



SMARTS

Supporting Me About Rights to Sexuality
**GENERAL SUPPORTED DECISION
MAKING (SDM)
Training Course
Slides**



Co-funded by the
Erasmus+ Programme
of the European Union



SMARTS

2020-1-ES01-KA204-082783

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.



SMARTS

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.



The following slides 2 to 13 are from a presentation prepared by

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...

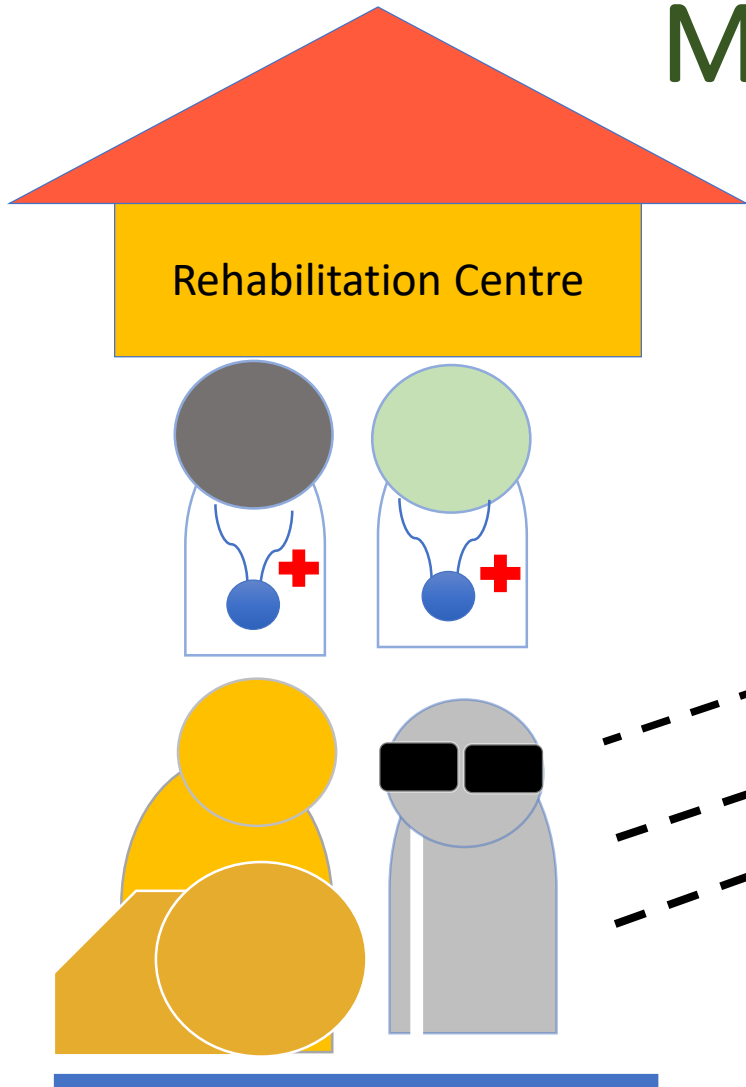
Collect and give money to provide for persons with disabilities.

The quality of the “care” is less important

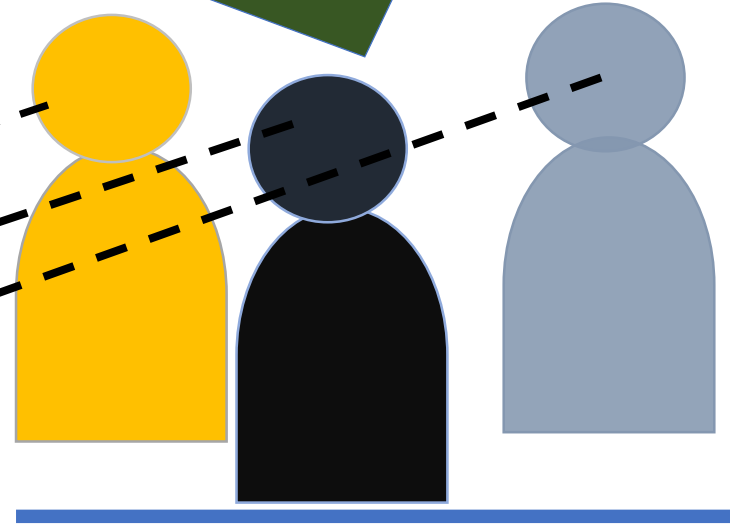
Who is the duty bearer on disability issues:

Benevolent persons, charity houses, homes, foundations, religious institutions ...

