



SMARTS

(Supporting Me About Rights to Sexuality)

Guidelines on Supported Decision Making in the field of sexuality for family carers.



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About these guidelines

The following Guidelines on Supported Decision Making in the field of sexuality are specifically addressed to the three main groups supporting Persons with Intellectual Disabilities (PwD) and/or Persons Mental Health Conditions (PwMHC). These three groups are families/family carers, professionals working in support services and service managers.

The guidelines will focus on Supported Decision Making (SDM) processes that address the wide range of different real-life contexts in which sexuality is present and that any member of these three groups might face when providing support to Persons with Disabilities from your specific perspective and/or labour context.

Please note that throughout this document, Persons with Intellectual Disabilities and Persons with Mental Health Conditions will be referred to as 'PwD' (Persons with Disabilities), or the 'SP' 'supported person(s)'.

The guidelines are structured as follows:

Please note: All of Sections 1 - 4 should be read by everyone, together with the relevant Sections from 5-14. Some readers may find it useful to see how others involved approach this issue and understand what concerns they might have.

- » **Section 1. An Introductory section:** you will be able gain awareness of the specific context regarding sexuality and persons with disabilities in general and specifically with regards to PwD.
- » **Section 2. General Supported Decision Making:** an introduction on the contents and process related to Supported Decision Making is-provided so that you can gather a broad overview on how it works and have some guidance on how it can best be implemented in a wide range of daily life wide-ranging situations.
- » **Section 3. Supporting Decision Making in the field of sexuality:** This section will address key areas that are intrinsic to the Supporting Decision Making in the specific field of sexuality and that you should be aware of when implementing the SDM approach in practice with PwD.
- » **Section 4. Safeguarding and sexual abuse.** There is the possibility that implementing Supporting Decision Making in the field of sexuality might uncover some form of current or past sexual abuse from the supported persons. This section will provide specific insights and orientation on these issues so that all involved are aware of this and know how to respond.
- » **Section 5. Supported Decision Making in the field of sexuality specifically addressed to support professionals.**
- » **Section 6. SDM & love, emotional attachment and relationships conflicts.**
- » **Section 7. SDM & contraception, retaining fertility and forming a family.**

- » **Section 8. SDM & taking care of your own body & sexually transmitted diseases.**
- » **Section 9. SDM & the use of the internet & social media for romantic & sexual purposes**
- » **Section 10. SDM & Pornography.**
- » **Section 11. SDM & 'commercial sex'.**
- » **Section 12. SDM and masturbation.**
- » **Section 13. SDM and inappropriate sexual behaviour**
- » **Section 14. SDM and sexual orientation**
- » **Annexes**

The SMARTS project & partnership in a nutshell

These guidelines have been developed within the **European Funded Project SMARTS**.

What is SMARTS all about? 'SMARTS' is short for Supporting Me About Rights to Sexuality and is an exciting project about sexuality rights and disabilities. It has a duration of 3 years, starting 1st September 2020 and finishing on 31st August 2023.

Brief context of the project: We all know that, historically speaking, people with disabilities were either not thought to have sexual desires, or if they did, it was something to be suppressed and not discussed. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) says very clearly in Article 12 that people with disabilities enjoy equal recognition before the law and legal capacity on an equal basis with others. In this regard, there is increased awareness on the importance of addressing the sexuality of persons with disabilities as an inherent right, with wide educative and informative material and resources being produced. However, in spite of the fact that a lot of excellent educational material and training has been produced to raise awareness about sexuality, it seems to have had a low impact so far with regards to how persons with disabilities are actually able to practise sexual activities and express their sexuality in whatever way they choose.

Main aim of SMARTS. The SMARTS Project is devoted to filling this gap, between knowledge learnt and practical implementation. Using a technique called Supported Decision Making the SMARTS project will explore ways to return to PwD control over their own choices about their sexuality. Using the SMARTS products, they are expected to become more empowered to make supported decisions regarding their sexuality and for supporters to feel better equipped to support decision making.

Project products: The project will produce the following deliverables:

- » Guidelines on supported decision making and practices in the field of sexuality for PwD are addressed to family, professionals and service managers.
- » Awareness toolkit for PwD.
- » Training course for professionals.

The Project partnership is made up by an international partnership of 5 organisations with complementary expertise:

» **Three service providers:**

- Astres Foundation, the project coordinator (Spain),
- Associação para a recuperação de cidadãos inadaptados da lousa (A.R.C.I.L) (Portugal),
- Theotokos Foundation (Greece).

» **Two technical partners:**

- Social Care Training (UK) producing staff training,
- EASPD (Belgium) representing service providers.

The project draws heavily for its use of SDM methodology on an earlier EU funded project / *Decide*. For more information on this project and SDM visit:

<https://www.supportgirona.cat/projectes/i-decide/>

Want to know more about the project? For more information about the project and to be able to download the project deliverables free of cost, please visit www.smarts-project.com.

List of abbreviations

- » **EU:** European Union.
- » **HIV/AIDS:** Human Immuno Deficiency Virus/ Acquired Immune Deficiency Syndrome.
- » **IPFF:** International Planned Parenthood Federation.
- » **LGBTI:** Lesbian, Gay, Bisexual, Transgender, Intersex.
- » **MS:** Member States
- » **PwD:** Persons with intellectual disabilities and/or mental health conditions.
- » **SDM:** Supported Decision Making.
- » **SP:** Supported Person.
- » **STD:** Sexually Transmitted Disease.
- » **UN:** United Nations.
- » **UNCRPD:** United Nations Convention on the Rights of Persons with Disabilities.
- » **UNFPA:** United Nations Fund for Population Activities (now known as The United Nations Population Fund).
- » **WHO:** World Health Organisation.

Introduction: Sexuality and persons with disabilities, a fundamental right for all

- ▶ **What is sexuality in the field of disabilities? Some key concepts to keep in mind.**

The overall concept of sexuality

Sexuality is a complex concept that can be quite difficult to define. It is often interpreted differently and can be viewed from a broad range of perspectives. According to the World Health Organisation (WHO 2006), sexuality can be defined as “*a central aspect of being human throughout life that encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, ethical, legal, historical, religious and spiritual factors.*”

Sexual and reproductive health: their importance in sexuality

Sexual and reproductive health and wellbeing are closely linked with sexuality. They are essential to safe and satisfying sexual lives and relationships. The WHO emphasises the fact that it is important to have a positive approach to sexuality. It should be focused on pleasurable sexual experiences free of coercion, discrimination and violence. This positivity aspect also needs to be shared and promoted by policymakers, educators and care providers in order to develop sexually healthy societies (WHO, 2006). Over the years, there has been a growing need for a positive and professional approach to sexuality of PwD. The sexual and reproductive health of PwD, as well as their access to sexual health services and information, have been systematically neglected. This neglect has been due to widespread stigmas, misperceptions and ignorance. (United Nations Department of Economic and Social Affairs, 2019, pp. 5).

Consent: a main aspect in the field of sexuality

The topic of sexuality and relationships is closely linked with emotions, feelings and desires. All of these can be expressed in many different ways and largely contribute to satisfying and safe sexual relationships. Consent is a main topic at the heart of sexuality. Indeed, recognising a partner’s emotions and feelings is key to understanding, giving and recognising consent to a sexual relationship that will be experienced as a pleasure by those who take part in it. Cognitive development was recognised by the WHO (2006) as one of the three issues that emerge when it comes to healthy sexual development. It entails the acquisition of the ability to think and reason abstractly, weigh consequences and make decisions. The UNCRPD (Art

23a) explicitly says that free and full consent of the intending spouses is a must for PwD to be able to marry and to found a family.

Recognition of emotions and desires

Several studies suggest that PwD can identify their own emotions and recognise facial expressions in others. This skill can even be further improved with training (Moore, 2001). More specifically, they are able to understand the difference between pleasant and unpleasant emotions. However, they have more difficulty recognising some specific emotions (McClure et al., 2009). These studies thus show that, with the right support and education, PwD can build the skill to learn about consent and make decisions based on not only their own emotions and desires, but also considering the feelings and emotions of the people around them.

► Legal context and state of play at EU-level

Different pieces of legislation at a glance

When it comes to sexual rights of PwD, there are different relevant statutes and regulations at European level:

United Nations Convention on the Elimination of All Forms of Discrimination Against Women (1979)	<ul style="list-style-type: none"> » International human rights treaty. » Guidelines to end discrimination against women. » Prevention of discrimination at 3 different levels: personal, organisational and national.
Programme of Action on the International Conference on Population and Development (1994)	<ul style="list-style-type: none"> » International action plan. » Human rights, sexual and reproductive health, gender equality. » One of the goals: access to reproductive and sexual health services, including family planning.
International Planned Parenthood Foundation's Charter on Sexual and Reproductive Rights (1997)	<ul style="list-style-type: none"> » Ethical framework. » Details the different sexual and reproductive health issues. » Advocacy tool. » Aims at increasing the capacity of Non-Governmental Organisations (NGOs) to work on human rights actions in the field of sexual and reproductive health.
EU Charter of Fundamental Rights (2000)	<ul style="list-style-type: none"> » Fundamental rights and liberties for citizens and residents in the EU. » Binds the EU States in 6 areas. » Some of these areas: dignity, freedom and citizens' rights.

<p>United Nations Convention on the Rights of Persons with Disabilities (2006)</p>	<ul style="list-style-type: none"> » International human rights treaty. » Protect and promote the human rights, dignity, fundamental freedoms and full equality of PwD.
<p>International Planned Parenthood Foundation's Declaration to Sexuality (2008)</p>	<ul style="list-style-type: none"> » Collection of human rights instruments. » Related to sexual and reproductive health and rights.
<p>United Nations 2030 Agenda for Sustainable Development (2015)</p>	<ul style="list-style-type: none"> » International strategy. » 17 goals set by the United Nations for 2030. » One of the goals: empowering girls and women.
<p>Yogyakarta Principles relating to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics (2017)</p>	<ul style="list-style-type: none"> » 29 international principles. » Application of human rights in relation to sexuality, gender and eradication of sexual exclusion and abuse of LGBTI (Lesbian, Gay, Bisexual, Transgender, Intersex) people.
<p>EU Strategy for the Rights of persons with disabilities 2021-2030 (2021)</p>	<ul style="list-style-type: none"> » Vision of the European Commission for 2021-2030. » Proposals, initiatives and commitments to improve the lives of PwD.

The main piece of legislation you should remember: the UNCRPD.

When it comes to human rights of persons with disabilities, the most important legislation to date is the **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)** and its Optional Protocol (2007). The UNCRPD contains several articles especially relevant to the matters related to the rights to sexuality of PwD.

- » **Article 3:** The international treaty recognises as one of its general principles the importance for PwD to have individual **autonomy and independence**, including the freedom to make their own choices.
- » **Article 4:** Additionally, it states (Art.4.3) PwD should be consulted and given the opportunity to be **actively involved** in decision-making processes about legislation, policies and programmes, including those directly concerning them.
- » **Article 22** dictates respect for privacy, stating that no PwD shall be subjected to arbitrary or unlawful interference with his or her **privacy**, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation.

- » On that note, Article 23 calls for effective and appropriate measures to eliminate **discrimination** against PwD in all matters relating to **marriage, family, parenthood and relationships**, so as to ensure that they can enjoy the right to marry (as long as there is full consent of the intending spouses), can retain their fertility, and can decide freely and responsibly on the number and spacing of their children. With regards to exercising these rights, they should have access to age-appropriate information, reproductive and family planning education, and should be provided with the necessary measures to do so.
- » Article 25: lastly, alongside the right to education (Art.24), the UNCRPD requires PwD to be provided with the same range, quality and standard of free or affordable **health care** and programmes as provided to other persons, including in the **area of sexual and reproductive health** and population-based public health programmes.

