



SMARTS

(Supporting Me About Rights to Sexuality)

General Supported Decision Making (SDM)

TRAINING COURSE SLIDES



Co-funded by
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Partners:



Learning Outcomes

On completion of this training learners will be able to:

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

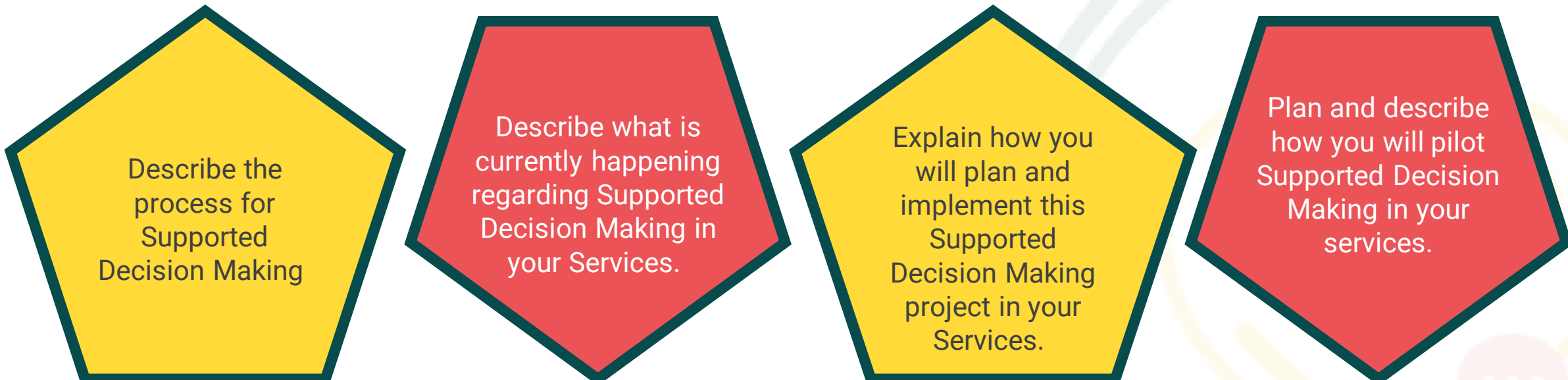
Describe what is meant by Supported Decision Making

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

Learning Outcomes

On completion of this training learners will be able to:



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.

A Human Rights Approach to Disability

All the work we are doing is based on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). It is also based on a Human Rights Approach to Disability.



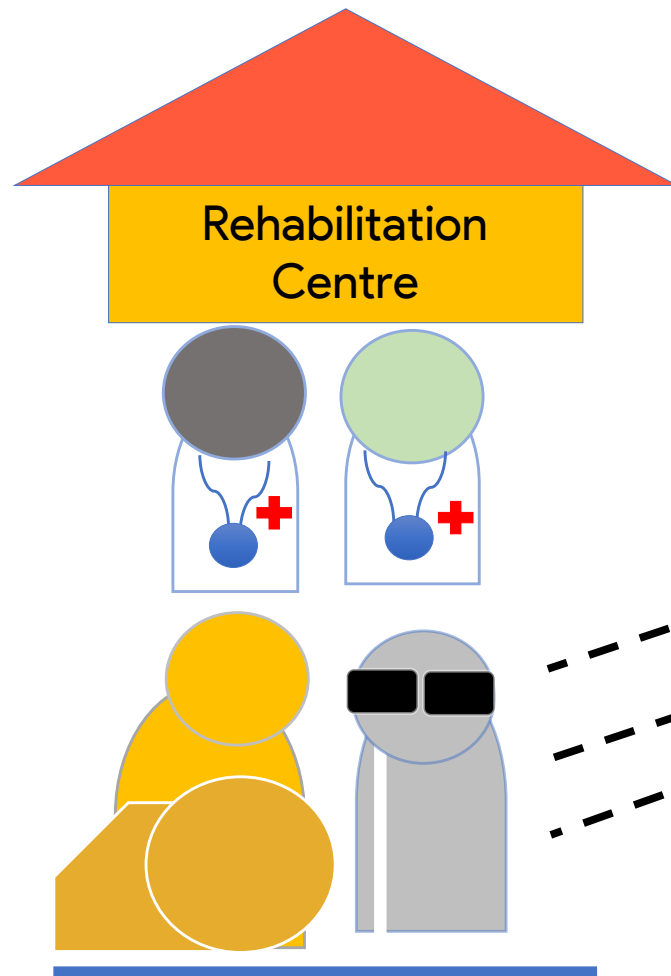
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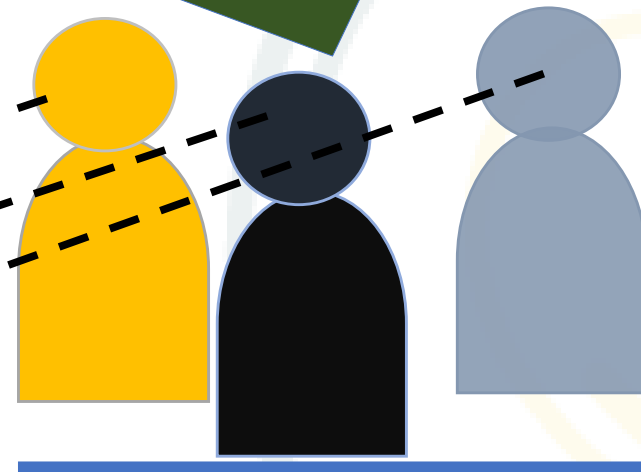
Charity Approach

