive process, where results change over time and need to cover a number of different aspects,

1. Firstly, supporters should assess the supported person's strengths and challenges to ensure support is given in the right way and at the right level.
2. Supported persons themselves are also asked to give feedback on the support they have received, and if it enabled them to make decisions they wanted to make. A specific tool has been produced for this: see the *Supported person feedback form*.
3. Finally, being aware that support is a multi-disciplinary process, the supporter has the opportunity to evaluate the involvement of others and reflect on his/her own interventions see the *Supporter self-assessment form*.

As a result of these assessments, the supported person and supporters should share this evaluation to understand any progress made or any adjustments needed. The assessment process is a powerful tool for motivation.

When does assessment take place?

It takes place after the SDM agreement has been signed, then afterwards periodically as needed. The frequency depends on the supported person's wishes and on the needs of the particular moment (eg in finance, to decide to ask for a loan, or in healthcare to decide about some treatment/operation)

What has to be covered?

This depends on the user's circumstances and the decisions, based on his/her wishes and on the supporter's advice. Assessment can cover all of the areas or just be limited to certain matters of particular interest and relevance to the supported person. Naturally there will be periodic revisions, so what is covered and assessed in each area can be modified.

What is the level of detail required?

The supporter should assess and review the level of detail needed to help the supported person make the decision(s) required. As such decisions are very individualised it is impossible to set a detailed and the level of detail will be different for each person.

When does it end?

In theory support for SDM will only end when it is not needed because the supported person is able to make their own decisions freely. New areas of decision making can be considered/added at appropriate times.

SUPPORTER SELF-ASSESSMENT FORM

Name of supporter:

Name of supported person:

Date: __/__/__

Note: the supporter should complete this form as a reflective activity.

1. Supported decision making: response of supported person.

During the period since the assessment, can you list the decisions the supported person had to make?

1. .
2. .
3. .

What kind of support did you provide?

1. .
2. .
3. .

What was the reaction from the supported person to your support? (choose one or more responses, and fill in the gaps providing further details)

1. The supported person took all the decisions, some of them relying on supporter's advice (Which decisions? What advice did you provide?)
2. The supported person took decisions but was not fully aware of consequences (which consequences had they overlooked?)
3. The supported person was afraid about the responsibility they now had to carry as a result of the decision itself (which?)
4. The supported person was unable to take some decisions (which and why?)
5. The supported person was able to take some decisions (which?)

SUPPORTER SELF-ASSESSMENT FORM

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What have you had to change in your approach to try to move forward with SDM?

How do you feel in about this change in your role to one based on *supporting decision making* instead of making decisions on behalf the supported person (substitute decision making):

More satisfied

Neither satisfied nor unsatisfied

Less satisfied

Could you explain why you feel like this?

What is your assessment of the network of professionals, friends and relatives supporting the improvement of the decision-making process? Please choose as relevant from the following:

It is a really effective and coordinated network?

Some participants are more active and effective than others (who and why do you think this is?)

Some participants are more in line with the new thinking around SDM and have adapted their behaviour and attitudes accordingly, but others have still to fully make this necessary change. Can you (if possible) give examples of each group and say why you think problems remain?

The Network is substantially ineffective and ill coordinated (can you explain why this is so?)

Could you explain your assessment?

Overall, how could you improve the decision making support?

Keep this completed form and take it with you to share when you next discuss progress on the SDM Agreement with the Facilitator

Feedback from the Supported Person Page 1 of 4

Hello, this short document will help improve the support you get from _____ (fill in the name of your supporter).

Please read the questions carefully and take your time to answer

them. _____ (fill in the name of your supporter). Will help you if you need support with this form. Your supporter will keep a copy of the form. You can keep one too and use it when you talk to your facilitator and you review /monitor how the Agreement is going.

Today is... __/__/__

1. Can you remember some decision(s) you have taken recently?

Please describe up to 3 of them in the box below

1.
2.
3.

