



SMARTS

**SUPPORTING
ME
ABOUT
RIGHTS
TO
SEXUALITY**

AN EASY-TO-READ TOOLKIT





SMARTS



SMARTS is a European Union funded project that is the product of a partnership between :

- The European Association of Service Providers for persons with Disabilities



Belgium



- Social Care Training Ltd



United Kingdom



- Associação para a Recuperação de Cidadãos Inadaptados da Lousã



Portugal



- Astres Foundation



Spain



- Theotokos Foundation



Greece





These guidelines are composed of **2 sections**:

- **Section 1** - To inform persons with **intellectual disabilities and with mental health conditions** of their rights and options regarding their sexual needs.
- **Section 2** - To help family caregivers in **identifying services** promoting the implementation of the sexual rights of their relatives with disability.

DISCLAIMER

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“ Table of contents ”

Section 1

In this section you will know about:

- Relationships
- Communication
- Sexuality
- Safety
- Intimacy
- Consent
- Abuse
- Your rights
- How can you be supported to make your own decisions?



Table of contents



Section 2

In this section you will find:

- A brief reminder of what Supported Decision Making is
- Key elements related to Supported Decision Making to be aware of
- Clues for choosing support services that are aligned with the Supported-Decision-Making approach
- Clues for identifying if current support services support sexual rights

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Section 1

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Relationships

We meet **different people** everyday.

Some people we know **for a long time**.
Other people we have **just met**.



We have **different feelings** for the people we meet.



The persons we meet mean different things to us.
This is called a "relationship".



Relationships

A relationship is a connection between **at least 2 persons**.

These people may care about each other.

This connection can come in many forms:

- **Family**

Family members are people who are related to you by blood or marriage.

Your parents, your brothers and sisters and your cousins are relatives.

Usually we have a close bond with our relatives



- **Friendship**

A friend is a person we feel closely connected to.

We can share personal information with a friend.

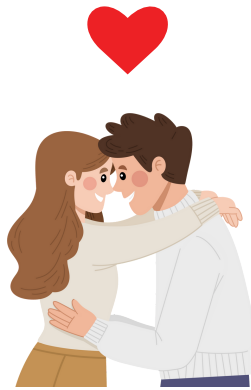
Friendship means trusting each other.



“ Relationships ”

- **Romantic relationship**

Special kind of relationship where two people are attracted to each other.



This can involve :

-Physical affection (hugging, holding hands, or kissing)

-Emotional closeness.

When you feel close to somebody you may want to share your feelings and thoughts with him/her.

The basic elements for all close relationships are trust and sharing.



“ **Communication** ”



Communication is key for your wellbeing and for forming relationships.

How do we communicate?

- By exchanging with someone
- It can take different forms:
it can be by words, messages, emjis, emotions



You are communicating with another person when:

- You smile
- You speak
- You shake hands
- You wave your hand to say goodbye



Communication allows you to express

- **Your needs**
- **What you want**
- **What you think**
- **What you like and you don't like**



“ Communication ”

- **We want you to make your own choice.**
- **It is your right to make your own choice.**

Some topics are more difficult to talk about because you might feel uncomfortable or shy.

But it is still very important to talk about them.

One topic for example is sexuality.

It is normal to feel embarrassed when talking about private matters.



- **So it is important to communicate and ask questions when you have some, even on topic like sex.**
- **Asking questions will help you understand about sexuality and help you make your own decisions about sexual matters**

You can also ask your service provider for a process that is called "Supported Decision-making"



“ **Sexuality** ”



A relationship may include sexual activity.

Sexuality is about our sexual feelings, who we are attracted to, and how we show that attraction.

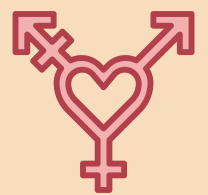
- **Sexuality is personal.**
- **You can be any person you want. It is okay to be who you are.**

For example, you might find that, although born a man, you feel that you are a woman (or vice versa).



- **You can decide to who you are attracted to. People express their sexuality in different ways.**

For example, a boy can be attracted to a girl, or to a boy, or to both, or to nobody.



- **It is important to respect everyone's choices and feelings.**
- **It is important to communicate your feelings and ask for support when you have questions or doubts.**



“ Safety ”

Before having sex of any kind, it is important to know **how to be safe**.