Medical Approach



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



Medical 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

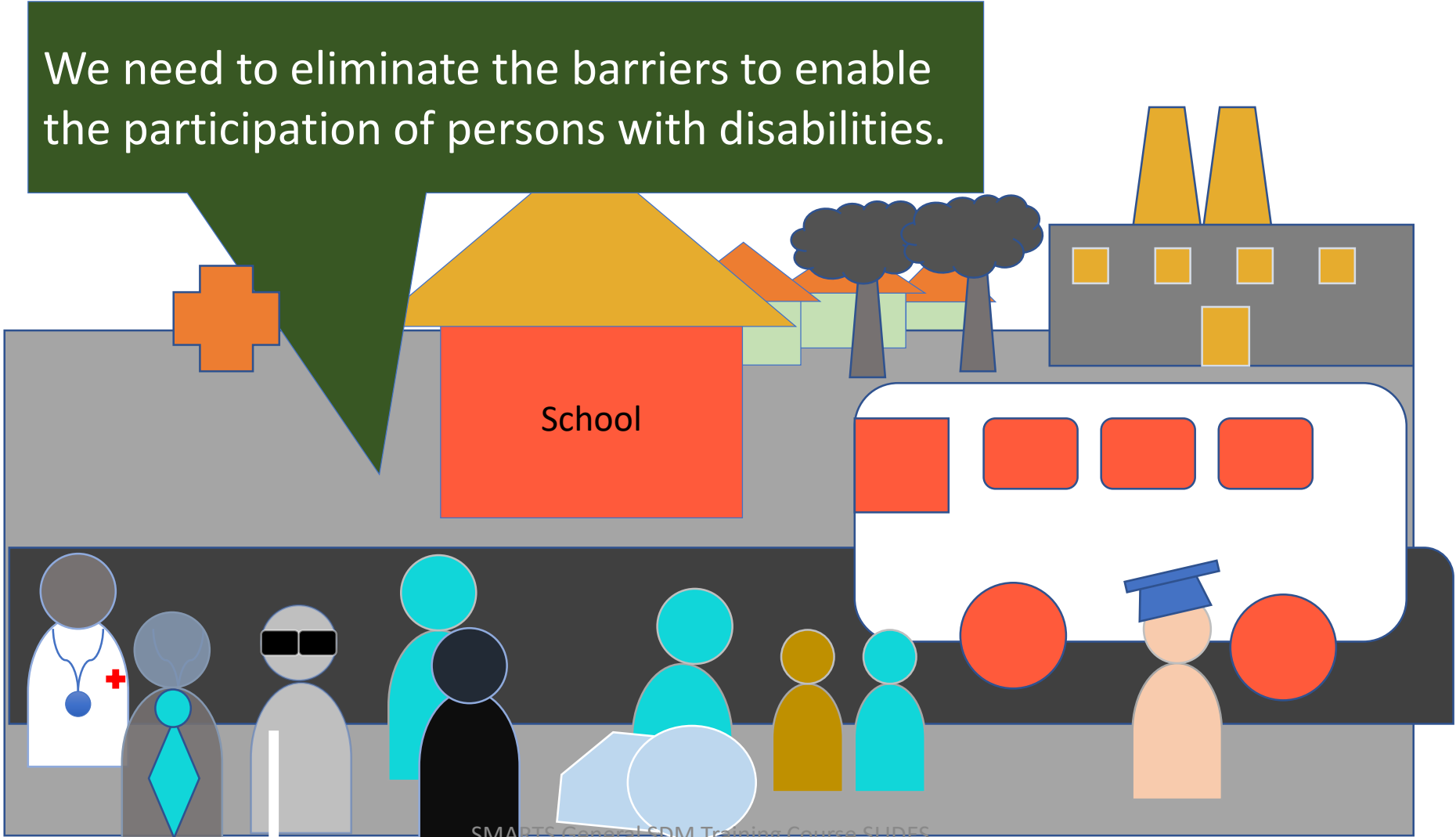
Often health ministry

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

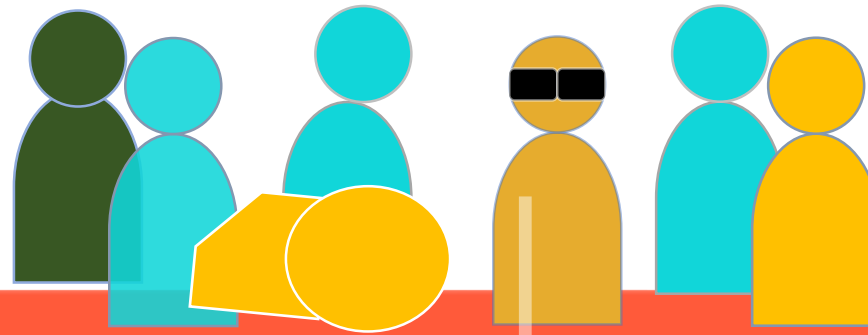
Make all public services and policies accessible and inclusive

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.

Human Rights Approach

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



Human Rights 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



SMARTS

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**

Supported Decision Making:

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



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