2. Has xxxxxx given you support to make any of these decisions?

 Not really	 Some of them	 Yes	 Don't know
---	---	--	---

If

 Not really

or

 Don't know

Why do you feel this way?

Supported Person Self Assessment Form

If  which ones?
Some of them

Which ones got no support?

What kind of support did you get?

 Not really good	 So so	 Good	 Don't know
--	--	---	---

NOTE to anyone helping the supported person to complete this form: If any 'don't know' answer then ask If you don't know, is it because you don't remember or are shy/afraid to ask questions or do you not understand the source of this feeling?

3. *Was the support you got useful to you in making those decisions?*

 Not really good	 So so	 Good	 Don't know
--	--	---	---

Supported Person Self Assessment Form

4. Was the support enough for you to take your decisions?

 Not really	 So so	 Yes	 Don't know
---	--	--	---

5. Are there things about the kind of support you received that you would like to improve? What would you like to see change?

What would you like to see change?

1. .
2. .
3.

6. Would you like to make more decisions for yourself (but with support as needed) in the future?

 Not really	 Somehow	 Yes	 Don't know
---	--	--	---

7. Do you think that xxx always respected your decisions?

 Not really	 Sometimes	 Yes	 Don't know
---	--	--	---

Supported Person Self Assessment Form

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8. Overall, how do you value the support received from xxx?

 Not really good	 So so	 Good	 Don't know
--	--	---	---

Keep this record safe and take it with you to share when you next talk to your facilitator.

SCENARIO DORIS.

- You are the Facilitator in a SDM service
- Doris is the Supported Person
- Jane is the Supporter

Doris is in her twenties and lives in a residential care setting on the outskirts of town. She moved in to the setting a year ago when she left a residential school where she had been since she was a child. The residential setting is staffed at all times and the residents are supported in their daily living skills, health, personal care and finances. Doris has intellectual disabilities and some Bipolar Disorder challenges.

Doris joined the Supported Decision Making Service a couple of months ago. She was very carefully matched with Jane as her Supporter. Jane is one of the staff who work at the residential setting and is a very experienced support worker who has known Doris since she moved in. Doris wanted support in deciding whether she should move from Residential Care to a Supported Living apartment in the town centre.

Doris and Jane have been getting on really well, having completed a SDM Agreement and written an Individual Plan. Without notification you receive the following message on your answer phone:

“Hi, It’s me Doris. I want to talk to you about Jane who you have set me up with? Well, I don’t like her. She isn’t doing her job right! Please call me as soon as possible”

Before you have managed to call Doris or Jane you receive a second message:

“It is Doris again, why haven’t you called me back? Well, I am not talking to Jane anymore. She is supposed to help me, and she is ignoring me. I’ve told her what I want to do and she won’t help me. I want a new supporter. I have asked Jenny; she works on nights across the road, I like her, she is my friend. She wants to help me do what I want to do. So, I am seeing Jenny on Thursday, bye.”

You contact Jane who sends you an email stating:

‘The SDM Agreement went very well, Doris wanted support in making a decision about where she should live. She didn't know whether she should stay where she is or move to a Supported Living Apartment on her own. We agreed in the Individual Plan that we would look at the pros and cons of staying where she is and of moving on. Earlier in the week we had been talking about the pros and cons of moving into Supported Living. Doris started to get agitated whenever I mentioned any ‘cons’ regarding moving. Although I tried to diffuse the situation, Doris threw all the paperwork on the floor. As well as the mugs and plates that were on the table, breaking a couple of items and making a real mess. She then walked out shouting that I only wanted her to stay in the residential care setting and I was rubbish. I don't think that Doris is ready for Supported Living at the moment, but I have not said that to Doris.

SCENARIO DORIS.

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As the Facilitator how are you going to manage this situation?

*Consider: What will you do first? What will you say to Doris? What will you say to Jane?
How can you resolve this?*