A more recent piece of legislation you should be aware of: the EU Strategy for the Rights of persons with disabilities (2021-2030)

Both sexual and reproductive health of PwD have also been recognised in the EU’s recently published **Strategy for the Rights of persons with disabilities** (2021), which is embedded in the European Pillar of Social Rights targeted at the year 2030. It explicitly calls for improvements in access for PwD to sexual and reproductive healthcare and prevention services.

► **Persons with disabilities and sexuality**

Persons with disabilities have sexual needs just like everyone else. Like any other human being, they have sexual desires, need affective relationships and want the freedom to express their sexuality.

If we think about the various reasons why anyone engages in sexual activities - it is immediately clear that human sexuality is quite complex! Exactly the same complexities apply to sexual activities and people with disabilities. Every person might have different reasons to engage in sexual activities. The reasons might be multiple, some of them might seem straightforward, and others far less obvious.

The study “Why humans have sex”, proposed to group the reasons why people have sex in 4 areas which include:

<ul style="list-style-type: none"> » For physical reasons (i.e., to reduce stress, for pleasure, because you are attracted to the person or want to feel physically desirable, because you are wanting to experiment). » For emotional reasons (i.e., to express affection, to express other feelings, to feel closer, for love, for commitment). 	<p style="text-align: center;">FUN FACT WHY HUMANS HAVE SEX</p> <p style="text-align: center;">A study found that there are over 237 reasons why people participate in sexual activities.</p> <p style="text-align: center;"><i>Can you think of reasons why to have sex? And reasons why not to have sex?</i></p>
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- » For **goal-related reasons** (for resources such as income, job, gifts, substances, to enhance social status like being more popular and telling friends, for getting back at someone, to make someone jealous, to reduce a headache, to help fall asleep).
- » For reasons related to **boosting self-esteem**, guarding the relationship, out of duty / pressure.

Sexuality can be regarded by some persons as a journey. If there is a lack of information or awareness-raising, persons with and without disabilities can feel overwhelmed by sexuality and the topics and questions it raises. Any person should feel empowered to make choices with regards to their sexuality that are right for their body and mind. However, the reality is that life is complex and that along the way there are obstacles, ups and downs which one needs to overcome.

Even now, many people still believe that PwD are either naturally asexual, or are not or should not be sexually active, which has been widely proven to be a misconception. This is clearly demonstrably wrong on so many levels: factually, morally and legally. This misconception also ignores their right and capacity to love and be loved, being intimate and caring.

Sexual wellbeing and health go beyond pleasure. Sexual wellbeing involves many other dimensions, including gender equality, recognition of sexual rights, the eradication of all forms of sexual violence, the fight against sexually transmitted infections, access to education or information about sexuality, but also not to be forgotten, and of utmost importance, love, affection and intimacy.

► Barriers for PwD to sexual and reproductive health and rights

As established in its definition, sexuality is a fundamental part of human life and universal nature. Yet, sexuality-based discrimination, societal stereotypes, and violence still pose significant threats today, especially to PwD.

Poverty: a barrier to the fulfilment of one's rights to sexuality

Poverty can be both a cause and a consequence of sexuality-based lack of information, inequalities and exclusions, resulting in poor sexual and reproductive health. People living in poverty could, for example, be missing out on proper care due to their inability to afford the necessary transportation to take them to services (WHO & UNFPA, 2009). The proportion of persons with disabilities living in poverty is much higher - in some countries even double - than that of the general population (United Nations Department of Economic and Social Affairs, 2019, pp. 5).

Sexual exploitation and abuse: a risk to be aware of

PwD, and particularly women and those with intellectual disabilities, are more likely to become the victim of **sexual exploitation and abuse** and even face **violations of their reproductive rights**. In some cases, PwD have been subjected to forced sterilisations, involuntary abortions (Tilley, McKenzie & Kathard, 2012), or procedures they do not understand and to which they have not given their informed consent.

Inadequate education preventing the expression of sexual desires

Another barrier for PwD is **inadequate formal and informal education** and information related to sexuality. Sex education is often not tailored to their needs, given solely by (formal) care workers, or taught from a physical standpoint, rather than providing a comprehensive schooling that includes the emotional and relational side of sexuality. Unfortunately, parents, health workers, and teachers have stated feeling unqualified to provide this particular education, as they are generally insufficiently trained, or do not feel comfortable communicating about sexuality (WHO & UNFPA, 2009). This is true even though there is a growing body of accessible material on this topic developed by specialists.

Lack of research in the topic: research and policies matter to implement and ensure the rights to sexuality

Another issue concerning the sexuality of PwD is the lack of research on this topic. Existing research is often outdated or insufficient. Additionally, there is little systematic follow-up and/or monitoring process based on progress indicators to ensure the effective implementation of policies and programmes.

The impact of these barriers on health

Due to these barriers restricting the access of PwD to sexual and reproductive health, they are at risk of being exposed to numerous health and reproductive threats such as unintended pregnancies, early childbirth, unsafe abortion and sexually transmitted infections including HIV/AIDS (United Nations Department of Economic and Social Affairs, 2019, pp. 64). Promoting a positive and healthy sexual development of PwD will require broad-spectrum understanding of these barriers to counteract them on both national and international levels.

Getting acquainted with Supported Decision Making (SDM)

► Introduction to Supported Decision Making in the framework of these Guidelines

These guidelines, in the framework of the European funded SMARTS project, are about providing guidance on how to better support PwD to make their own decisions in the field of sexuality, using the Supported Decision-Making Approach (SDM).

SDM can be used in all fields of the life of a person, that is ranging from the area of finances, health, leisure and many, many more! SDM can be used to make any decision actually!

Within this section, the key aspects of the SDM will be introduced. The aim is that anyone interested in this topic gets a comprehensive overview of its key elements and way of working.

We would like to note that the SDM methodologies and processes that will be presented in these guidelines are based on those developed in the I Decide project which was funded by the Erasmus+ Project of the European Union. For more information on the I Decide Project please visit: <https://www.supportgirona.cat/projectes/i-decide/>

► SDM and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)



SDM mechanisms are a key tool in implementing the (UNCRPD). The Convention requires Member States, decision-makers, professionals and society as a whole to move away from the well-established '**medical model**' of disability.

That model sees persons with disabilities in a passive role - as 'patients' who can be helped through medical treatment. This creates dependency and separateness. Instead, the UNCRPD asks Member States to challenge themselves and embrace and adopt the **Human Rights Approach**. This is the only way to ensure full and equal enjoyment of all human rights to persons with disabilities. The Human Rights Approach sees disability as an evolving concept that results from the interaction between persons with impairments and various attitudinal and environmental barriers to full participation in society. It promotes and respects the inherent dignity of PwD, focusing on equal opportunities, non-discrimination and inclusion.

The move from a Medical to a Human Rights model can be difficult, but it is vital to the establishment of Support Decision Making (SDM).

The Convention establishes that PwD have the right to be provided with personalised support so as to overcome the barriers that hinder their full and effective participation in society on an equal basis with others. The Convention's approach establishes that the primary purpose of 'support' is not just to provide services or support in the best interest of the person (this is often known as the substitute decision-making approach), but rather to provide support or services based on the will, wishes and preferences of the person receiving support. SDM is a process that enables the PwD to make his/her own decisions.

The SDM approach cannot be detached from a 'co-production' approach. 'Co-production' implies that the supported person participates in the design, implementation and evaluation of the service or the support they receive, generating a double impact. Firstly, the service itself is more effective at identifying the goals to be achieved, because it addresses problems identified or expressed directly by the supported person. Secondly, the supported person becomes empowered, because he or she is treated as an equal partner by professionals or other stakeholders, and his or her views are valued and respected.

Co-production is present at every stage of the SDM process because it demands – to the highest possible degree - the involvement of the supported person when defining the support needs, selecting the supporter, agreeing on the terms of the support provided and assessing satisfaction or evaluating the results.

Article 12 in the framework of the UNCRPD

Article 12 of the UNCRPD asserts the rights of persons with disabilities to enjoy legal capacity on an equal basis with others in all aspects of life, including their right to have equal access to own or inherit property and to control their own financial affairs. All of this is subject to safeguards which are proportional and tailored to the personal circumstances and applied during the shortest possible period.

Article 12 of the CRPD states very clearly that legal capacity is not to be confused with mental capacity, and the ability to make decisions, but it means the equal recognition of persons before the law. *No one should be deprived of their legal capacity, just because the person needs help in making decisions.*

Moreover, governments should provide PwD with any support they might need in their decision-making. Support can be both "formal and informal" and can constitute "arrangements of varying type and intensity". The type and intensity of support should take into account the diversity of PwD. Also, a range of appropriate measures should be available for them to receive adequate support, according to their will and preferences. Support could encompass providing information in plain language or easy-to-read documents, explaining different options, or, in some exceptional cases, articulating an opinion based on a deep knowledge of the will, wishes and preferences of individuals, stemming from a long-lasting trusting relationship between the person needing support and the person providing it. The opinions and decisions of the person with a disability should always be taken into account and respected, whatever the person providing support thinks of that opinion or decision. Implementing Article 12 of the CRPD requires a shift towards respecting Human Rights by replacing the substitute decision making approach with supported decision making.

In practical terms, exercising legal capacity means making decisions for oneself in all areas of life including medical treatment, housing, employment, relationships, finances, children, family planning, or property, amongst others. The Convention defines such arrangements as, for example, support networks, support agreements, peer and self-support groups, support for self-advocacy, independent advocacy or advance directives.

The SDM methodology described in these guidelines is driven by UNCRPD principles, so it is vitally important that any supporter following them fully understands, embraces and supports the Convention and its principles.

► So...what is Supported Decision Making (SDM)?

Support Decision Making (SDM) creates the right conditions for a PwD to make informed decisions on his or her own. Decisions are *not* made by others on their behalf or in their best interests. To do that is to slip back into *substitute* decision making.

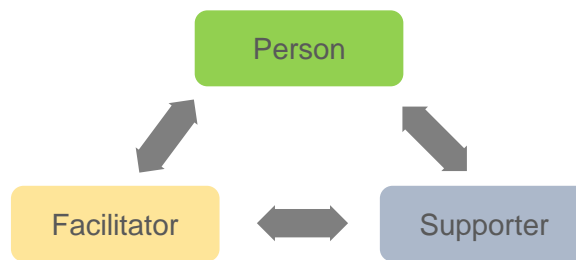
Duty of Care

We all have the right to make mistakes and unwise decisions (- we often learn from these!) 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. The balance between the right to autonomy and the right to protection can sometimes be a difficult one to maintain. We should consider this issue on a case by case basis, and great care must be taken to ensure that PwD are not treated differently from others during this process, and the fact of their disability must not be used to deny them their human rights. For example, action would likely be taken to prevent someone without an intellectual disability from committing suicide, harming others or self-harming (risk of immediate significant harm/death), but not be taken to deny the same person the right to smoke or eat an unhealthy diet, even though these activities could cause significant longer term harm. The key here is in making sure that the supported person understands the possible consequences of their actions and makes their decisions in the light of this. This is a very important issue to which we will return at different points throughout this guidance.

The SDM Agreement

The SDM Agreement is a key tool in the SDM process. It is a written document created to formalise the SDM process and is signed by the supported person (a person with a disability), the 'supporter', (who commits to provide guidance, support and assistance in making decisions in the areas of life defined in the document by the supported person) and the 'facilitator'. These roles will be defined and explained more fully below.

Making PwD aware of the SDM service and providing information about it is perfectly acceptable. The roles established in the agreement must be based on a trusting relationship with someone who will be the supporter and another person who will act as facilitator. The supported person must also be able to cancel or modify the agreement at any given time if they are unhappy with how it is working.



The SDM Agreement: a 3-way relationship

Although the UNCRPD is a legally binding treaty, at the time of writing only a few countries worldwide have made the necessary legal reforms to include, incorporate and recognise instruments based on the will, wishes and preferences of the PwD into their legal frameworks.