SMARTS

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



SMARTS

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 help the supported person analyse the different options.

To support the supported person to complete reviews and assessments

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



SMARTS

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 the 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:

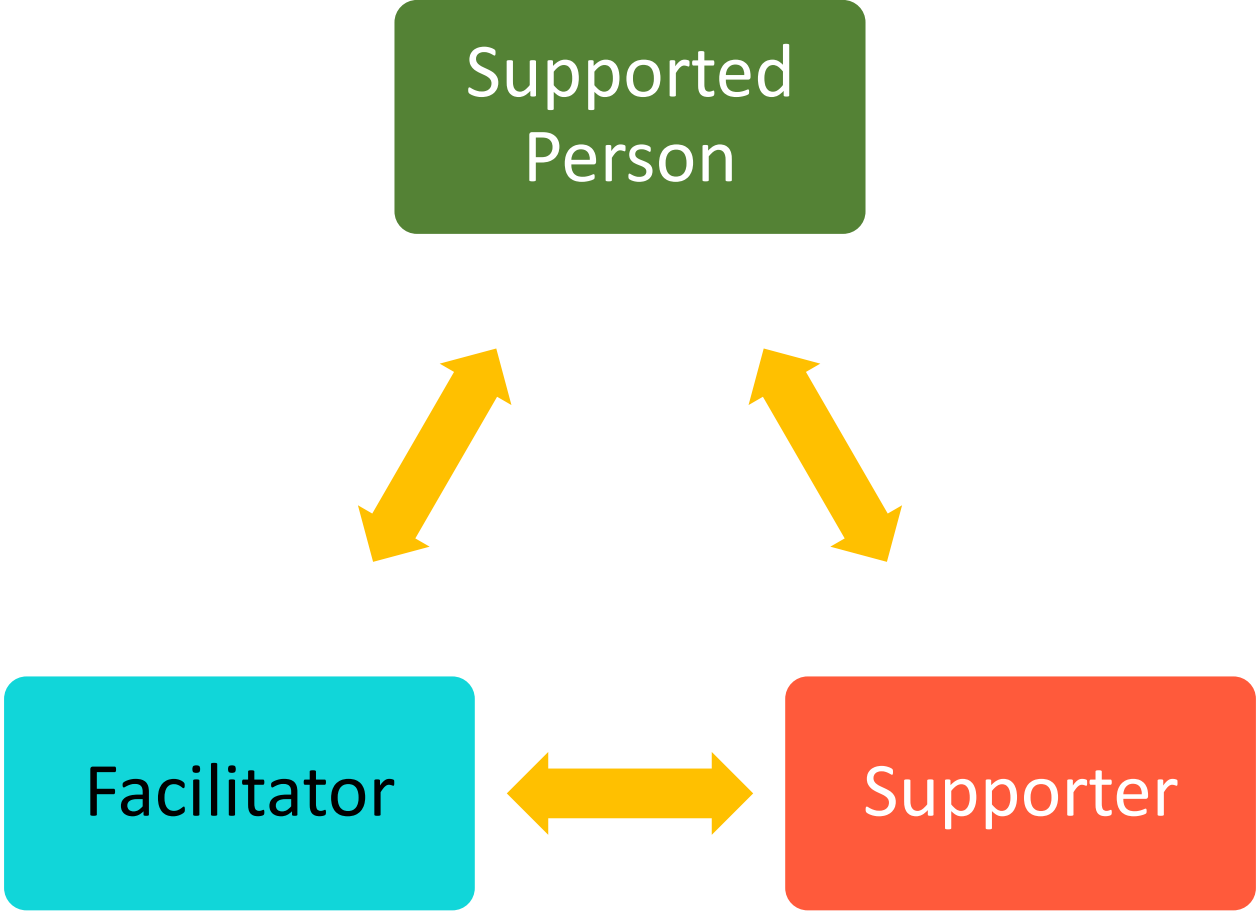
The facilitator needs to have a complete understanding of the SDM process and the terms of the SDM Agreement and should be able to communicate, using suitable language, both with the supported person and the supporter_ using mediation strategies and soft skills such as assertiveness.