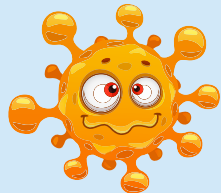
There can be infections that can make you ill.



It is a bit like during winter when you get sick because of a cold.

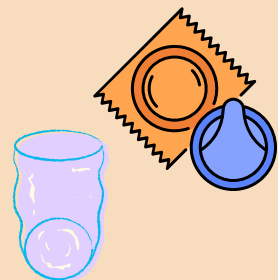
You can catch an infection through sex if you are not being careful.

This kind of infections are called: "Sexual Transmitted Infection" (STI).



To protect yourself from STIs, you should wear a condom while having sex.

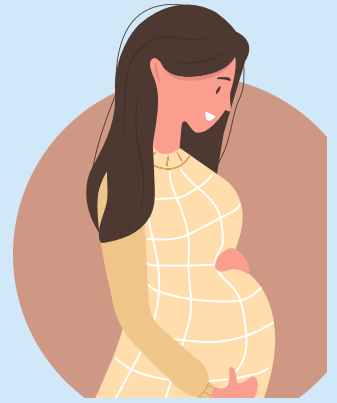
There are condoms for men and condoms or dental dams for women.



You should get expert advice on how to avoid STIs.

“ Safety ”

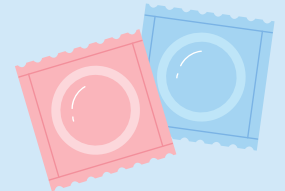
Protection such as condoms can also prevent you or your partner from getting pregnant.



You can easily learn how to use them on the internet.

You can also look at this website [here](#).

You can also ask someone you trust, such as a friend, relative or service provider.



There are other tools that can protect you or your partner against pregnancy, such as pills.



It is important that you talk to your doctor to find the best solution for you

“ Intimacy ”

Intimacy means "closeness".

You can be close to someone, in an emotional or physical way or both.

It depends on your relationship with this person.

Emotional relationship is when you feel a connection towards someone.



Physical relationship is about touch and closeness between bodies. It can be:

- Kisses
- Hugs
- Sex
- ...



- **Nobody should force you to have physical intimacy.**
- **Nobody should touch your body if you don't want them to.**



“ Consent ”



Communication is essential !

By communicating you can make and express your choice.

For example, you can say whether you feel comfortable with a situation or not.

You can say whether you feel comfortable with doing something or not.

CONSENT is the word we use to say that you agree to do an activity with someone.

For example, someone asks you to give them a kiss. If you want to, you can say yes. You give your consent.



Or if someone asks to touch you. You do not feel comfortable with that and you don't want them to. You just say no. You do not give your consent.



“ Consent ”



- **You have the right to say NO to things you don't want**
- **You can consent to some things and not consent to others.**

For example, you can say yes to kissing and cuddling

but you can also say 'no' to taking your clothes off or having sex.



Be aware everyone you like might not be a nice person.

You have a good relationship when there is respect.

- Respect is about respecting you as a person.
- Respect is about respecting your decisions.

Everybody has to respect your decision to give consent or to not give consent.



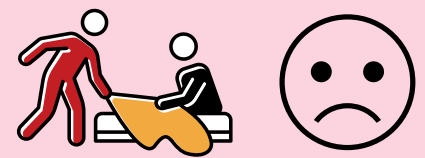
“ Abuse ”



There is **ABUSE** when someone does not respect your right to say no.

For example, there is **abuse** when:

- The person who wants to have sex with you makes you feel sad because you don't want to have sex with them.



- The person wants to hurt you because you don't want to have sex with them.



- The person is harassing you, hurting you or does not respect your right to say no.

If you don't feel safe, if you feel bad or if you are abused, ask for help and talk about it with someone you trust.



You can also go to the **police station** or call an **emergency number** to explain your situation:

- 112: This is the emergency number that every country of Europe uses.
- 101: This is the emergency number for the police in Belgium.
- 1712: Violence, abuse, and child abuse hotline in Belgium.



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Your Rights

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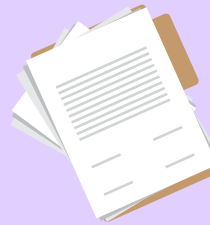
You have **RIGHTS**

A right is something that is yours, that you can claim and that the others have to respect.