How this approach sees disability:	Persons with disabilities are in a tragic situation.
	Persons with disabilities cannot take care of themselves
	Persons with disabilities inspire compassion
	Persons with disabilities are objects of benevolence
How this approach proposes to treat disability:	They need our help, sympathy, charity...
	Collect and give money to provide for persons with disabilities.
	The quality of the “care” is less important
Who is the duty bearer on disability issues:	Benevolent persons, charity houses, homes, foundations, religious institutions ...

Medical Approach



Poor people, we should fix them, so they can participate.



Charity Approach

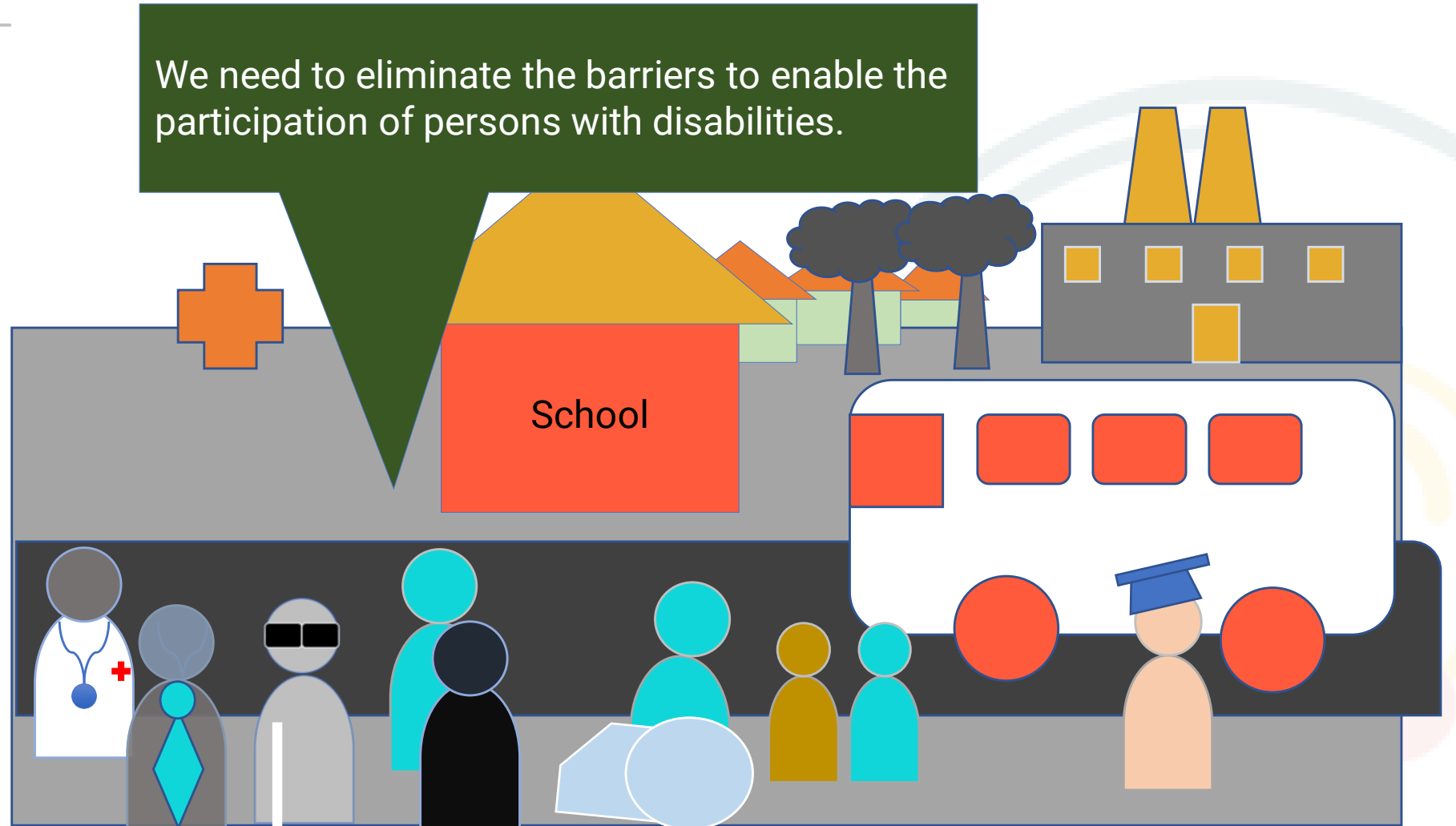
How this approach sees disability:	Persons with disabilities need to be cured.
	Persons with disabilities play the passive role of patients.
	Persons with disabilities are considered abnormal.
	Persons with disabilities are unable to live independently
How this approach proposes to treat disability:	Persons with disabilities need as much rehabilitation as possible to reach the best extent of normality, in order to access rights and participate in society.
Who is the duty bearer on disability issues:	Doctors and health authorities.
	Often health ministry.