In practice, this means that:

- » The SDM Agreement is not legally binding, because it is not yet recognised under almost all national legal frameworks, although this will change over time.
- » There are no formal records of the SDM Agreement in any public Registry or approved by accredited, competent or legal bodies.
- » The Agreement by itself will not give any legal rights to the supporter to access or deal with services, external professionals or the social network of the supported person in order to get information, even if that information would be helpful or useful for the supporter or the person.

This lack of formal legal support for SDM in most countries is a drawback, but in practice it does not prevent SDM from being provided and significant gains in personal autonomy and choice are still possible.

► Creating a SDM Service

The SDM Agreement

1. Setting up the SDM Agreement

Professional obligations under the SDM Agreement include:

- » *A duty to provide the support service.* By signing the agreement, the people involved commit to support the person with a disability.
- » *A multidisciplinary professional approach.* SDM Agreements do not belong to any particular profession by definition, although SDM Agreements may involve a wide range of professionals such as social workers, care workers, lawyers, health professionals, or disability practitioners. Relevant social networks of the supported person – families, friends, flat-mates or other acquaintances – have to know about the existence of the SDM so that:
 - they may help in the effective operation of the Agreement;
 - they may provide innovative ways to support the individual.

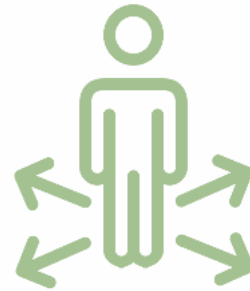
Standard confidentiality procedures and GDPR regulations will of course apply when dealing with personal information.

Roles in the SDM Agreement

Roles in the SDM Agreement

The three main roles in the SDM Agreement are:

- 1) The supported person;
- 2) The supporter;
- 3) The facilitator.



There are three general principles that all the parties in the SDM Agreement must follow:

- » All of the work and actions conducted under the SDM Agreement will be based on the wishes and preferences of the supported person.
- » The final decision has to be made by the supported person.
- » All decisions made by the supported person have to be accepted by the supporter, regardless of his or her own personal or professional point of view.

The roles of each of the parties are:

1. *The supported person will need to be able to:*

- » Express a wish to receive support or to end the support.
- » Communicate their preferences and express their wishes.
- » Develop a trusting relationship with (an) other person(s) whom they wish to receive support from (the supporter).
- » Indicate what kind of decisions or areas they may need support with.
- » Be aware that they are making the final decision (and not the supporter).



2. *The supporter:*

The supporter can be anyone in the person's immediate environment, family, friends, and social network or from a professional support service. The SMARTS project envisages the use of a supporter who will be able to coordinate resources and services available to the person, although we recognise that this may not always be possible.

The supporter will need to have the following skills and values:

- » The ability to respect and value the supported person's autonomy and dignity and to understand and respect the supported person's goals, values and preferences.
- » The ability to use and understand the supported person's preferred method of communication.
- » The ability to respect the particular decision-making style of the supported person and to recognise when and how support may best be offered to the person.
- » The ability to form a trusting relationship with the supported person and to spend as much time as required to support the person to make each decision.

- » Empathy and the ability to communicate clearly with the supported person in an appropriate and accessible manner.
- » To be able to reflect on their own practice.

Main tasks to undertaken by the supporter.

- » To assess the skills of the supported 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 supported person, an Individualised SDM Plan to help the person to take his/her own decisions.
- » To research materials and resources to help the supported person to understand the information they need to make their own decisions.
- » To assist the supported person to obtain advice from different sources.
- » To support the supported person at meetings with outside organisations or professionals to obtain information and explore options.
- » To help the supported person analyse the different options.
- » 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 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.

Note: *it is NOT necessarily the supporter's role to implement the SDM decision.* The allocation of a key worker who will organise the implementation of the decision is a matter for the staff team/organisation. It should be whoever is the best person for that job. This may well be the supporter, or it may be someone else. If it is someone else, then the recording of the SDM process will provide a very helpful starting point for the new worker:

- » to support the supported person to complete reviews and assessments;
- » to observe and record all the activities and actions arising from the SDM Agreement.

2. *The facilitator*

The facilitator works on the support relationship externally and is seen as a safeguard and advisor during the different steps of the SDM Agreement. The facilitator will be responsible for advising and guiding the supported person and the supporter when formalising each SDM Agreement. The facilitator's role can be understood as a specialised manager of the relationship between the supported person and the supporter.



The facilitator helps to create that relationship on a clear basis, monitor it and resolve any doubts or conflicts that may arise on both sides. In effect, the facilitator acts as a safeguard, ensuring the supported person's rights are respected.

The facilitator's role can be summarised as follows:

- » 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.

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 main stages of Supporting Decision Making

In practice, completing an SDM process will be carried out through four main stages, from requesting the service at the beginning to evaluating the support received at the end. The next diagram summarises the four stages of the SDM process.



Stage 1: Requesting the SDM service

The person with a disability will ask for support to make decisions in different spheres of their life. Usually, persons express their wishes to someone working in their support service or to a professional or a peer they know. In practice, those persons (who will potentially act as supporters and receive the request for support) must also be able to recognise how the SDM process could help a particular person, and report it to their organisation, manager or supervisor. From that point, a meeting with the person requesting support should be organised to introduce the SDM process, including a potential facilitator selected from a list or a pool of

persons prepared and skilled to exercise that role. The facilitator will explain to the supported person all the details about their rights, introduce the different people involved in the process, their roles and how the SDM process will work.

Stage 2: Identifying the supporter

Identifying the supporter is an essential part of the process. The supporter must be willing to explain things/actions in a neutral manner and enable the supported person to make their own decision - even if it is a decision the supporter disapproves of. It is crucial to understand, acknowledge and respect that the person requesting the support has the right to choose the person who will provide the support.

The facilitator will help the person to identify a supporter. The supported person could ask for more than one supporter, depending on the kind of decisions to be made. An interview will be held between all the parties to confirm the suitability of the proposed supporter.

Stage 3: Defining Content

The SDM Agreement is a time-limited commitment and it should be reviewed periodically. Updating and reviewing the contents and scope of the SDM Agreement every six months should be considered standard practice, even though its duration may vary depending on individual circumstances.

The SDM Agreement can be cancelled or terminated at any time by the supported person.

Contents of the SDM Agreement

In order to create an SDM Agreement, professionals should ensure the following elements are explicitly stated in the document.

- » The names of the Supported Person, the Supporter and the Facilitator.
- » A brief description of the three different roles.
- » As detailed a description as possible of the decisions in which the supported person needs support for in each relevant area.
- » The length and/or review date of the agreement.
- » Procedures to amend or cancel the agreement.

A standardised SDM Agreement template, with some examples, is provided in Annexe 1:

The Individualised SDM Plan

Once the initial assessment has been done, it is important and appropriate to ask the supported person for specific areas, topics, situations or issues where the person needs support taking decisions. The supporter must record these as the first item of the Individualised plan. The Individualised SDM Plan must include actions to be carried out for each issue, in order for a decision to be made, and the actions should be adapted to the skills and abilities of the supported person. The Individualised SDM Plan must reference the

resources, services or individuals from the social or professional network(s) that will be involved in each action, as well as the timetable of action to develop the plan effectively.

The Individualised SDM Plan should include, but not be limited to, information about how to:

- » Search for sources of information;
- » Coordinate actions with other support services or professionals to get information;
- » Communicate with the support services and the supported person's social networks about the issues included in the SDM Agreement;
- » Specify the actions to ensure the information and actions are well understood by the supported person;
- » Identify the different options with pros and cons for each issue or decision;
- » Support the person to get advice from experts where appropriate;
- » Communicate the decision made to the person's support services or social networks;
- » Actions to help implement the decisions made by the supported person.

The next task will be to coordinate the resources available to implement the Individualised SDM Plan. It is important to record observations and comments to evaluate the plan's effectiveness (i.e., did the actions taken help the supported persons to achieve their goals?) and its efficiency (i.e., quantify the amount of work or time needed to achieve the goals). The plan may be adjusted to take these considerations into account.

The frequency of the SDM working sessions will depend on the complexity of the issues to be decided and the actions to be conducted. As a general rule, one session per week is desirable.

A template for the individualised plan, with an example, is provided along with an Individualised SDM Plan Blank Form in Annexe 1:

Stage 4: Evaluation of the SDM service

Satisfaction with the SDM Service

Regular satisfaction assessments are encouraged, using the documents provided in Annexe 1. While this may vary from person to person, we suggest it should be done at least every two months. Look at the assessment documentation in Annexe 1 for both the supporter (*'supporter self-assessment form'*) and the supported person (*'supported person feedback form'*). Self-administration of these is the norm, but the supported person might need help looking at the results and this could lead to changes in the process or trying different ways to improve the support provided to the supported person.

The facilitator is the person in charge of supervising not only the SDM Agreement and monitoring the process, but also looking at the progress made by the supported person or the supporter. The facilitator's role includes being aware of the quality of the relationship between both parties. The review and use of the results of the self-assessment and feedback forms could be the starting point. Timely, scheduled and accurately recorded interviews with the supported person and the supporter will provide continuous checks on satisfaction and progress made and suggest any necessary adjustments.

Completed examples and information about the supporter self-assessment form and the supported person feedback form are available in Annexe 1, together with blank versions for use.

SDM Agreement review

Every six months the whole SDM Agreement should be reviewed and, if necessary, revised. Feedback should be shared between the three parties involved in the process. When required, an extension to the agreement will be made, including new issues or modifying or updating existing ones. In other cases, the SDM Agreement will not be renewed because the person doesn't want to receive support anymore or simply because it is not needed. There is no specific form for this review. The existing SDM Agreement form should be discussed and considered.

List of SDM forms/documents

- » SDM Agreement.
- » Individualised SDM plan.
- » Supported person feedback form.
- » Supporter self-assessment form.

List of SDM Process meetings

- » Satisfaction assessment: meeting held every 2 months between the supported person and the supporter. Forms used: supported person feedback form and the supporter self-assessment form. This meeting should be merged with the SDM review/evaluation, between the supported person, the supporter and the facilitator. Forms used: all current forms used.
- » SDM agreement review: meeting held between supported person, the supporter and the facilitator every 6 months. Form used: original agreement form, updated as needed.

Implementing SDM in the field of sexuality

► Introduction: Why use SDM in the field of sexuality?

SDM is a way to uphold a person's rights in general and also applies specifically in the field of sexuality. The SDM approach can be key to supporting PwD and to ensure a person makes their own decisions with regards to their reproductive and sexual health. The following chapter will provide guidance on the key aspects to take into consideration when providing decision making support, this time in the specific field of sexuality.