Where can you find your rights?

In many **documents**, including



- **United Nations Convention on the Rights of Persons with Disabilities**

You can access it online [here](#)



- **European Disability Strategy for 2021-2030**



You can access it online [here](#)

Ask someone to help you look for them and to explain to you what you don't understand.



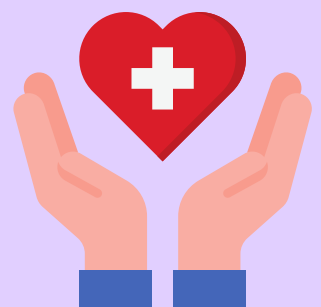
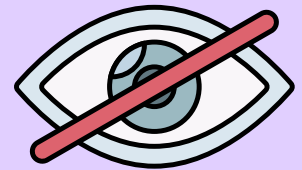
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Your Rights

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Examples of some of your rights

- **Right 1: You have the right to make your own decision.**
- **Right 2: You have the right to privacy.**
- **Right 3: You have the right not to be discriminated against.**
- **Right 4: You have the right to get access to free or affordable health care.**



“ Supported Decision Making ”

"Supported Decision Making" or "SDM" means that you are supported with the information you need to make your own decisions.

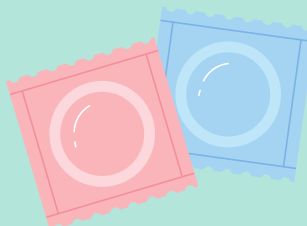
- **To make your decision, first you will be provided with information**
- **You can ask all the questions you have**
- **You can choose persons to provide you with support. These persons cannot make the decision for you.**
- **You make your own decisions**



You can ask for information and for support to make a decision any topic you want.

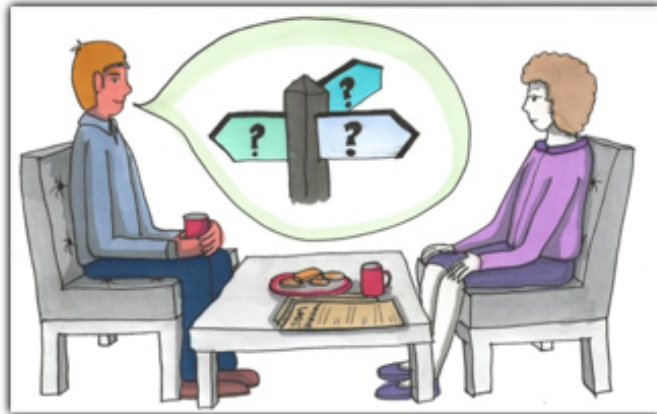
For example:

- How do I use a condom?
- What should I do if someone is abusing me?



Supported Decision Making

What is 'SDM' ?



Tom and Jane met for a coffee and Tom told Jane all about his decision. Jane told Tom how the SDM Service works.



The next week that they met they filled in the SDM paperwork. First the Supporter Agreement. Then they made an Individual Plan all about how they could help Tom make his decision.



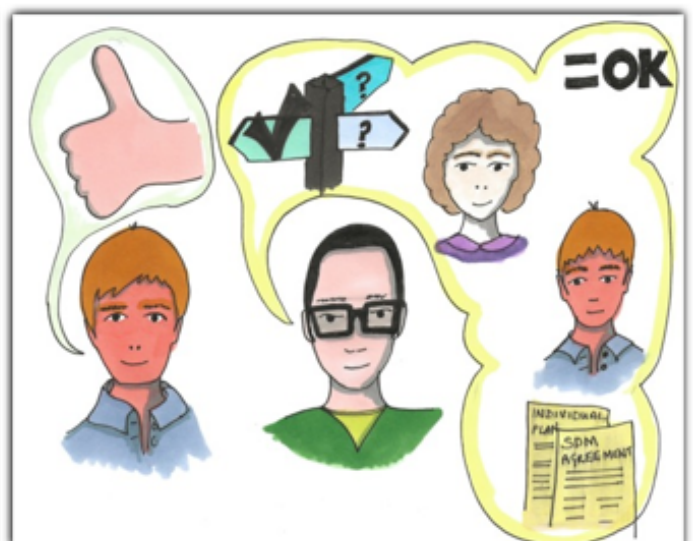
They talked about the pros and cons of each decision option.