Consequences of charity/medical approaches



Social Approach

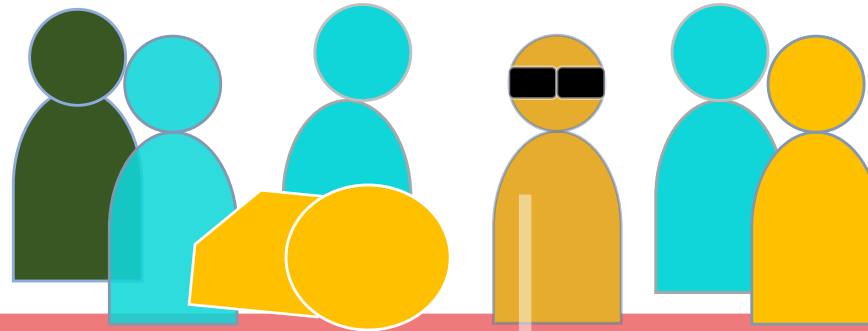
We need to eliminate the barriers to enable the participation of persons with disabilities.



Social Approach

How this approach sees disability:	Disability is the result of a wrong way of organizing society: thus, persons with disabilities face bias and barriers that prevent their equal participation.
	Disability is not an individual problem and mainly lies in the social environment that can be limiting or empowering depending on many factors.
	Persons with disabilities can and should participate in society.
How this approach proposes to treat disability:	Eliminate environmental barriers that constrain the participation of persons with disabilities, including attitudinal barriers.
	Enable the participation of persons with disabilities in public policymaking.
	Make all public services and policies accessible and inclusive.
	Ensure accessibility
Who is the duty bearer on disability issues:	State, all ministries, Society.

Persons with disabilities are part of human diversity



Being human has a broad spectrum of possibilities

MANY WAYS OF WALKING	MANY WAYS OF SEEING	MANY WAYS OF THINKING	MANY WAYS OF COMMUNICATING	MANY WAYS OF INTERACTING	Etc.
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Human Rights Approach

We, persons with and without disabilities, are part of the same society and we have the same rights and obligations



Social Approach

How this approach sees disability:	Ensures full and equal enjoyment of all human rights to persons with disabilities and promotes respect for their inherent dignity.
	Focuses on equal opportunities, non-discrimination on the basis of disability and participation in society.
	Requires authorities to ensure rights and not restrict them.
	Views persons with disabilities as rights-holders
How this approach proposes to treat disability:	Enforce laws to ensure full inclusion in all social aspects (school, family, community, work, ...)
	Apply policies to raise awareness.
	Respect equal recognition before the law.
	Regulate the private sector.
Who is the duty bearer on disability issues:	State, all ministries and society.

Key principles of a human rights approach

Inclusion

Participation

Accessibility

Non-discrimination

Respect for
difference and
diversity

Equality of
opportunities

Respect for inherent
dignity

The Convention's concept of disability

Disability is an evolving concept and results from the **interaction** between **persons** with **impairments** and attitudinal and **environmental barriers** that hinders their full and effective **participation in society on an equal basis with others.**

The Convention's concept of disability

Is driven by the principles of the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD), especially Article 12.

Is based on the Human Rights Model of Disability.



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Is a process that allows people with disabilities to make their own decisions based on their own wishes and preferences.

Includes a co-production approach at every stage.

Can be formal or informal.

Is very different from substituted decision making.