They are the following:

Areas underpinning SDM provision in the field of sexuality are:	<ul style="list-style-type: none"> » Identifying and addressing the need of the SP, » Communicating about sexuality, » Reflective listening about sexuality, » Myths, » Growth Mindset.
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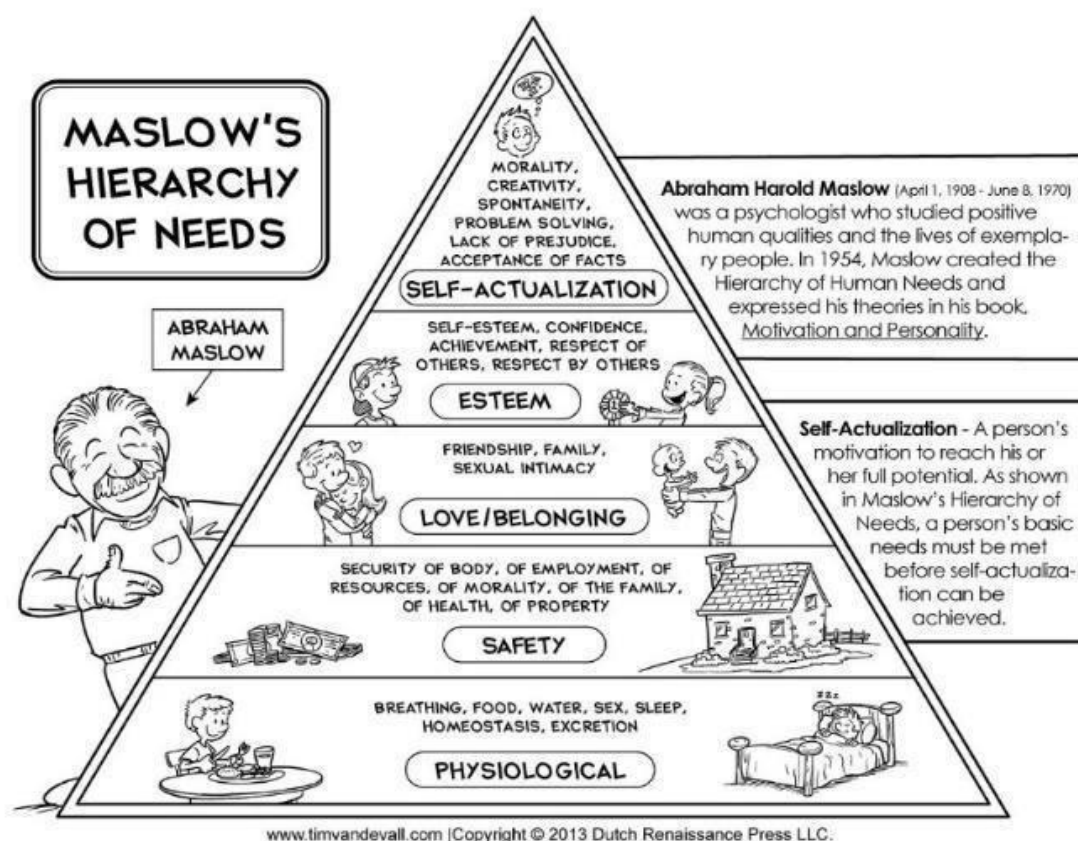
They will be described in detail in the following sections:

Introduction: Why use SDM in the field of sexuality?

The first key aspect to take into consideration when providing SDM in the specific field of sexuality is to be aware of the needs of the person we are supporting. A 'need' is understood as the sense of lack that a person might experience and that activates his/her desire to get what is lacking. Needs can be physical such as appetite or thirst, or psychological, objective or subjective. A hierarchy of needs can be established, as defined on the Maslow and Henderson scales:

AFFECTIVITY AND SEXUALITY IS A HUMAN BASIC NEED
 Already in 1943 SEX became part of the basic needs, which are the ones that must be satisfied and attended first.

In 1943 'sex' was already recognised as part of the basic needs of humanity: which are the ones that must be satisfied and attended first.



Self-awareness of PwD of their own needs is a starting point for needs identification and support

Achieving self-awareness of their own needs can be complicated for PwD. All human beings, from early childhood, are subjected to a variety of sensory/physiological stimuli that make them aware of their own needs and confront them with continuous decision making to address such needs. For them, these stimuli can be limited or restricted due to a wide range of circumstances, such as sensory limitations or the different views and approaches from supporters about what information and level of awareness PwD should and are able to have.

This could be characterised as the 'don't ask, don't tell' approach. If supporters don't ask PwD about sex and sexual needs, and never talk to them about it - their expectation is that perhaps sexual needs will just 'go away' and never happen.

The result of this is that PwD are often not sufficiently aware of their own sexual needs, or the wide variety of options available to address them. This denies both reality and the basic human rights of PwD. Information can open the door to self-awareness. Information, training and support to learn about and understand sexuality may well be needed before PwD can identify and articulate their own needs.

One way to help a PwD and their supporters to recognise sexual needs is through the recognition of emotions linked to them.

Emotions are neither positive nor negative. All emotions have a purpose, are valid and necessary. Emotions can be understood as our travel companions telling us what our needs are. For example, if a PwD feels sad about losing someone, he/she might probably need the

contact of another person for comfort; or if s/he feels afraid, s/he will need some level of protection in order to feel safe. In this regard it is essential PwD can learn to recognise certain emotions and receive support to express their responses, so that their needs can be properly identified and addressed.

When addressing and supporting needs in the field of sexuality, the earlier such needs are detected by supporters, the better. Long unmet needs can trigger negative behaviours and situations ultimately affecting the quality of life of the PwD generating frustration and isolation. If needs are detected at an early stage, they allow wider learning opportunities and decision options, this helps to avoid scenarios in which the situation deteriorates and triggers/ encourages one-sided interventions, which is contrary to the SDM approach.

Useful tools for the identification of needs of the Supported Person (SP)

Capacity building based on games

Through games it can be possible to identify if the SP holds an adequate relationship with other people. For example, by observing interactions of the SP with others through games and play contexts, aspects such as if the SP does not dare shake hands, to touch another person, if the physical contact is excessive and inappropriate or if he/she uses harsh comments. This can open the possibility of talking to them about general interaction with others, sexual relationships and managing physical contact. Space to address questions and/or needs can be offered.

Stimulation exercises

Within a training context or within the programming of support activities, it is possible to use exercises allowing the SP to discover new areas, such as their own body, the body of others, relationships with others, expressing feelings, expressing agreement or disagreement, expressing moods, setting boundaries for privacy...

Personal interviews

Once a link between the supporter and the SP has been established it is possible, through semi-structured interviews, to talk openly with the SP about sexuality, their preferences, needs, knowledge and experiences. different support tools can be used, e.g., drawings, comics, stories, pieces of movies.

Interviews with families/persons of reference

An additional way to identify needs of the SP is by interviewing relatives or other persons of reference such as friends, legal guardian, always with the permission of the SP. This can help supporters to gain additional perspectives and insights regarding a specific context and options for ways forward.

Observation

As simple and mundane as 'observation' might initially appear it is a key tool allowing us to gather a lot of information and is very valuable in helping to identify and support needs. We observe in order to know the PwD, to learn about his/her context and needs.

Keys for good observation:

Focus on the here and now and try to keep objectivity. We are, of course, aware that subjectivity cannot be avoided 100% and that complete objectivity is not possible. Judgements are part of life and may involve value judgements. Taking this as a starting point, when observing, try to focus on making your views transparent, articulated with evidence and open to challenge.

“Differentiate what you think is happening
from what is really happening.”

► **Communicating about sexuality**

The second key aspect to take into consideration when providing SDM in the specific field of sexuality is to ensure good communication between the SP and the supporter. Good communication will help avoid misunderstandings and ensure specific needs, preferences and wishes are fully and adequately understood and addressed.

What is communication?

Communication is what we do a large part of the time, if not all the time. We use a lot of different words to describe this: conversation, chat, discussion, interview, etc. All these suggest the spoken word, but we now also have communication via social media such as blogs, tweets, messaging, emojis, etc. Communication is much more than the spoken or written word, it is any form of interaction with another; it can be a smile, a glance, a movement of the arm, body or facial expression. Interaction and communication are essential in establishing and expressing an individual's needs, choices, expectations.

Why do we communicate?

Everyone needs to communicate. It is a basic instinct and essential to stay alive, become part of society and know that you are valued and wanted by those close to you. A total lack of opportunity to communicate (or an unwillingness to do so) can be very damaging to an individual – not only in practical terms (e.g., How would you ask for food or attention?) but also in social and emotional terms. Very few people choose to be hermits. We communicate so that we can reveal part of ourselves to others and express our will. These are powerful motivators to communication.

Explaining the process...

In order for interpersonal communication to take place, it is essential that there are at least two participants available to invest in a “partnership” that enhances shared understanding. The partners interact through messages and feedback, using different channels to carry out this exchange. There will always be some kind of noise or barrier to good communication – which can be actual background noise or even the simple fact of having different ideas about the topic under discussion – that has a distorting effect over the information being shared. Although each communicator has his/her own culture, values, experiences which may

influence the way they understand each other at the start, over time they will start to share a common set of experiences in communication, becoming both more experienced in the process and gradually getting to know each other better.

What about Alternative Augmentative Communication?

Some PwD may face difficulties in communication and use Alternative and Augmentative Communication (AAC). AAC may be defined as a set of tools and strategies with the purpose of overcoming the varying daily communication barriers. AAC can take many forms in addition to speech: eye gaze, gestures, pictographic symbols, writing, facial expressions, touch, photographs, objects and parts of objects, speech synthesisers, etc. As a rule, an AAC System uses various resources and forms of communication, according to the individual needs and abilities of the communication partner. The form is less important than the function... mutual understanding is all that really matters (Burkhart, S / D).

► **How to communicate about sexuality**

First and foremost: How comfortable do you feel in approaching this topic with the supported person? If you are unsure or uncomfortable, it may be necessary to take some time for your own reflection and personal development.

When having a conversation about sexuality and intimacy, there are some key aspects to take into consideration:

- » Talk naturally, whilst also recognising that some topics might be intimate and create initial discomfort.
- » Demonstrate a willingness to listen, showing your belief in the person.
- » Speak clearly and calmly, avoiding jargon and complex terminology and using simple but correct information, with concrete examples.
- » Use simple day-to-day activities and routines to contextualise the topics being discussed.
- » Address social rules and value and respect everyone's privacy.
- » Be prepared to respond appropriately to the disclosure of unhealthy, vulnerable, risky or abusive situations and know when to refer on to the right person if such things are disclosed (see Section 4 below for further information on this).
- » Be able to demystify your own and the person's myths and beliefs about sexuality and intimacy.
- » Pay attention to verbal (e.g., speech) and non-verbal (e.g., facial expressions, body posture) behaviours.
- » Promote the autonomy of the person.

When and where to communicate about sexuality and intimacy with the PwD

The topic of sexuality & intimacy is one to be explored only when the relationship is established between the PwD and the supporter and allows for a comfortable and trusting conversation to be established. In some situations, however, it may be necessary to approach this topic earlier in the process, if a major question or conflict in relation to this issue has come up.







Whenever you decide to approach this topic with the PwD, or if they decide to approach you with some related question, it is very important to ensure privacy and confidentiality of the exchanged information. Having this conversation only with the persons involved and in a reserved space is the best practice to adopt.

How to communicate about sexuality and intimacy with the PwD

Communication is “a two-way street”! It is as important to be listened to and understood, as it is to be able to actively listen to the other person. Being open about what communication may look like and how it may be co-created is also fundamental.

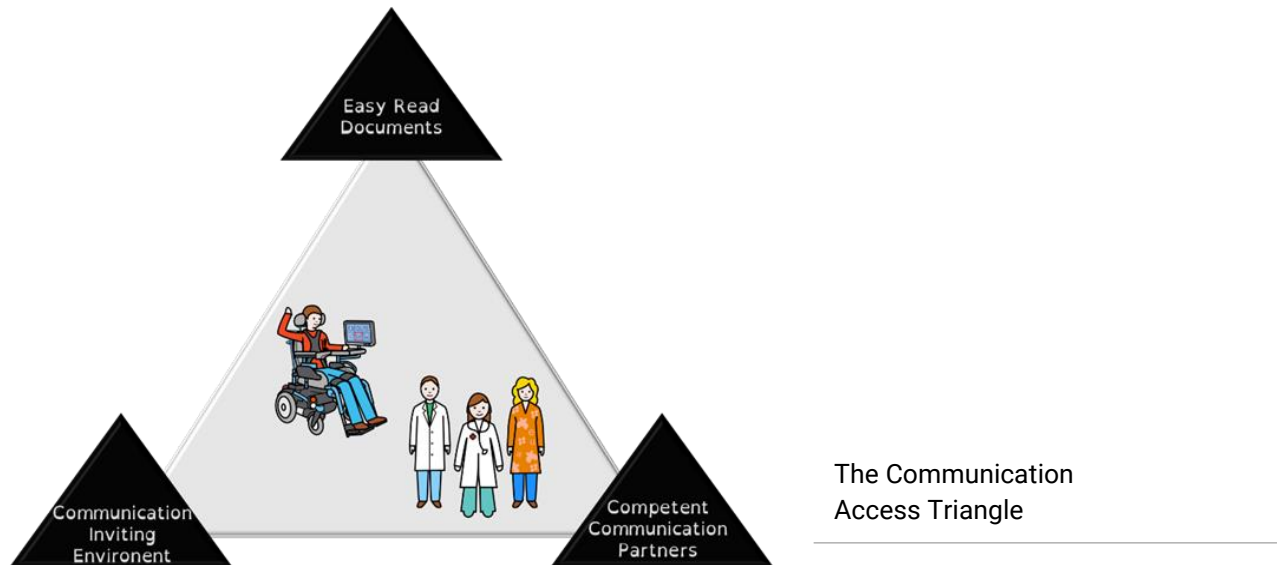
In order to communicate with PwD about sexuality and intimacy, it is important not to feel afraid of addressing the issue, since it is a subject with similar importance to many others (e.g. sleeping and eating).