They looked at all of the good and bad points of each decision.



They talked about all the good things and bad things about the decision. They also talked about how some people may not like the decision he makes. But even if some people do not like his decision the most important thing is that he is happy with his decision.



When Tom had made his decision with the help of the SDM Service. He met with John, who wanted to check that Tom was happy with everything that the SDM service had done to support him in his decision making. Tom was very happy, he thought Jane had really helped him to think about the different decisions he could make and what might happen if he made them. Tom was very pleased with the SDM Service. He told all his friends about how good it was.

Supported Decision Making

What is 'SDM' ?



Tom has a decision to make, he does not know what to do!



He talked to his friend who told him about a place he has seen that might be able to help.



He called at the place his friend had told him about.



The man, called John invited him in to talk about SDM.



Tom told the man all about the decision he had to make. The man said that they could help.



Tom was worried that the people at the SDM service would try and tell him what to do.



John told him that they were there to help him to make his decision they would not make his decision for him. That would be **Substituted Decision Making Not Supported Decision Making.**



Tom
The Supported person

Jane
The Supporter

John
The Facilitator

John introduced Tom to the role he would have with his support in his decision making. John will be the Facilitator; he will make sure everything is going ok. Then he introduced him to Jane. Jane will be his Supporter. Tom had met Jane many times before, at a group that he goes to. Tom likes Jane.

“ Supported Decision Making ”



The role of the supporter

- The supporter can help you to make decisions about your sexuality and your relationships.
- This person will listen to you and respect what you are saying.
- The supporter will give you information that you need to make a decision.

A helpful supporter is someone who:

- **Respects your autonomy and your dignity.**
- **Understands your feeling.**
- **Communicates clearly with you.**
- **Listens to you.**



You can ask to have a different supporter if you feel like the one you currently have does not understand you.

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Section 2

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“ Supported Decision Making ”



If you are a family carer, this section will serve you as a guide to provide support to your loved ones and better identify services that support their sexual rights.

SDM in Support Services

Having SDM established and working well in a service is the best possible stepping stone to supporting the sexual rights of persons with disabilities. Also SDM can operate in many different areas of someone’s life and is of great benefit to people using the service, their relatives and staff too.

Once the ‘principles’ of SDM are established and accepted in a service, extending that approach to the more challenging areas of sexual rights will be made much easier. Sexuality and sexual expression is just another area where the supported person expresses that they want help to understand it and make decisions for themselves.

“ Supported Decision Making ”

"Supported Decision Making" or "SDM" means that the supported person is supported with the information enabling them to make their own well-informed decisions.



CHALLENGES WHEN IMPLEMENTING SDM IN SUPPORT SERVICES

Of course, you may well find opposition to taking SDM to this logical conclusion and you may again need to find allies amongst service users, staff and families. You may well still see the 'gap' between what people say they do and what they actually do.

Make sure that you celebrate SDM successes – not only with regards to sexual matters – but about any area where listening to and empowering people to make their own decisions has worked out really well. This includes people learning from their own mistakes and deciding to try another way as a result of it not working out well before.

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Supported Decision Making

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IF YOU WANT MORE INFORMATION

The SMARTS project has a number of partner organisations and all of them would be willing to help in whichever way possible. The contact details for each organisation are in the Family Carer's Guide.

DO NOT BE AFRAID TO USE SDM

Finally, it is important to recognise that 'supporting sexual rights' includes a wide range of behaviour such as flirting, holding hands and being close to someone emotionally and physically, having boy/girlfriends (and losing them too!) and kissing and cuddling etc.

It is great mistake to assume or expect that the promotion of someone's sexual rights will in all cases result in sexual intercourse. Just because it might have that result does not mean we should act and think as if it will always do so! Look at wider society and the huge variation of sexual and (far more often) non-sexual relationships which take place.

Why should the range of relationships involving persons with disabilities be any different?