The Principles of Supported Decision Making

People with disabilities have equal rights with others under the law

People with disabilities should have control over their own lives

The wishes and preferences of people with disabilities should be respected

A range of measures should be available to support people with disabilities in their decision making, reflecting their diversity

People with disabilities have the right to make mistakes and to take informed risks

Duty of Care

We all have the right to make mistakes and unwise decisions (we often learn from these) but as supporters of people with disabilities we also have a duty of care. This means:

We have a responsibility to ensure the safety and well being of those we support

We must balance the right to autonomy and the right to protection

We must treat people with disabilities the same as we would treat people without

We must ensure the people we support understand the possible consequences of their actions and make their decisions in the light of this

We should only intervene when there is an immediate risk of serious harm or death (eg suicide or harm to others)

The basis for SDM in Services

Supported Decision Making is a service that should be offered by organisations supporting people with intellectual disabilities

The organisations should be committed to replacing Substitute Decision Making with Supported Decision Making

Those involved in delivering the service should have a full understanding of the SDM principles and processes

The main tasks of the Supporter in SDM

To assess the skills of the person in relation to decision-making in the specific areas listed in the SDM Agreement.

To explore with the supported person those areas where the supported person might want help with decision making.

To build and implement, jointly with the person, an Individualised SDM Plan to help the person to take decisions.

To research materials and resources to help the person to understand the information they need to make their own decisions.

To assist the supported person to obtain advice from different sources.

The main tasks of the Supporter in SDM

To support the person at meetings with outside organisations or professionals to obtain information and explore options.

To support the supported person to complete reviews and assessments

To help the supported person analyse the different options.

To support the person at meetings with outside organisations or professionals to obtain information and explore options.

The main tasks of the Supporter in SDM

To help the supported person communicate the decision(s) to his or her family and others and to enable a good implementation of the person's choice. When necessary, the supporter will advocate for the decision to be implemented.

To ensure the supported person has understood the pros and cons of the options involved in a decision.

To ensure the supported person has understood the possible consequences of the decision

To observe and record all the activities and actions arising from the SDM Agreement.

The skills and values of a supporter

Commitment to the principles of the UNCRPD and an understanding of how the SDM process differs from substituted decision making.

Ability to value the supported person's goals, values and preferences, and respect their right to make mistakes and take risks.

Ability to respect the particular decision making style of the supported person and recognise when and how support may be offered.

Ability to form a trusting relationship with the supported person and to spend as much time as is required to support the person to make each decision.

The skills and values of a supporter

Ability to research information to support the decision making process.

Ability to communicate clearly with the supported person in an appropriate manner.

Ability to respect the decision of the supported person even if the supporter believes it is not the best decision.

Ability to use Reflective Practice to ensure the service is meeting the needs of all involved.

The role of the facilitator in advising and safeguarding

To provide advice on how the SDM Agreement works.

To help the supported person identify suitable supporters.

To assist the supported person and the supporter in resolving any disputes.

To make regular contact with participants to check that support arrangements are working, using supervisory skills.

To monitor and record the natural end or termination of the SDM agreement and to inform those involved in supporting it that the agreement has ended.

Ability to use Reflective Practice to ensure the service is meeting the needs of all involved.