As general recommendations, it may be useful to remind yourself to:

	<p>RELAX: Most of the time, when the PwD says he/she wants to have a relationship or have a conversation about sexuality, people become anxious, because it is immediately assumed that sexual intercourse has or may soon take place.</p>
	<p>REMEMBER: Before sexual intercourse is even considered and/or discussed, there is normally a long process, starting from meeting the person, creating a relationship and, eventually, becoming intimate and sexual partners. There are also many other themes related to sexuality and intimacy that are subjects worthy of reflection.</p>
	<p>REVEAL: Sexuality is a subject like any other of human behaviour, that it is experienced by all people. Many people do not normally talk about their sex life to others or may feel awkward about this, but when the need to do so arises, it is normal to seek help from others. Having the confidence and being encouraged to talk to someone you can trust about it is essential.</p>
	<p>REACH DEEPER: Start the conversation with an easier subject that leads to all the other more specific, and sometimes, uncomfortable issues. This may help you and the PwD.</p>
	<p>RESEARCH: Let the conversation develop by using open and non-invasive questions, depending on the person and your relationship with him/her, and let the conversation evolve naturally.</p>
	<p>REFLECT: Listen carefully and help the PwD consider all the possible options, supporting him/her with clear and rigorous information. Think about your own feelings, how prepared and comfortable you are to deal with the topic and, if necessary, ask for professional help.</p>

► **Communication Access and... How to improve it?**

In order to create good communication access, it is fundamental to consider the Communication Access Triangle!



Here are some ideas to create Inviting Communication Environments:

- » Organise spaces where people can sit down and have a calm and private conversation.
- » Create an environment with the minimum or (better still) no visual distractions.
- » Create quiet environments, eliminating or diminishing competing noise in the space.
- » Provide relevant information around the space (e.g., visual supports for communication - communication tables with pictures to facilitate the understanding of complex vocabulary).
- » If appropriate, clearly inform the participants ahead of the conversation about the schedule of the meeting, the intended purpose, the topic to explore etc.

Here are some ideas for adapting Easy Read Documents:

1. Create a clear index that facilitates the navigation within the document.
2. Use simple vocabulary, supported by pictures and examples.
3. If complex or specialist terminology is needed, provide a glossary with simple and practical explanations.
4. Use clear, shorter and active voice sentences.
5. Use one sentence per line, avoiding the splitting of sentences between lines.
6. Avoid long paragraphs split between pages.
7. Use simple, clear and non-serif fonts for the text, using size 12 or more.
8. Format the text aligned to the left, avoiding long blocks.
9. Keep the spaces between the lines 1,5 or more.

10. Use pictures to support understanding, consulting with PwD about its appropriateness.
11. Provide the main ideas or a key message at the end of each section of the document.

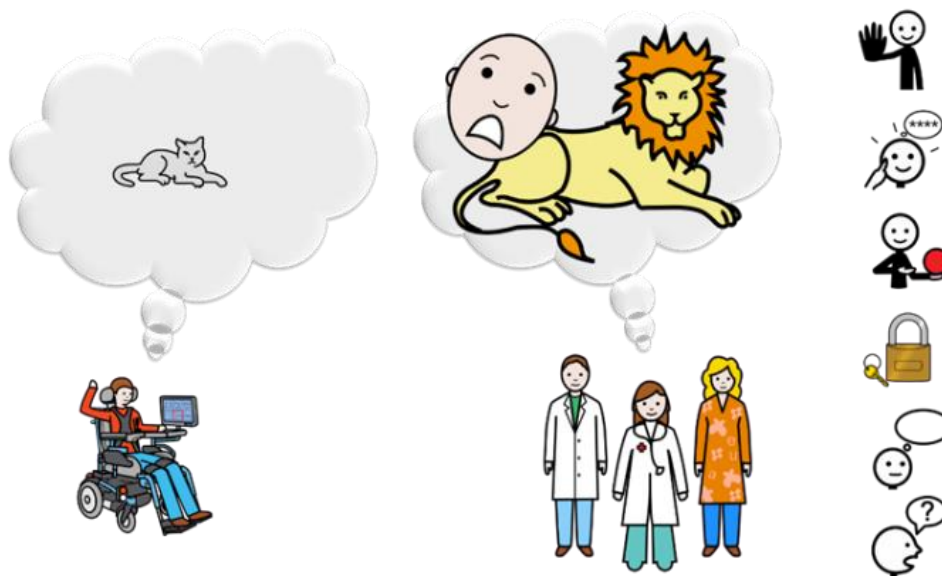
Here are some ideas to improve your role as a Competent Communication partner:

- » Use reflective listening paying attention to verbal and non-verbal aspects of communication.
- » Provide verbal information, enhanced by the use of visual supports.
- » Create pauses and provide time for the other person to process the information and respond.
- » Balance the conversation between your own initiatives and your partner's initiatives.
- » Balance the conversation between questions, comments and clarifications.
- » Share the responsibility for any misunderstandings or communication breakdown.
- » Learn from misunderstandings and communication breakdowns and find new ways to enhance the success of communication.

Available resources and other related projects:

- » CHANGE UK - [CHANGE - Learning Disability Rights Charity - Easy Read \(changepeople.org\)](http://changepeople.org)
- » Learning Disability England - [Easy Read Information – Learning Disability England](#)
- » Easy Read Guidelines - [comm basic guidelines for people who commission easy read info.pdf \(easy-read-online.co.uk\)](http://easy-read-online.co.uk)

Having a conversation with PwD about sexuality and intimacy does not have to be difficult! It is very dependent on our own attitudes, myths, beliefs and concerns. Bearing in mind that sexuality is a natural issue, a natural and simple approach is the one to use.



The expectations of different parties about communication about sexuality

► Reflective listening about sexuality

The third key aspect to take into consideration when providing SDM in the specific field of sexuality is reflective listening.

Listening is one of the building blocks of communication. Effective listening is based on the ability to listen reflectively, in order to accurately decode a sender's communication message (Khanna, 2020). This ability is not an inherent talent, but a skill that can be developed through practice.

Reflective listening is a term used to describe an attentive, involved listening approach, focused on gaining insight on the sender's perspective (Khanna, 2020). It is a "checking out" procedure to make sure that both the sender and the receiver understand the true content of the communicated message. Reflective listening emphasises that the content of the sender's message is not to be altered by any additions from the receiver, such as advice, assumptions, conclusions, evaluations, analyses, or personal values and opinions (Arnold, 2014). As a process, it comprises attending skills, and reflective skills.

(You can check <https://www.gordontraining.com/free-workplace-articles/active-listening/>.)

Attending skills ensure that the receiver's full attention is focused on grasping the true message communicated by the sender. Some attending skills are:

Communicating interest: communicate involvement to the sender, offering minimal encouragement through verbal ("uh-huh, "tell me more") and nonverbal cues (maintain eye-contact, nodding).

- » *"I had the most terrible day at work"*
- » *"Tell me more about it. What happened?"*

Paraphrasing/Summarising: paraphrasing and summarising ("What I hear is..." / "I believe you are saying that...") offers back to the sender their message, in the words of the receiver. This technique clarifies content and promotes mutual understanding.

- » *"The manager always gives me loads of tasks to do. They are impossible for one person to complete!"*
- » *"So, you are saying that your manager has unrealistic expectations of you about the workload he gives you."*

Asking for clarifications: Unclear assumptions and premature conclusions can greatly distort the content of the message. At points where more clarity is needed, clarification questions are encouraged to avoid miscommunication ("what exactly do you mean by...?", "Am I right in thinking that...?").

- » *"That's right. I feel like I am going to explode."*
- » *"What exactly do you mean? What will you do if you <<explode>>?"*

Asking open-ended questions: open ended questions provide information with minimal direction and are a good tool for exploring and understanding the sender's perspective.

- » *“That is a tough situation. How do you feel about all that?”*

Once the concept of the sender’s message has been grasped through attentive skills, the next step is the reflective process, which follows two directions (Karnieli-Miller, 2019):

Reflecting the perspective of the sender: reflecting the sender’s perspective is the process of communicating back to the sender both the content of the message and the feeling that underlies it. The purpose is twofold: first, to allow the receiver of the message to verify the accuracy of their understanding of the sender’s point of view and inner experience; second, to allow the sender to “hear” their own personal meanings, gaining greater understanding of themselves. Once again, the aim is to stay true to the message already expressed, without imposing personal views or assumptions.

“What I understand is that your workload and your manager’s unrealistic expectations on your performance have taken a toll on you. You sound stressed and frustrated.”

Reflecting on oneself (Self-Reflection): self-reflection is a process of introspection that focuses on increasing self-awareness and self-understanding about what is going on inside oneself during the course of listening. This includes noticing the personal thoughts and feelings that arise while listening to the sender’s message, especially those that interfere with being open to their perspective. During self-reflection, some questions that can be asked are:

- » *What part of the message triggered my emotional reaction?*
- » *Does my point of view permit me to listen actively and reflectively right now?*
- » *Am I really trying to listen, or waiting for my turn to speak?*
- » *Am I really trying to understand the sender’s point of view, or trying to impose mine?*

Exploring these questions can help identify and manage personal judgements and opinions that interfere with listening, leading to a decrease in the noise of communication.



► Exploring values and attitudes about sexuality

The fourth key aspect to take into consideration when providing SDM in the specific field of sexuality is to be aware of your own values and attitudes about sexuality, since they play a major role on how we relate and react to certain topics.

What are attitudes and how do they influence behaviours?

An attitude refers to a set of emotions, beliefs, and behaviours about a particular object, person, thing, or event. Attitudes are often the result of previous experiences or education, and they can have a powerful influence over behaviour.

While attitudes tend to be enduring, they can also change. Psychologists define attitudes as a learned tendency to evaluate things in a certain way. Such evaluations are often positive or negative, but they can also be uncertain at times (Cherry, 2021).

The strength with which an attitude is held is often a good predictor of behaviour. The stronger the attitude, the more likely it will affect behaviour. Attitude strength involves personal relevance and if an attitude has a high self-interest for a person, it is going to be extremely important. As a consequence, the attitude will have a very strong influence upon a person's behaviour. By contrast, an attitude will not be important to a person if it does not relate in any way to their life (McLeod, 2018).

Components of an attitude

An attitude's structure can be described in terms of three components, in the ABC model of attitudes (McLeod, 2018):

- » **Affective component:** This involves a person's feelings/emotions about the attitude object. How the object, person, issue, or event makes you feel. For example: "I am unfamiliar with and therefore shocked by homosexual relationships".
- » **Behavioural component:** The way the attitude we have influences how we act or behave. For example: "I cannot tolerate having friends that have a homosexual orientation and will react negatively if a PwD expresses his/her intent in having a homosexual relationship".
- » **Cognitive component:** This involves a person's beliefs and values about an attitude object. Your thoughts and beliefs about the subject. For example: "I believe that the right sexual orientation is heterosexuality".