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Introduction

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SOME THINGS TO THINK BEFORE YOU START

- 1** The first step is to read the Family Carers version of the main SMARTS guide. This will give you lots of ideas to think about alongside helping you reflect on what you truly think and what is best for your relative*.
- 2** You might also find it useful to have a quick look at the other versions of the SMARTS guide – so that you can have some idea of the kind of things that staff and service managers might be coping with. It is always a good idea to understand how their view of this issue will be affected by a different set of concerns. If you can put yourself in their position for a moment and think how you might feel if you were being asked to help someone express their sexual rights and feelings.



*We use the term 'relative' to cover any kind of family member - sons, daughters, brothers, sisters, uncles etc

“

Introduction

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Be 100% clear and confident about the fundamental rights of all this.

- The UN Convention on the Rights of Persons with Disabilities is very clear about the rights of persons with disabilities to enjoy the same freedom of sexual expression and choice as everyone else, to get married and to become a parent.
- All countries in Europe and the EU as a whole have signed the Convention and therefore, services in all those countries should now be putting it into practice.
- Make sure you understand what Supported Decision Making (SDM) is and be clear about the huge difference between SDM and the old fashioned (but much more common) version called Substitute Decision Making - where someone else makes the decision on behalf of your relative with disabilities. Think of your own family history – in the past that might easily have been you making substitute decisions! If so, are you now willing to hand over that power to your relative bearing in mind their particular abilities.

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Introduction

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In the same way that you have made some kind of ‘journey’ to arrive at your present thinking about the sexual rights of your relative, do remember that many services are probably making that same kind of ‘journey’ – or at least trying to – but they might not (yet) have got as far as you have in their thinking and actions.

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‘Actions speak louder than words’ – do not be surprised if there is a gap between what you are told is the policy of an organisation and what actually happens in a service. Of course this can happen in any aspects of a service (eg food, leisure time, daily routines etc) but it is much more likely to happen in areas such as promoting sexual rights because this is, for some, seen as controversial. Also, it brings lots of challenges and arguments and it is often easier just to ‘leave things as they have always been.’ It might be easier for everyone - except the person at the centre who will continue to be denied their sexual rights – but being ‘easier’ does not make it right.

“ Chapter 1 ”

Looking at a possible new service?



This Chapter assumes that you are looking at a new service for your relative which is appropriate for his/her disability. Of course, looking at a 'new' service might also mean you can compare it with the service your relative is currently getting, or it might be that this is the first service of this nature that they will have.

The best way to approach this issue is to separate out in your mind the answers to two different questions:

- What does the prospective service say about this issue?
- What does the prospective service do about this issue?

WHAT DOES THE SERVICE SAY ABOUT SEXUAL RIGHTS & THE SDM APPROACH?

The “This-is-not-an-issue-here” approach

Organisations often deal with difficult questions about sexuality in ways which deflect or hide the underlying issue.

For example, residents may in fact be expressing their sexuality in different ways, but this is not recognised, leaving them at risk of mis-information and uninformed choices. If the service does not acknowledge that the people it supports are sexual beings, just like all of us, then it is easier to ignore behaviour or statements (eg such as holding hands and saying “X is my boyfriend”) as things of no significance.

“ Chapter 1 ”

Looking at a possible new service?



WHAT TO DO FIRST

Read all the written information you can get about the service. This includes any recent publicly available reports by inspectors and any publicity material the service produces. If available, you might also usefully ask to see their policies and procedures documents.

WHAT TO LOOK FOR IN THE DOCUMENTS



- Is the importance of the UN Convention on the Rights of Persons with Disabilities recognised? Is it even mentioned?
- Look for any references to Supported Decision Making. What is said about how decisions are made and who makes them?
- What (if anything) is said about relationships between those using the service? Is this encouraged or welcomed?
- What (if anything) is said about relationships between those using the service and someone outside the service?
- Is the service single sex or mixed sex?
- Does the service claim to be ‘user focused’ or ‘putting the individual at the centre’? If so, does it give any examples of how this works in practice?
- Does the service have a related religious connection (eg a Catholic or Orthodox supporting organisation)? If so, how does this affect the attitudes and actions of the staff and the service’s approach to sexual rights?

“ Chapter 1 ”

Looking at a possible new service?



Most importantly – what do documents NOT say?

If there is no mention of such matters anywhere in the documents – then it becomes even more important to ask all the right questions!