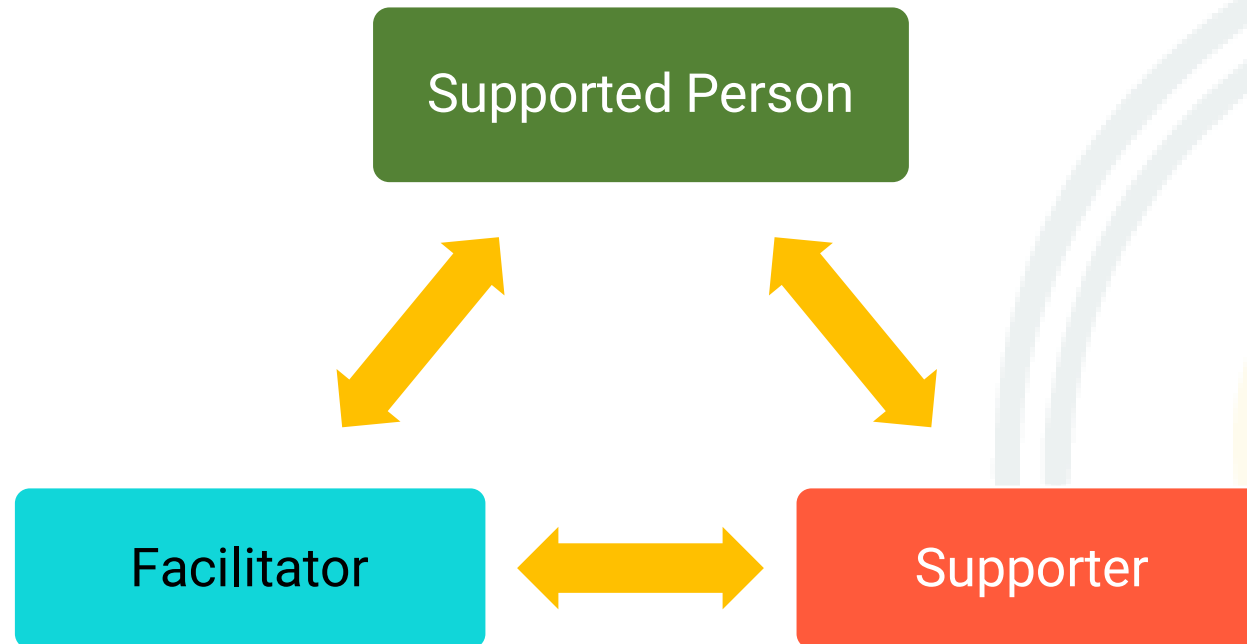
Skills and values of the facilitator

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

The supported person or the supporter may approach the facilitator to clarify or improve the SDM agreement's content or to terminate the agreement.

The facilitator can be a professional - ideally from the supporter's employing agency or service – or a peer from the supported person's social network or a family member who has the required knowledge and skills.