Common attitudes about the sexuality of PwD

The attitudes of staff and family carers to sexuality are especially crucial as they often control the access which individuals have to sex education and to opportunities for sexual expression (Ryan and McConkey, 2000).

Esmail, Darry, Walter and Knupp (2010) suggest that individuals with disabilities are commonly viewed as asexual due to a predominant idea of sex and what is considered natural in this field. A lack of information and education on sexuality and disability was felt to be a major contributing factor towards the stigma attached to disability and sexuality. Societal attitudes

and perceptions are driven by education and knowledge; if there is no exposure to sexuality and disability, society will probably have a narrow understanding of these issues.

Many people consider PwD to have insufficient awareness of their own sexuality and to be uninterested in establishing intimate relationships. According to statements of parents of PwD, they feel unprepared to offer their children sexual education and often fear that their son/daughter would not know how to express their sexual impulses in a socially acceptable manner and that a conversation about sex would only serve as encouragement for sexual behaviour.

Parents of PwD often worry that their sons/daughters might fall victim to sexual abuse and can therefore be rather restrictive when it comes to allowing them to have sexual experiences. Due to inadequate knowledge and the existence of prejudice, the sexual behaviour of men with intellectual disabilities and/or mental health conditions is often seen as abnormal in some way, while the sexuality of women with intellectual disabilities and/or mental health conditions is reduced to things like intimate female hygiene and protection against sexually transmitted diseases and pregnancy. These attitudes often result in the sexual drives of PwD being suppressed and/or the challenges presented by sexual behaviour ignored (Tamas, Jovanovic, Rajic, Ignjatovic and Prkosovacki, 2019).

Common myths about sexuality and PwD

PwD are rarely seen as sexual beings which leads to a range of myths and misconceptions surrounding disabilities and sex. This is the fifth key aspect to take into consideration when providing SDM in the specific field of sexuality. These myths contribute to perpetuating a distorted and false view on the topic.

What (not) to believe in?

If one is unaware of one's own beliefs, values and behaviours, one may develop strong attitudes about sexuality and disability that influence personal judgement and professional practice. One may actually start to believe in myths; widely held but false beliefs or ideas, often used to explain natural or social phenomena. Frequently, the myths we believe in are based on traditional ideas and stories that are spread around, as well as influenced by our own attitudes.

However, should one really rely on false beliefs and ideas to make judgements and decisions? Or... Shouldn't we follow international standards and evidence-based practices?

Myths or Facts – What do you choose to believe in?



Regarding the sexuality of persons with disability, there are several misconceptions that may distort how one thinks and influence our choices. Here are some common myths about this issue:

<p>PwD are asexual</p>	<p>One of the biggest barriers for PwD to expressing their sexuality is a negative societal attitude to them and the widespread assumption that they are not sexual. Like anyone else, PwD are “people first” and, therefore, are sexual beings like all of us, with sexual desires, feelings and fantasies.</p> <p>Another barrier is that some PwD may not be independent, for example, in terms of ‘self-care’ and may rely on others for this; in this case, the PwD may be seen as child-like and rendered sexless. However, no matter if, when, how, or with whom, they choose to express or not express their sexuality, all human beings are sexual beings, if they choose to be.</p>
<p>PwD are hypersexual</p>	<p>Interest in sex is seen as different between PwD and non-disabled people. In the case of PwD, some people may believe that their sexuality is exaggerated or even alarming. This has more often to do with the public expression of sexual behaviours by some individuals, than with the frequency with which they occur. This situation may occur among some people with more severe forms of intellectual disability (Maia & Ribeiro, 2010), who may inappropriately display sexual or sexualised behaviours publicly, unaware of the inappropriateness of such expression. There is not a real relationship between exaggerated sexuality and the organic issues of disability.</p>

<p>The sexuality of PwD is different</p>	<p>Disability may even compromise some stages of the sexual response and have functional implications on how sexual relationships are developed, but it does not prevent a person from having sexuality and from experiencing it pleurably. A person with a motor impairment, for example, may not be able access his/her own body or the body of a sexual partner without physical assistance, but that does not mean that with the appropriate support the sexual exploration itself will be abnormal, atypical or less pleasurable.</p>
<p>Sexuality of PwD is dysfunctional</p>	<p>In order to reflect on this myth, it is important to question oneself. Is there an ideal sexual functionality? Or is sexuality just functionally diverse for everyone? Whose problem is it, when the difficulty is to accept diversity in terms of how, when and with what materials and equipment sexual experiences take place?</p>
<p>Sexuality of PwD is secondary</p>	<p>Everyone values sex differently. If someone lives with a disability, he/she will likely have people around telling her/him that they have got more important things to deal with. However, is that really true? For whom? Who gets to decide that?</p>
<p>PwD are not at risk of sexual harassment/abuse</p>	<p>People with disabilities are far more likely to be victims of sexual assault; statistics suggest between 2 to 10 times more likely. People with developmental disabilities are at risk of being sexually abused because they are frequently taught to comply with what others are asking them to do, and they often want to please others and so may have difficulty differentiating appropriate from inappropriate situations (Basile, Breiding & Smith, 2016). Here is a good reason to teach SDM in this field and to clearly explain what is safe and what is dangerous!</p>
<p>PwD are not capable of becoming parents</p>	<p>Creating a family is a natural part of human existence and many people with disabilities choose to have children of their own. It is an established Human Right and everyone should have his/her opinion and decision respected.</p>
<p>PwD can't make good choices regarding family planning</p>	<p>In many cases for PwD the decision to have or not to have children may be challenging and require assistance or even the consent of parents and/or guardians. Even in such cases, PwD should be encouraged to have autonomy and responsibility and be supported in order to make their own choices, benefitting from all the support needed/provided. The lack of support for the PwD, more than the disability by itself, may be a burden and create challenges in making the best-informed choices and in taking care of a family and a household.</p>

<p>PwD are always heterosexual and their gender matches their sex</p>	<p>As with any part of the community, PwD can and do identify as Lesbian, Gay, Bisexual, Transgender, Transsexual, Queer and/or Intersex (LGBTQI). However, as sometimes people with a disability are incorrectly seen as being asexual, people without disability may forget this fact.</p> <p>PwD are sexual people, have feelings and want to demonstrate them. The physical, sensory or intellectual characteristics of a person should not be constraints on the expression of their sexuality. The sexual behaviour and preferences of each person are individual and unique, whether or not they have a disability.</p>
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Wherever the context you are working in or the kind of assistance you give to the PwD it is important that understanding of the lives of PwD are based on rigorous and real information and not on misconceptions or traditional ideas. Even more important, it matters that life decisions are made by the PwD him/herself, with all the necessary support.



► **Growth mind-set**

The sixth and last key aspect to take into consideration when providing SDM in the specific field of sexuality has to do with maintaining a growth mind-set that allows supporters to move beyond preconceived beliefs and ways of doing things and be open to new knowledge and new situations.

The importance of maintaining a growth mind-set

People who have a "fixed mindset" believe that many of our abilities, including the way we think, are "fixed" and cannot change. People who demonstrate "growth mindsets" believe that most of our abilities can be developed through hard work and dedication. Having a "growth mindset" means that you understand, that you can improve, learn and think in different ways throughout time, as long as you put in the effort.

Growth mindsets understand the importance of persistence and determination, especially when dealing with new challenges (Cherry, 2020).

When supporting PwD in accessing their right to sexuality, having a growth mindset is important because it can help us overcome obstacles we may face when learning something new, dealing with a novel situation or developing new skills; in fact, we, family carers and professionals and managers, are all learning and evolving in this field.

Safeguarding and Sexual Abuse

There is the possibility that implementing Supporting Decision Making in the field of sexuality by supporters might uncover some form of current or past sexual abuse from the Supported Persons. This section will provide specific insights and orientation on this issue so that supporters are aware of this and prepared for it.

► Safeguarding and sexual abuse

'Safeguarding is what we do to keep people safe from abuse, bad treatment, neglect or exploitation. Most of the time when people talk about safeguarding, they are talking about protecting children or vulnerable adults.' (Mencap 2021)

Adults with intellectual disabilities and mental health conditions are particularly vulnerable to abuse. They are termed 'vulnerable adults'. This is because:

- » They may not recognise abuse.
- » They may not feel able to ask for help, particularly if they rely on the abuser to meet their needs.
- » They may not know where to go to for help and have limited access to options.
- » They may not have the communication skills to verbalise what is happening.
- » The signs of abuse may be seen as part of the person's condition and missed, misinterpreted or ignored.
- » They may be less likely to be believed.
- » They may be used to doing things to please other people.
- » They are likely to be in a less powerful position than the abuser because of their disability/mental health condition, which makes abuse more possible.

Abuse can be emotional, physical, sexual, institutional or financial. 'Abuse' is something that is happening that should not be happening (acts of commission). 'Neglect' is something that should be happening but isn't (acts of omission) e.g., receiving adequate food and clothing or access to medical care. The person abusing or neglecting is always in a position of power relative to the person who is their target. This means that sexual abuse may also take place between two persons with disabilities. This may happen where the relationship is (or was) unequal due to differences in ability or other factors. It could also be the result of learned behaviour on the part of one of the actors. Sexual abuse in this situation should be responded to in the same way as when the abuser does not have a disability, with any additional factors thoroughly taken into account.

The present guidelines, in the framework of the SMARTS project, focus on sexuality and encouraging/empowering PwD to talk about, make decisions about and engage in sexual activities, with their own informed consent and control. Within this context there will be

opportunities for abusers to manipulate situations in order to sexually abuse supported people. Safeguarding therefore becomes particularly important and is an essential aspect. Everyone needs to feel protected and safe and to have confidence that ensuring the rights of PwD to sexuality and intimacy does not bring with it increased risk of sexual abuse. In order to achieve this, safeguarding needs to be thoroughly understood and practised by all parties. This means:

- » Understanding what sexual abuse is and being able to spot signs and symptoms.
- » Knowing how to respond to disclosure of sexual abuse.
- » Understanding the limits of confidentiality
- » Knowing the kinds of touch that are appropriate.
- » Knowing how to report concerns and use organisational procedures.
- » Helping PwD to know how they can keep themselves safe.
- » Keeping within the boundaries of a professional relationship.

All supporters should keep in mind organisational policy and procedures in place to deal with sexual abuse (as part of a wider safeguarding package). This ensures that supported people and supporters will have the best protection and support when negotiating the complexities of this issue, and beyond. Training is an important part of this.

► What is sexual abuse?

Although sexual abuse has very specific components, it is important to recognise that there are overlaps with other forms of abuse. For example, it always involves emotional abuse and exploitation, and sometimes also involves physical abuse. Sexual abuse is involvement of individuals in sexual activities to which they may not have given informed consent, may not fully comprehend or with which they do not wish to continue. Sexual abuse usually involves acts performed by the abuser on the person who is abused, but it may sometimes involve situations where the perpetrator forces or persuades the other person to do things to the abuser or others.

Sexual abuse can involve any of the following:

- » Inappropriate touching.
- » Rape or attempted rape.
- » Being made to perform sexual acts.
- » Sexual harassment.
- » Being photographed/videoed for sexual purposes.
- » Being made to look at photographs/videos for sexual purposes.
- » Being made to watch sexual acts.
- » Indecent exposure.

► What are the signs and symptoms of sexual abuse?

The following list contains some of the major signs of sexual abuse. These can of course also have other causes, but the possibility of sexual abuse should always be in mind when you see any of them, especially if they happen suddenly or out of character. It is also important not to make assumptions that the behaviour you see is a result of the supported person's condition. Always question and share with others to establish a broader view.