WHAT TO ASK



TO MANAGERS AND STAFF



- If the service is single sex – ask why? Are there any plans to make it mixed sex in future? In a single sex service how do the staff react to sexual activity between the people using the service or with people from outside the service?
- What is the attitude of the service towards ‘girlfriends and boyfriends’? Are they allowed, just ‘tolerated’ or encouraged?
- Ask how decisions are made regarding individuals who use the service? (The most common answer is some form of ‘case conference’ where various engaged professionals (possibly with a family member present) encourage or persuade the supported person to agree with the meeting’s collective decision. That is NOT supported decision making!)
- Ask how the service expects the staff to react if they found a couple kissing and cuddling?
- Ask how the service expects the staff to react if they found a couple in bed together?

“ Chapter 1 ”

Looking at a possible new service?



- Ask how the records of people they support are kept confidential? Who has access to them? Will you have access to them? If so, how do they know that your relative has already agreed to this?
- Can the service point to current or past service users who have partners (including marriage)? How (if at all) did the service support the development of these relationships?
- What information and guidance is available to people using the service about relationships, sexual rights and/or contraception? Is this information accessible for persons with intellectual or other disabilities?
- How many people using the service have asked for this information/guidance in the past?
- Does the service already have staff (internal or external) who are able to give advice and guidance to individual service users about relationships and sexuality?
- To what extent is the service willing and able to provide privacy to service users for them to engage in romantic/sexual activity?

“ Chapter 1 ”

Looking at a possible new service?



- Does the service use a lead care worker approach? How is the lead care worker chosen? Will your relative have any choice in this decision? Can someone change their lead worker if they don't like them?
- What training is given to lead care workers around relationships and sexuality?
- If you are unable to find out what the policy of the organisation is on this, it would be reasonable to ask the service manager about it. If you learn that the organisation does not have an official policy about this, then you should ask why. Does the service intend to develop one in the very near future?
- Finally, there is the uncomfortable matter of any forms of abuse – including sexual abuse – in the past history of the service. For many years, many services closed their eyes and minds to this by saying ‘It could never happen here!’. Recent history shows all too clearly that this is all too often simply not true. If it happens the important thing is how a service deals with it. It would be sensible to ask the Manager what would happen if an instance of sexual abuse was established.

“ Chapter 1 ”

Looking at a possible new service?



Asking service users about this is obviously a 'sensitive' issue, so asking direct questions is not a good idea.

SERVICE USERS

They might not want to talk about it at all – which is perfectly understandable - just put yourself in their position and you can see why!

Even so it may be possible to get some level of confirmation (or not) of the answers you get from the managers /staff. Every conversation will be different and you must be careful not to pry into private matters. It can take several conversations before you can get a clear picture of the service from the viewpoint of someone who actually uses the service. It would also be wise to try to get more than one viewpoint.

- You could simply start by asking them casually about what choices they get for the many daily things they do. For e.g. when to get up, what to wear, what to eat.
- What do they do in the day or at the day centre or at their job (if they have one)? Did they get to choose to do that or was it just 'given' to them. If they do not get choices about these everyday things, they are very unlikely to have choices about sexuality!
- Ask them what they like doing in their leisure time. Are they especially 'good' at something?

“ Chapter 1 ”

Looking at a possible new service?



- Ask them how they get on with other service users and the staff? Do they have a favourite? Why is s/he their favourite?
- If the opportunity arises from some comment freely made to you (and only if!) you might then ask about boyfriends/girlfriends and see what kind of response you get – not simply ‘do they have one?’ but more about how public/acceptable this is in the service.

Another valuable source of information can be found from relatives of other people who use the service. Be careful how you approach this topic because they might not share the same view as you do about the importance of supporting the sexual rights of their relative(s) in the service. Even so, you can usually find out if the service is a happy place, how well it responds to individual needs and how (in general terms) they deal with relationships and sexual matters.

Of course, other rights and elements have to be considered when looking for a new service providers (such as the location, accessibility, size, cost, etc).



But, the right to express your sexuality is fundamental and all services should now be able to respond appropriately to that. **Choosing any service should not mean having to accept that your relative will lose any of their human rights at all.**

“ Chapter 2 ”

Looking at the current service?



This Chapter deals with the situation where you really don't have much choice about a service – it might be the only one available in your area – so what you can do and say will always be influenced by other factors compared to the situation in Chapter 1.