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

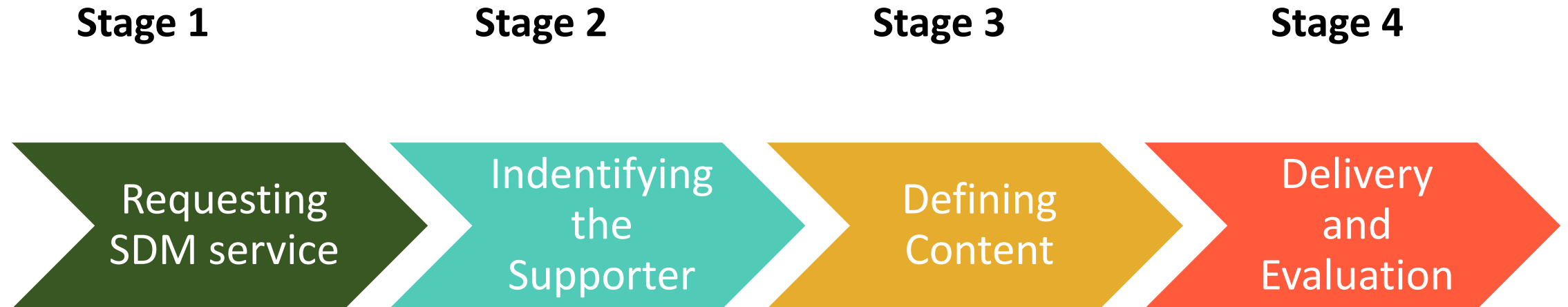
The facilitator can be a professional – ideally from the supporter's employing agency or service – or a peer from the supported person's social network or a family member who has the required knowledge and skills.