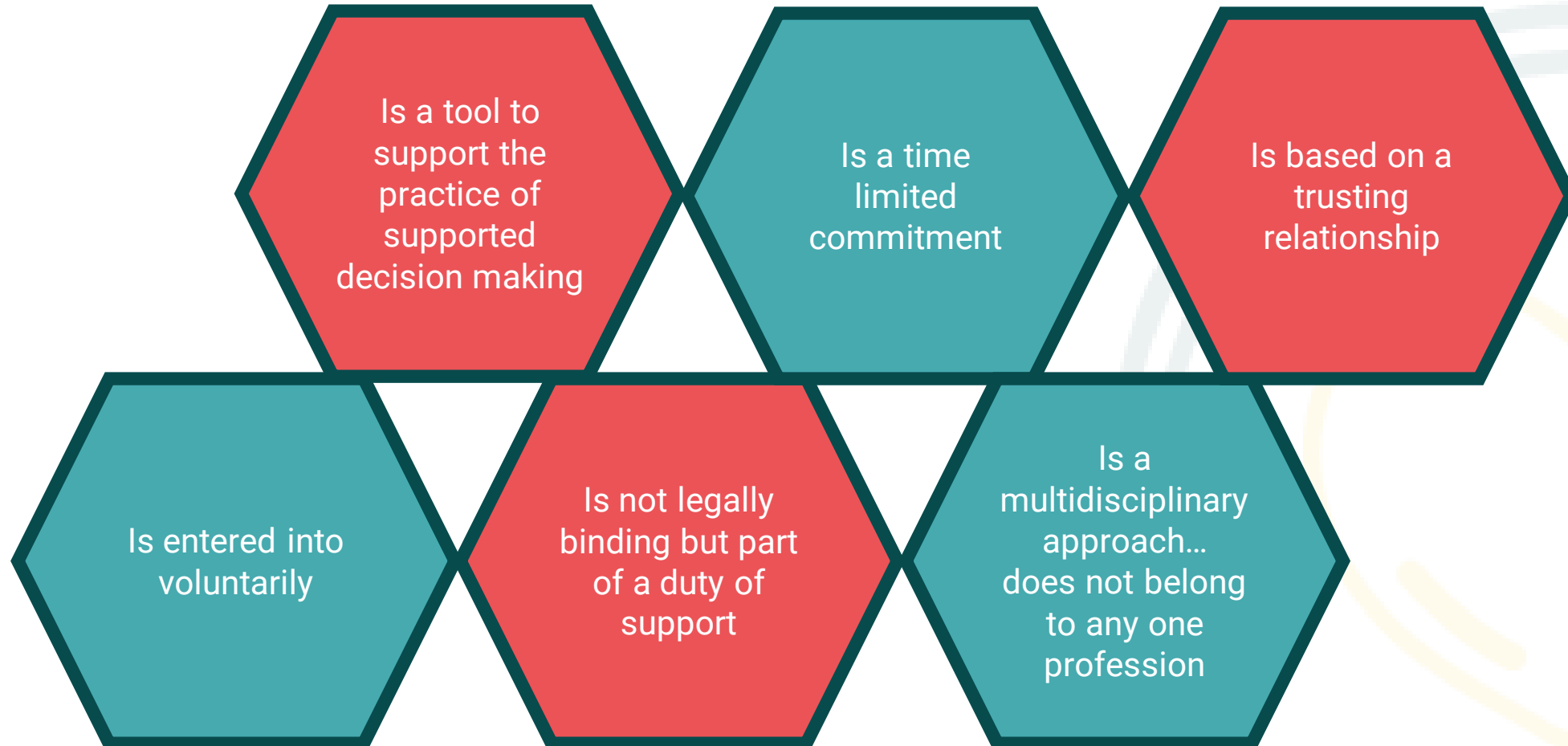
The relationship between the parties



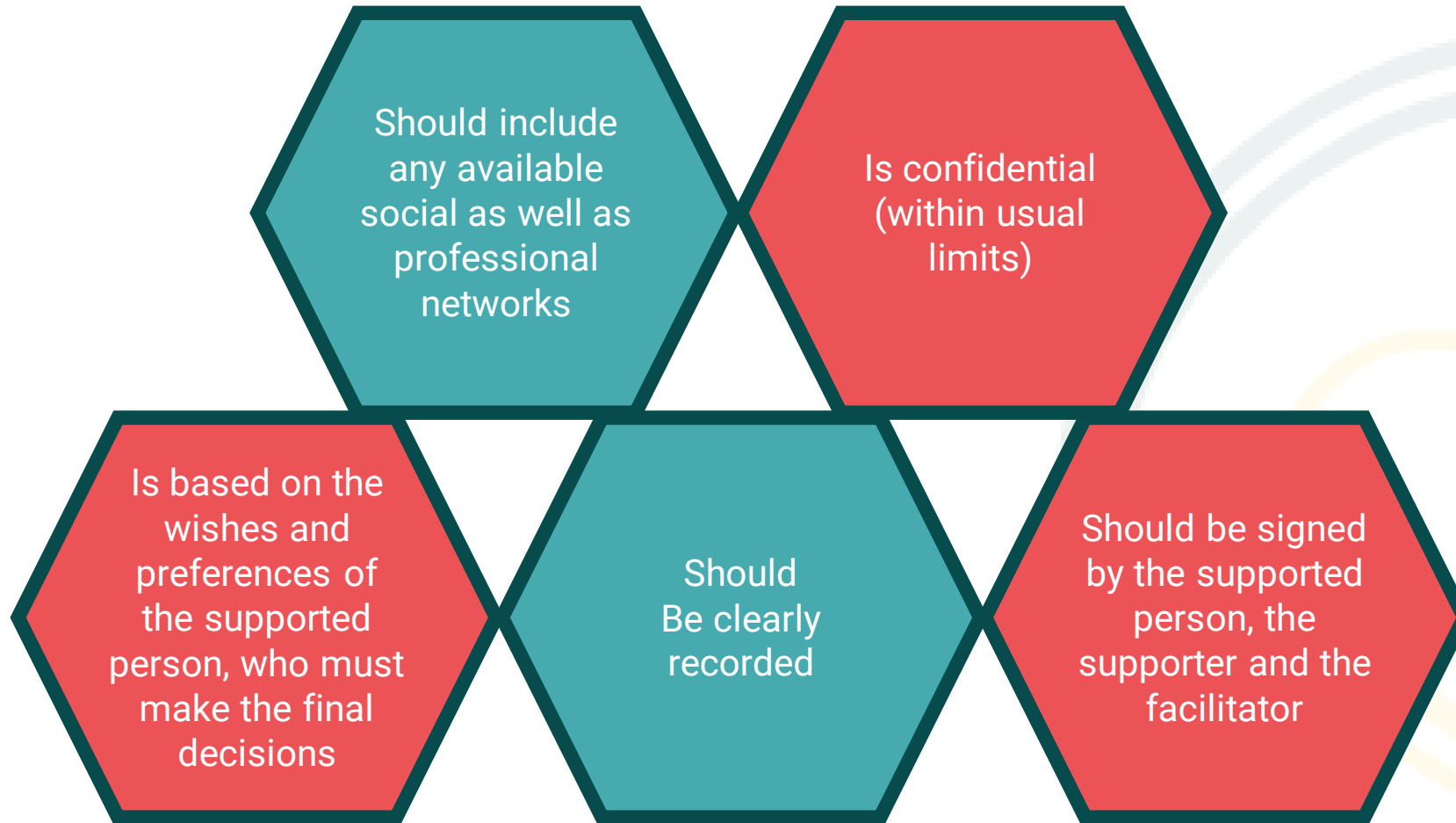
The SDM process



The SDM process



The SDM process



Formal SDM process meetings:

SDM
Satisfaction
Assessment: meeting held every 2 months at the same time as the SDM Review/Evaluation between the supported person and the supporter. Forms used: supported person and supporter self assessment.