- » Bruising around the breasts or genital area.
- » Sexually transmitted diseases or infection or discharge from genitals.
- » Complaints of minor ailments such as headache, tummy ache.
- » Talking inappropriately about sex.
- » Changes in sleeping pattern.
- » Sudden bed wetting or soiling.
- » Partial disclosure "it's a secret".
- » Withdrawal.
- » Pregnancy.
- » Low self-esteem.
- » Upset or agitated.
- » Avoids a particular person.
- » Obsessive ritualistic behaviour.
- » Changes to eating pattern.
- » Deterioration in personal hygiene.

► What should I do if someone discloses sexual abuse to me?

Within the project you are building open and trusting relationships with PwD encouraging discussion of sexual matters in an easy manner, without embarrassment. It may be the first time the supported person has had the opportunity to do this. It may be the first time they have learned words to describe particular sexual activities or body parts. They will feel safe and confident within this context and this will inevitably lead to some people disclosing sexual abuse that has happened to them in the past, or even that is currently happening.

When a PwD discloses abuse to you, this may take place in a number of ways:

Full or open disclosure

The person tells you directly and openly about the abuse. This may be completely unexpected and you may feel very shocked.

Partial or hidden disclosure

The person hints or indicates in some way that abuse has taken place, but then quickly changes the subject. He/she may seem unable or reluctant to give you any further details.

Indirect disclosure

The person talks about abuse generally, or in connection with another person, and seems to be looking for your reaction.

For most people, summoning up the courage to tell someone else that something strange, unpleasant, shameful, frightening and secret has been happening to them is very difficult. The person who has experienced the abuse is likely to be struggling with all sorts of feelings and fears about what will happen if he/she talks about the abuse including:

- » being afraid of not being believed.
- » blaming him/herself for the abuse.
- » worry that others will side with the abuser.
- » feeling too scared to be able to talk about it.
- » not having the vocabulary to describe what has happened.
- » worrying about possible physical violence from the abuser to him/herself or others if he/she tells (this may have been threatened).
- » not knowing what will happen once he/she has told about the abuse.
- » being afraid of making people angry.
- » worry that his/her family will turn against him/her.
- » worry about being taken away from home, family, friends (this may also have been threatened by the abuser).
- » worry about what his/her friends will think.
- » worry that it won't make any difference if he/she does tell.
- » worry that nothing happened last time he/she tried to tell, so - what's the point of doing it again?

A person may feel extremely embarrassed at what has happened to him/her. He/she may want you to:

- » not tell anyone else.
- » not involve the police.
- » not ask him/her to have a medical examination.

It is possible that you might be the first person to be told about the abuse. This places a particular responsibility on you.

Because the person who wants to disclose abuse may worry about upsetting you or making you angry, he/ she may only hint or half-tell about the situation to begin with, to test your reaction. It is important to be patient and let him/her tell you in his/her own time.

Here are some more suggestions that might be useful in supporting a person tell about abuse:

- » Show the person that you are taking what he/she is saying seriously. Show sympathy and concern, but don't make comments or judgements about what the person is saying.

Making comments such as 'why did you let him?' or 'why didn't you tell anyone?' can make the person feel that the abuse was his/her fault.

- » Be prepared to believe the person. Taking what the person is saying seriously can sometimes feel difficult if the disclosure does not seem to make sense, you know the alleged perpetrator and feel that he/she would not have done such a thing, or the person has previously made unsubstantiated allegations.
- » Remember that your role is not to conduct an investigation, or act as the judge or jury. You are there to support the person in front of you and for the time being it is important to give him/her 'the benefit of the doubt'.
- » Don't pressurise the person to give details of the abuse or ask leading questions. It is very easy to make suggestions to the person about what might have happened to him/her, or introduce things that he/she hasn't already mentioned into the conversation, for example 'Do you mean that he touched your breasts?'. Leading questions are particularly tempting when the person disclosing has difficulty finding the right words or you are in a hurry to hear his/her story.
- » Do not pressurise the person to give details about the abuse. If the person needs help to talk about what has happened, use simple, open questions such as 'What happened next?'
- » Show care and compassion but do not give sweeping reassurances. To promise that 'it will never happen again' or that the alleged abuser will be 'put away' is making an assurance that you cannot guarantee. It is more honest to tell the person that you care about him/her and that you will support him/her and make him/her as safe as possible.

Things you should do:

- » **Stay calm:** this is not as easy as it sounds. It can feel stressful and upsetting to listen to someone who you care about disclosing that they have been abused.
- » **Listen patiently:** it may be difficult for the person to talk about it, so you may need to give him/her a lot of time.
- » **Let him/her take his/her time:** often you may suspect that someone is being abused by the way that he/she is behaving or reacting to certain situations. He/she may be unable to tell you directly about what has happened, either because he/she cannot communicate verbally or because he/she does not have a full understanding of the situation. The person needs to be given enough time to 'tell his/her story' or the opportunity to understand what is happening and to help the person may be lost.
- » **Use the supported person's preferred communication method.** It is important to make sure that the person has the right signs and symbols available to 'tell his/her story' e.g. signs and symbols for sexual parts of the body and sexual activities.
- » **Reassure him/her that he/she is not responsible for the abuse.** It is very likely that the person will, in some way, feel responsible for the abuse. Tell him/her clearly that the abuse was not his/her fault.

- » **Thank the person for telling you.** The person may have taken a long time to decide to tell someone what has happened. Keep reassuring him/her that telling was the right thing to do and praise him/her for her bravery.
- » **Explain what you are going to do now.** You should always tell the person what you will do with the information. You must explain that you have to tell other people and that you cannot keep the information confidential.
- » **Record what the person has told you, as soon as you can, using his/her own words wherever possible.** This is very important for any future investigation of the allegation. Write a factual account of your conversation with the individual as soon as possible. Try to use the person's own words to describe what happened. Date and sign this and give it to a relevant manager.
- » **Get support for yourself.** It is important not to under-estimate the possible effects on yourself of listening to a disclosure of abuse. Even though you may be experienced in this field of work, or feel that you coped well with the situation, you may well be left feeling anxious, distressed or angry. After being involved in a disclosure of abuse, it is important that you do not deny your own needs in your attempt to respond to someone else's. You need an opportunity to talk about what has happened and to express and reflect on your own feelings.

► What about confidentiality?

PwD have many parts of their lives known to others, often discussed without their knowledge or presence. It is a basic human right to have privacy and to be in control of your own information. The organisation's policies and procedures will be designed to protect this right and ensure that information about a supported person is only passed to others with their consent or on a 'need to know' basis. This principle is particularly important when PwD are revealing intimate and private areas of their lives. However, there are some times when keeping information confidential is not so clear cut:

- » When sharing information in team meetings or supervision, it is important to carefully consider *which pieces of confidential information really need to be shared*. It may be possible to limit content and still convey what is necessary.
- » When the information you have received indicates that someone is being abused, neglected or exploited, *it is important that this information is not kept confidential and that organisational policies and procedures are followed*.
- » When the information you have received indicates that harm may come to the supported person (e.g., self-harm) or to a third party, it is important to follow your duty of care and to share this information with appropriate others.
- » When the information you receive indicates that illegal activity has taken place or will take place, it is important to report this to the relevant authorities.

► What sort of touch is OK?

- » Touch is OK where:
- » It is agreed or negotiated with the recipient or their advocate.
- » It does not carry any sexual intent or sexual gratification on the part of the person doing the touching. This is more important than the place on the body that is being touched. PwD may need help with intimate personal care and will need to be touched on their genitalia. When this is done with no sexual intent or gratification on the part of the person touching, this is OK. On the other hand, non-sexual parts of the body e.g., hair, or a knee, can be touched in a way that carries sexual intent or gratification. This is not OK. In other words, it is the intention of the person touching that is important here, not the place being touched.

► What should I do if I suspect sexual abuse may be happening?

The worst thing you could possibly do is to decide not to think about it or to do nothing! There is always something that you should do.

- » You must always respond if you suspect that abuse could be occurring. Your role is to notice and to report things that make you feel concerned or suspicious that something is not right. You do not have to **know** that abuse has taken place or **believe** what you have been told. Remember that supported people are vulnerable and relatively powerless. They are relying on you to speak up on their behalf if you think they might be at risk.
- » Don't ignore or dismiss your suspicions. Remember that you are not responsible for deciding if abuse is taking place, but you are responsible for passing on your concerns. If, in the end, it turns out that there is a reason other than abuse for what was making you worried, you have still done the right thing by reporting it.
- » Be clear about the organisation's policy on abuse and follow its procedures. The procedures are there to help you do the right thing.
- » Tell a manager as soon as you suspect that abuse could be taking place and get guidance and support about what to do next. You should be clear where to go if it is the manager who is the suspected abuser. This may be another manager or someone outside of the organisation.
- » Remember that it is *not* your role to investigate whether abuse has taken place.
- » If you and the manager decide that it is appropriate to obtain more information by talking to the person that you think might be being abused, choose a time and a place where you can do this undisturbed. Never discuss this in front of others unless the person concerned specifically wishes to have someone with him/her. (This must be his/her choice, not that of the other person). Speaking with the person who may have been abused must be done very carefully, and leading questions avoided. In some countries anything else could interfere with or undermine the process of collecting evidence if the police and courts were to become involved.

- » *Don't* discuss the matter with the person/people who you suspect may be carrying out the abuse. If abuse is taking place, telling the perpetrator about your suspicions could put the abused person at even more risk. It could also distort the justice of a proper investigation.
- » After you have reported an allegation or suspicion of abuse, check what action has been taken. If an investigation is taking place, it might not be appropriate for you to know all the details of what has been decided, but *you have a right to know what conclusions have been reached.*

► **How can I help the people I support to keep themselves safe?**

One of the best ways to guard against sexual abuse is to equip supported people with the knowledge and understanding that will help to keep them safe. This should always be part of a wider safeguarding package. It is never appropriate to leave the responsibility for safety entirely in the hands of the supported person. SMARTS will contribute to helping keep supported people safe from sexual abuse, as it is designed to give them information about sex and sexuality and to empower them to know what they like, what they want, and to feel confident to talk about things they may previously have found embarrassing or frightening. It will give them the means to communicate worries and concerns as well as make informed choices.

Here are some of the ways you can help the people you support to keep themselves safe:

Ensure that they know:

- » that they have the right to say 'NO' to anything they do not like or want;
- » who/how to tell if they are unhappy about any sexual approach/contact, and what will happen next;
- » where and how they can have access to materials aimed at PwD (easy read).

SDM in the field of sexuality specifically addressed to family carers

► These guidelines are for families/family carers

These guidelines are aimed at all those family members who are carers of PwD.

The guidelines have been created to support family carers in providing a meaningful and adequate implementation of the SDM approach in the field of sexuality. Also, this section will discuss some of the usual challenges family carers face and provide guidance on how family carers can manage those challenges within the SDM framework.

As a family carer, you are probably hoping that your son/daughter turns to you, when they have a concern about a sexual issue. You are also probably hoping that, when they open up, you will be able to guide them towards the direction that you think is best, even protect them from making bad choices – after all, isn't that what families are for?

As a family carer, your urge to protect and guide the supported person towards your idea of happiness is understandable. However, SDM has a bit of a different view to propose. When applying SDM, you should keep in mind that your role is to leave this urge on the side, and help the supported person discover their own decisions around their sexuality.

At this point, you are right to wonder: "How do I do that?"

It is true that SDM requires you to put aside some behaviours that come naturally to you as a family carer. However, for all the behaviours you put aside, there are other skills to learn and use. The aim of this chapter is to guide you through some of the most useful skills that family carers need, and address some of the most common challenges that family carers face, when implementing SDM.

► Learning to really listen

One fundamental new skill to implement SDM is to learn how to listen. Listening attentively to the supported person's experience is a process called **reflective listening**. When we are listening reflectively, we are trying to understand the supported person's point of view. You will have seen more general information about this earlier in these guidelines, at Section 3 as family caregivers, your goal could be to listen with an open mind, without judgement, while trying to acknowledge and accept your son's/daughter's personal choice.