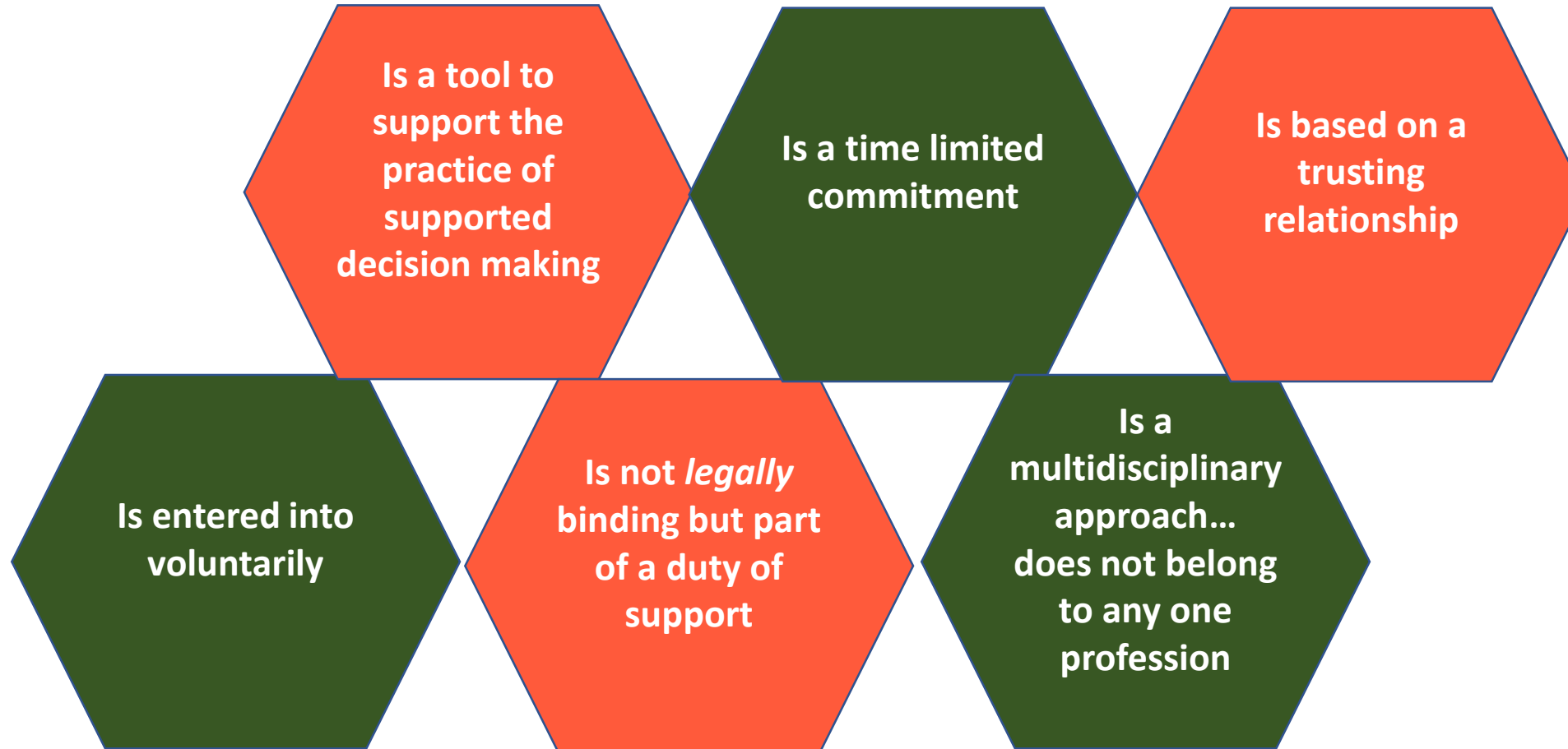
The relationship between the parties:



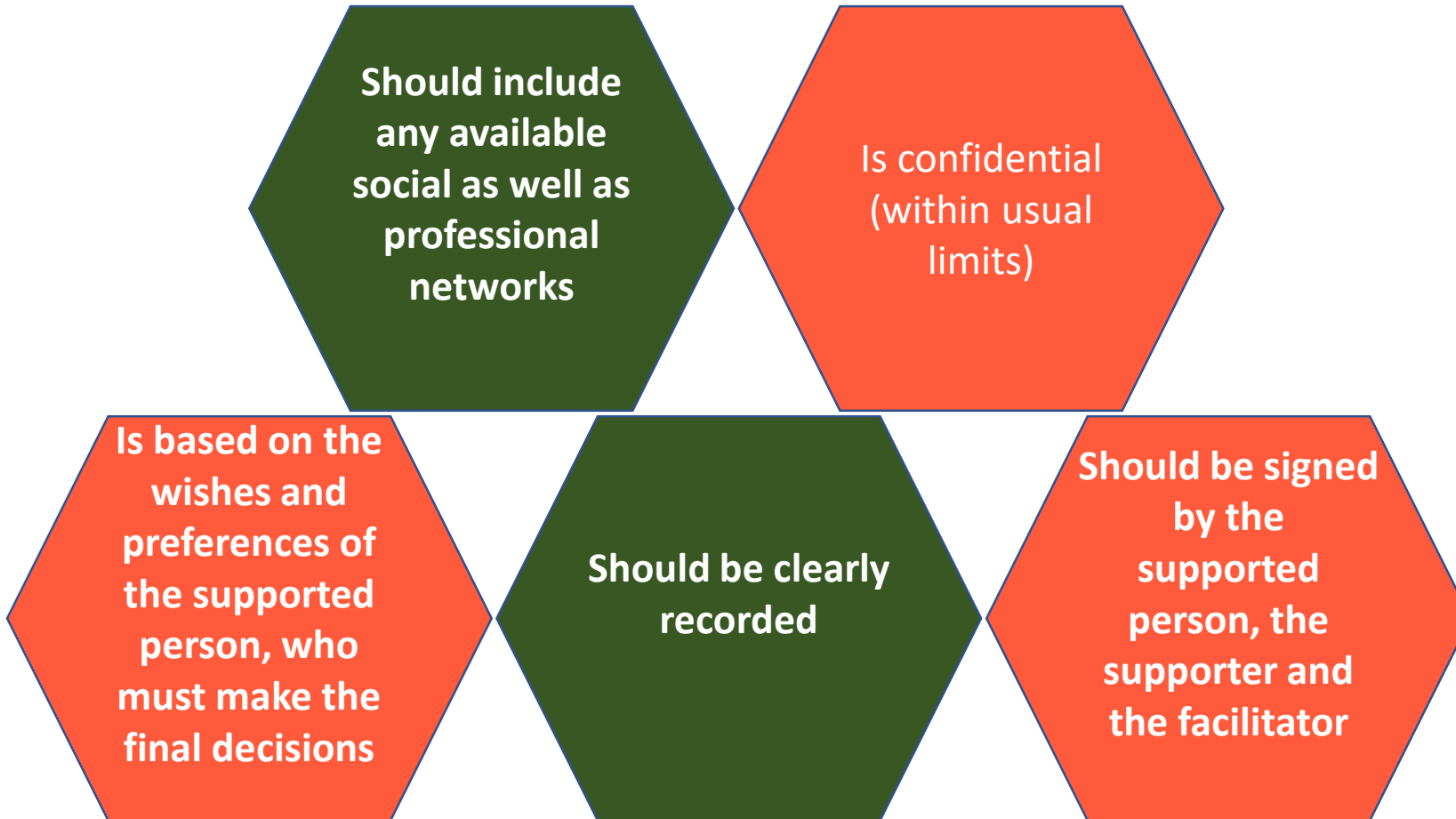
The SDM process:



The SDM Agreement:



The SDM agreement:



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



SMARTS

SDM Agreement Form (worked example)

SUPPORTED DECISION-MAKING AGREEMENT

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 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



SDM Agreement Form (worked example)

- 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.

SDM Agreement Form (worked example)

My supporter is not allowed to make decisions 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

to find a supporter who I like 

to help me understand how the Agreement works, 

to help me if I don't get on with the supporter 

to check if the arrangements are good and if I am happy with them

to help me change the Agreement if needed and 

to confirm when the Agreement has ended 

This agreement starts today and will continue for 2 more months.

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

SDM Agreement Form (worked example)

I agree to act as a supporter.

(signature of supporter) (printed name of supporter)

Jenny Jones JENNY JONES

I agree to act as a facilitator.

(signature of facilitator) (printed name of facilitator)

R Rogers RAY ROGERS

Signature

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

S Smith SALLY SMITH

Signed at: (place). *My house*

Date: : *20th February*



SMARTS

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 | Actual end date: 30/05/2019 |
| 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? | | |
| What to do next? (if not enough SDM improvement achieved) | | |




Supported Person Self Assessment Form (Blank):

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?

If some of them



Which ones?

Which ones got no support?

What kind of support did you get?

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



NOTE for the supporter for DON'T KNOW answer: If don't know, is it because they don't remember (ask question based on shared experiences), if shy/afraid

Was the support enough for you to take your decisions?

Not really So so Yes Don't know



Supported Person Self Assessment Form (Blank):

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



Not really.

so so.

Good.

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

1.

2.

3.

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



ly

Sometimes



Yes

Don't know



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



ly

Sometimes



Yes



Don't know



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

Not



't know



Thank you very much!!!!

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

Supporter Self Assessment Form (Blank):

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
3. consequences (which consequences had they overlooked?)
4. The supported person was afraid about the responsibility they now had to carry as a result of the decision itself (which?)
5. The supported person was unable to take some decisions (which and why?)
6. The supported person was able to take some decisions (which?)

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



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/RxUbKlAZn5s>



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

TRY YOUR METHOD DEPENDING ON YOUR POSITION AND INFLUENCE IN THE ORGANISATION

| 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 |

*From P. Kotter and Leonard A. Schlesinger (2013), Harvard Business Review

SMARTS General SDM Training Course SLIDES

How to overcome resistance to change

TRY YOUR METHOD DEPENDING ON YOUR POSITION AND INFLUENCE IN THE ORGANISATION

| 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 (UNCRC)

Modernize the service and not be left behind

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

-

-



SMARTS

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)

-

-

Piloting the general SDM Service.