SDM
review/evaluation:
meeting held every 2 months at the same time as the SDM Satisfaction Assessment between the supported person, the supporter and the facilitator. Forms used: consider all current forms in operation.

SDM
Agreement review:
meeting held between supported person, the supporter and the facilitator every 6 months. Form used: original agreement form updated.

SDM forms:

SDM Agreement

(initially 6 months duration). Signed doc kept by the three parties

Individualised SDM plan

(updated every 2 months). Kept by the supporter and known to the supported person and the facilitator

Supported person self-assessment form

(updated every 2 months). Kept by the supported person and known to the supporter and the facilitator

Supporter self-assessment form

(updated every two months). Kept by the supporter and known to the supported person and the facilitator

SDM Agreement Form (worked example)

Annexe 1: The SDM Agreement

SDM AGREEMENT (Example) FORM

Page 1 of 3

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 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.

SDM AGREEMENT (Example) FORM

Page 2 of 3

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 a consumer.

(e.g. *When I make purchases through the internet.*)

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 way 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 supported 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.

SDM AGREEMENT (Example) FORM

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- 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 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)

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

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

Jenny Jones

Ray Rogers

Sally Smith

Signed at (place): **My house**

Date: **20th February**

Form for Individualised plan (worked example)

I DECIDE INDIVIDUALIZED SDM PLAN

The supporter should take time to ensure the supported person fully understands this recording of the plan.

Name of Supported Person	Name of the Supporter	Name of the Facilitator
Simon	Chris	Erica
SDM topic(s)	Health. Simon (the supported person) would like help in deciding how he can lose weight	
Plan of Activities	<p>We (Simon & Chris) agreed that:</p> <ul style="list-style-type: none"> We need to find and understand information about what a healthy weight is for Simon's height. 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). <p>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.</p>	
New Skills involved	<p>What extra help does Simon need on the computer to be able to search for information through the internet? How to monitor and record Simon's weight loss/gain</p>	
Start date: 10/03/2019	Predicted End date: 01/05/2019	
How have the activities progressed?	<p>It has been easy for Simon to understand the dietician and what following a diet means. 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 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.</p>	

Form for Individualised plan (Blank)

Name of Supported Person	Name of the Supporter		Name of the Facilitator
SDM topic(s)			
Plan of Activities			
New Skills involved			
Start date:	Predicted End date	Actual end date	
How have the activities progressed?			

Supporter Self-Assessment Form (Blank)

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Feedback from the Supported Person Page 1 of 1

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.

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

Not really
 Some of them
 Yes
 Don't know

If not really or if you don't know,

Not really
 Don't know

Why do you feel this way?

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Supported Person Self-Assessment Form Page 1 of 2

If Some of them ones?

Which ones got no support?

Has XXXXXXXXXXXX given you support to make any of these decisions?

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

Not really good
 So so
 Good
 Don't know

4. Has XXXXXXXXXXXX given you support to make any of these decisions?

Not really
 So so
 Yes
 Don't know

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Supported Person Self-Assessment Form Page 2 of 2

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

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

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.

Supporter Self-Assessment Form (Blank)

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Page 1 of 2

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?

4.

5.

6.

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?)

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Supporter Self-Assessment Form

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 what you feel like this?