You won't want to do or say anything that might:

- put your relative's place in the service in danger of being cancelled
- make him/her feel anxious or embarrassed
- with staff/other service users because of what you have said/done
- unsettle him/her to the extent that s/he might want to leave
- cause him/her to be treated so differently from other service users that this becomes obvious and a cause for complaint by others

Equally you don't want to:

- see your relative's rights to sexual expression denied or disrespected
- sit idly by and do nothing to change old/bad practices and attitudes
- achieve positive change just for your relative in the service – everyone in the service should have their sexual rights supported and promoted
- accept that there is nothing you can do to improve matters

“ Chapter 2 ”

Looking at the current service?



So, just like anyone promoting a change in attitudes and policies, you are always walking a difficult pathway. This involves finding and making allies in the push to change services. You might find ‘allies’ in the management of the service, amongst the staff or the other relatives of people using the service. Of course, the opposite is also true – you may find strong opponents of change anywhere in the service.

First steps to change

Firstly, ask around staff and other relatives about how they think the service is implementing the UN Convention on the Rights of Persons with Disability? Be prepared to get some strange answers, such as:

- ‘What’s that?’
- ‘We just do as we are told.’
- ‘The people here can’t do that sort of thing.’
- ‘Oh yes. We know all about it. It doesn’t really apply to us.’
- ‘Oh, yes. We did all that years ago, it’s never been a problem.’
- ‘We are trying to do this, but it takes time and effort and progress is slow but steady.’

The final answer is the best possible one you can hear. Your own experience and that of your relative with disabilities might well support what you hear from others. If a service says they have ‘already done all this’, be very careful to check that their claim is true.

Chapter 2

Looking at the current service?



Next, get a clear idea about how decisions are now made regarding the lives of the people using the service. For example, ask yourself what has happened to your relative in the service so far? That should give you a good guide.

Think about things like:

- Was your relative with disabilities present and able to express their wishes in any discussions about things which would affect his/her life? (eg changing rooms/ sharing a room with a new person, getting a job, changing their daily activity/routine etc)
- Were you present and involved too? Did your views influence any decisions?
- Were you speaking for yourself and/or for your relative? How did you find out what you relative wanted to happen?
- More widely, in your experience so far, do important things just 'happen' to people using the service, with limited or no involvement at all?

Once you have a clear idea about the amount of involvement service users have in decision making that affects them, you will then have a better idea of how far you have to 'travel' on the journey to SDM and the promotion of sexual rights in the service.

“ Chapter 3 ”

Checklist for Family Carers



Use the questions below as a way of getting an overall view of what a service is doing about supporting the sexual rights of the people it is supporting.

Many questions will not have a simple Yes/No answer, so we have also provided choices which allow you to record some replies which show some level of knowledge/understanding of the question.

There is no 'target score' for a service to have, but if you have any ticks in the "No/not at all" column then perhaps you should think carefully about how that situation can be changed!

Section Two has some useful tips on how to push for changes in such services.

“
Chapter 3
 ”

Checklist for Family Carers



Grade your answers to the question below on your overall impression of the service. <i>In your view does the service ...</i>	Yes/ totally	Mostly OK	So/ so	Only a little	No/ not at all
...know about the UN Convention on the Rights of Persons with Disabilities and what that means for people's sexual rights?					
...successfully try to implement the Convention in the way the service is run?					
...know about Supported Decision Making (even though they might not call it SDM)?					
... really make SDM work well in the service (ie: people using the service are <i>always</i> supported to make their <i>own</i> decisions about their life?)					
...explain things about relationships and sexuality in a way so that <i>both you and your</i> relative can understand them?					
... listen to the views of the people who use the service and (where possible) follow their wishes?					
... listen to what family carers have to say about the support their relative gets?					
...have clear policies around relationships and sexuality <i>which respect people's rights</i> ?					
...in day to day practice make any provision for the sexual rights and sexual expression of people they support?					
... have past experience of supporting individuals to express their sexuality?					
...have staff or access to experts who can help people with relationship/ sexual matters?					
... think that this is something which needs to be talked about?					
...actually deliver on what it <i>says</i> it will do about this topic?					
...put the person using the service at the centre of decision making on this?					



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Thank you for reading

**We hope this toolkit has helped you
understand a bit more this aspect of
life!**