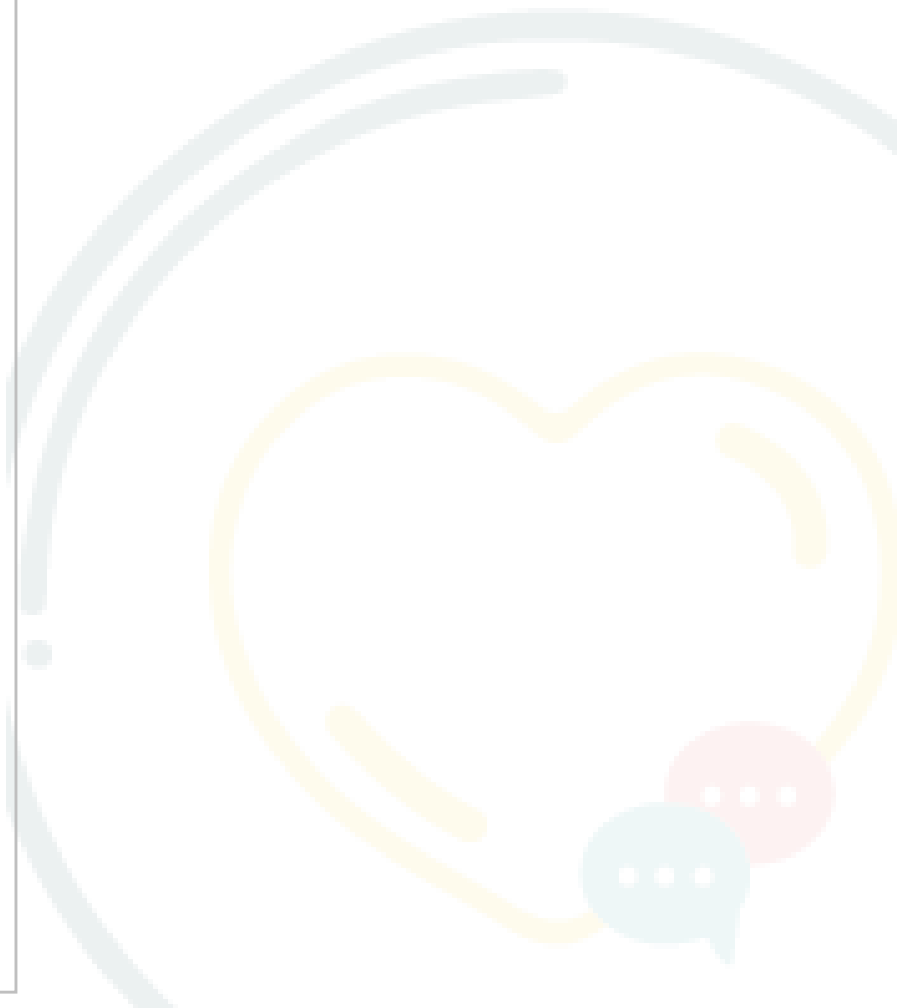
What is your assessment of the network of professionals, friends and relatives supporting the improvement of the decision-making process? Please choose as relevant from the following:

- 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 what you feel like this?

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.



Implementing an SDM service

Before selling SDM: be prepared to feel the resistance to change.

Some services may be very open to the introduction of SDM. Others may resist the change required on a variety of levels.

<https://youtu.be/RxUbKIAZn5s>



Implementing an SDM service

How to overcome resistance to change

Determine the optimal speed of change.

Use your analysis of situational factors to decide how quickly or slowly your change should proceed. Move quickly if the organisation risks are high if the present situation isn't changed.
But proceed slowly if:

Resistance will be intense and extensive.

You anticipate needing information and commitment from others to help design and implement the change.

You have less organisational power than those who may resist the change.

How to overcome resistance to change

Determine the optimal speed of change.

Method	How to Use	When to Use	Advantages	Drawbacks
Education	Communicate the desired changes and reasons for them	Employees lack information about the change's implications	Once persuaded, people often help implement the change	Time consuming if lots of people are involved
Participation	Involve potential resisters in designing and implementing the change	Change initiators lack sufficient information to design the change	People feel more committed to making the change happen	Time consuming, and employees may design inappropriate change
Facilitation	Provide skills training and emotional support	People are resisting because they fear they can't make the needed adjustments	No other approach works as well with adjustment problems	Can be time consuming and expensive; can still fail

How to overcome resistance to change

Try your method depending on your position and influence in the organization.

Method	How to Use	When to Use	Advantages	Drawbacks
Negotiation	Offer incentives for making the change	People will lose out in the change and have considerable power to resist	It's a relatively easy way to defuse major resistance	Can be expensive and open managers to the possibility of blackmail
Coercion	Threaten loss of jobs or promotion opportunities; fire or transfer those who can't or won't change	Speed is essential and change initiators possess considerable power	It works quickly and can overcome any kind of resistance	Can spark intense resentment toward change initiators

Reasons why my service should implement a SDM

To be used by Managers

To align the service with the human rights based model of support

To fulfil the international legal framework (UNCPRD)

Modernize the service and not be left behind

To provide a better service to the users (users satisfaction)

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Reasons why my organisation should implement a SDM service

To (future) Supporters and Facilitators

To be more egalitarian with users regarding power relations.

To help users exercise their autonomy (identity building).

To realize the user's satisfaction and therefore increase their satisfaction with work.

To acquire useful and new competences (avoiding burn out).

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Piloting the general SDM Service

Work across their delivery partnership (in country) to help identify a minimum of 20 service users and supporters (the mix will be decided by the delivery partners) per delivery partner who could benefit from general SDM. This should be undertaken in the first 6-8 months of the piloting period (pilot 0) but can be added to throughout the life of the project.

Work within their organisation to set up general SDM

Work to implement SDM structures, or act as a facilitator or supporter, dependent on their position within the organisation

Act as an 'ambassador' to others (other providers, user groups, parental groups, regulators, policy makers) for the benefits of general SDM and help to increase the number of agencies using SDM. Staff should choose the position that most suits them on a spectrum of influence and support. This could range from speaking positively to others about SDM to taking part in formal presentations.



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