Reflective listening: what it is and what it is not:

Take a moment to think about what you would do if your son/daughter wanted to discuss with you a problem or concern around a sexual issue. Maybe you would offer solutions and advice? Maybe you would try to reassure them that things will be fine? Maybe you would try to convince them about what you think is best for them?

These responses, although common to all of us, are not helping to listen reflectively. If you want to learn what listening reflectively is and what it is not, have a look in the box below:

What reflective listening is not:

- **Ordering and warning**

Example: *"You will never have a proper relationship if you pay for sex"*

As a family caregiver, you may have the tendency to "know what is best" for your son/daughter. However, the SDM framework proposes that the supported person is able to make his/her choices, even if those choices are not the ones you would prefer.

- **Moralizing / Offering advice and solutions**

Example: *"It is best to wait for «the one» to have sex with. In life, you must be patient."*

It is very understandable that advice comes naturally to you as a family caregiver – and it comes from a place of your own values system, from what you perceive as right or wrong. The SDM approach suggests that it is perfectly fine to hold your personal opinions and attitudes, as long as you are respecting different opinions and attitudes that the supported person may hold.

- **Criticising**

Example: *"You are not mature enough to have a sexual relationship. You should wait until you are older."*

Accepting another point of view is not always easy, especially when your wish is to protect your son's/daughter's wellbeing. However, your goal in the SDM process is accepting the supported person's choice without judgement, even if it is different from the one you would hope for.

What do you notice in that table? Do you feel that your son/daughter would be free to make his/her decision?

What reflective listening is not:

As you may have noticed, the strategies on the table above are not really a way to understand, but more of a way to introduce a personal view, attitude or opinion.

This is the core difference and the fundamental component of reflective listening: it is not a process of offering personal judgements, arguments or opinions, but a process of understanding and clarifying another person's point of view and needs, so that they can decide for themselves.

This is the basis of reflective listening, but also the essence of SDM. In SDM, your role is not to guide your son/daughter towards what you think is best, but to support him/her in uncovering his/her needs and choices.

This may be quite challenging for you as a caregiver.

Some phrases to help you out on your first steps with reflective listening could be:

- *“Tell me more about...”*
- *“What do you think about...”*
- *“How do you feel about...”*
- *“What I hear you saying is that...”*
- *“What I understand from you is that...”*
- *“You sound...”*
- *“What do you think you could do about...”*
- *“What do you think could help you?”*
- *“What can I do to help you?”*

Next time your son/daughter talks to you about a sexual matter, you could give this new way of responding a try and see how it works for you.

Reflective practice: Listening to ourselves

One part of reflection has to do with really listening to the person in front of us. Another part of reflection has to do with taking a moment to really listen to ourselves. Reflective practice is a way of “self-reflection”, where we take a moment to ask some questions to ourselves. Reflective practice is crucial in SDM, to ensure that we are doing what we need to do: support and listen, without imposing our personal views. Throughout this chapter, you will find questions to ask yourselves. This “reflective training” could be your guide to self-reflect when implementing SDM.

► **What about my own opinions and beliefs and values?**

As a family carer, you carry, of course, your own morals, opinions and beliefs around sexuality. However, as we already discussed, SDM requires turning the spotlight away from your personal beliefs, while focusing on the supported person’s point of view. This requires a certain amount of “openness” to the other person’s experience, that is, being willing to see things from their perspective. Sometimes, this means that you may have to take a look at your own beliefs, and ask yourself some questions:

- » *“What are my personal beliefs, opinions and beliefs around sexuality?”*
- » *“Do these beliefs permit me to listen reflectively to the supported person’s perspective?”*
- » *“Do I want to understand my son’s/daughter’s point of view, or introduce my personal beliefs to him/her?”*

There is more general information about attitudes, beliefs and values earlier in this Guidance, in section 3. Not all beliefs are flexible. It is important that family carers recognise when their personal opinions make reflective listening challenging for them. When this is the case, we are talking about a great difference between the points of view of family carers and the supported person, that is, a **clash of values**.

About values:

What comes to your mind when you think about your “personal values”?

Personal values are a collection of beliefs and principles that guide decision-making and choices. They are what one considers “good” and “worthy”. In other words, values are our personal rules that define in a great deal the way we behave, the way we interact with others, and our personal choices concerning the way we live our lives. This is why most people have strong feelings about their values, especially when they are challenged or opposed. Parents and family carers create the first source of values for a young child. It is true that family carers wish that younger members adopt a common set of values, and their wish seems granted up to a certain age. However, as children enter adolescence or young adulthood and gradually gain independence, they start to slip away from this given set of values, forming their own. This new set of values may range from “simple” matters, such as the way of dressing and having fun, to more “serious”, such as religious beliefs and, of course, beliefs around sexuality.

There are several areas for which each of us develops and follows values through our lifetime. Some examples are the following:

General values	General values	Social and political values
<ul style="list-style-type: none"> ▪ <i>Being honest & trustworthy</i> ▪ <i>Adding value to the world</i> ▪ <i>Taking personal responsibility</i> ▪ <i>Showing compassion to those in need</i> ▪ <i>Being respectful & nonviolent when interacting with others</i> ▪ <i>Always doing your best work</i> 	<ul style="list-style-type: none"> ▪ <i>Working in a team</i> ▪ <i>Making education a priority</i> ▪ <i>Keeping in mind the part that your job plays in society.</i> ▪ <i>Treating co-workers, fellow students, customers, & authority figures the way that you want to be treated.</i> ▪ <i>Following the law & respecting those who enforce it</i> 	<ul style="list-style-type: none"> ▪ <i>Treating everyone equally regardless of ethnicity, race, religion, or sexual orientation</i> ▪ <i>Being honest & respectful when interacting with others</i> <ul style="list-style-type: none"> ▪ <i>Participating in community & team work maybe voluntarily</i> ▪ <i>Treating others as one would like to be treated</i>

Similarly, as for the above areas, each parent has formed his/her values on sexuality issues. Gradually, within each family, the family values are developed for all the above areas.

Values and sexuality:

Sexuality values and the decisions family caregivers have to take on **when/if** and most importantly **how** to communicate them to their sons and daughters is a delicate and controversial matter. Even more so when the son/daughter happens to be a PwD.

The first step towards deciding whether and how you would like to approach your son/daughter and talk to him/ her about sexuality, would be to explore your own values. Take a couple of minutes to think to yourself which are your and your family’s basic values on Sexuality.

Questions like:

- » At what age do I think a young person is ready to experience his/ her first sexual intercourse?
- » Should a person wait to be married before having sex?
- » Do I believe that sexual orientation is a free choice for each person?

Sexual and other factors that define your personal and family value system include:

<ul style="list-style-type: none"> ▪ <i>Gender</i> ▪ <i>Age</i> ▪ <i>Sexual Orientation,</i> ▪ <i>Marital Status</i> 	<ul style="list-style-type: none"> ▪ <i>Social and professional status,</i> ▪ <i>Family tradition-History,</i> ▪ <i>Culture,</i> ▪ <i>Historical era.</i>
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So, your personal sexual value system is based on your personal beliefs, attitudes or feelings about sex and sexuality.

Personal values and SDM: Fears and challenges for family carers

No matter how liberal your values on sexuality issues may be, when it comes to PwD decisions and actions may prove to be more complicated. Concerns and fears regarding your son's/daughter's psychological wellbeing and physical integrity, interfere inevitably with how you feel your he/she will be able to decide about his/her sexual needs and wishes.

Examples of some of your concerns would probably be the following...

- What if my son/daughter is abused, hurt, rejected...?
- If he/she wants to get married, will he/she be able to cope with the responsibilities a family requires? Is she/ he ready to become a mother- father?
- If they have children, will they also have a disability? If so, who would take care of them?
- I feel unprepared to give responsible information about love, relationships, sex to my son/daughter. I do not know how to communicate information in a simple way.
- I am afraid this will lead him/her to misconceptions, he/she will be mixed up and I won't know how to help him/her.
- What if he/she falls in love with a prostitute?
- I am not sure if my son/daughter can make safe choices regarding romantic partners, to manage sexual urges or desires and make appropriate decisions about reproductive management.
- My son/daughter is unable to distinguish between private and public behaviours.
- My son/daughter does not realise the need of others for personal space. His/her habit to greet people by touching their arm, may be mistaken for sexual harassment.

Those concerns are very common across family carers. Your initial values concerning your son’s/ daughter’s sexuality are filtered through:

- a. Your fears and worries about him/her,
- b. The “popular” Myths built around the sexuality of PwD (you can read more about this earlier in this guidance, at Section 3),
- c. Your doubts on how to initiate conversations with your child for such delicate, personal issues.

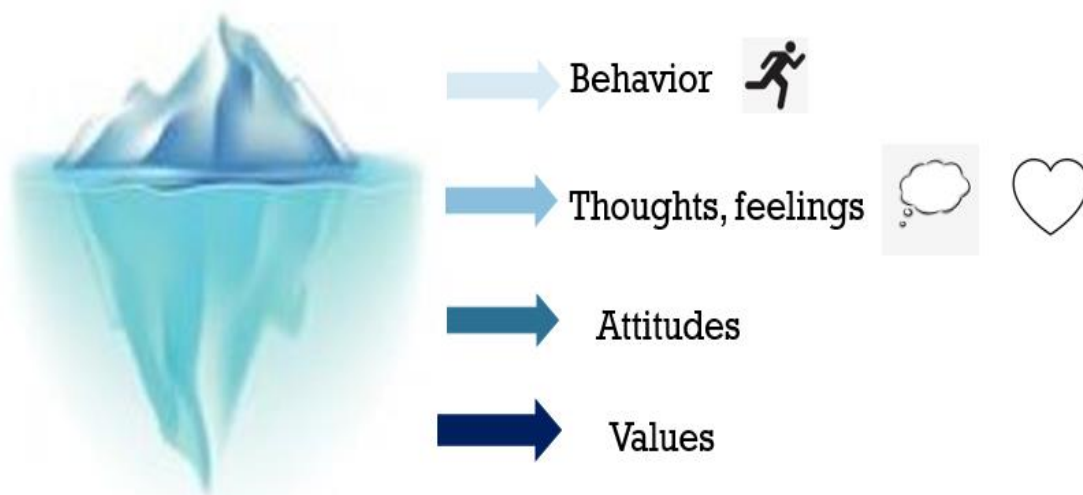
Your personal values lead to your current attitudes towards a PwD’s rights to equal choices and opportunities for sexual and emotional fulfilment.

► **About attitudes**

(see more about attitudes earlier in this guidance at Section 3)

Bring in mind a person, situation or idea that you strongly like or dislike (in other words, that you have formed **attitudes** about). There are probably many thoughts running inside your mind about it. Also, you may have certain feelings about it. Finally, you may want to do something about it. Those are the three components of attitudes: they make us think, feel, and respond to them with actions. In that way, our attitudes become visible through our behaviour.

To make things clearer, have a look at the picture below...



The behaviour is just the ‘tip of the iceberg’. Our thoughts, feelings, attitudes and values go deep, and actually form the basis for our behaviour.

What about my attitudes?

As a family caregiver, you may have formed your attitudes around the important subjects of caring for the supported person. The supported person’s sexuality is most probably one of them - sexuality itself is a subject that raises strong attitudes in most people. Sexuality is not an easy subject for family caregivers.

Some common attitudes of caregivers concerning the sexuality of the supported person seem to be the following:

Attitude	Challenge for family carers	Thoughts
<p>“Talking about sexual issues seems challenging...”</p> <p>You may be reluctant to talk about sexuality with your son/daughter.</p>	<ul style="list-style-type: none"> ▪ <i>You are afraid of “awakening” sexual desires that would otherwise remain “inactive”.</i> ▪ <i>You think that sexuality is out of the supported person’s interest, due to immaturity or a limited social circle.</i> ▪ <i>You face communication challenges with the supported person - you are not sure you can explain sexual subjects in a comprehensive way.</i> 	<ul style="list-style-type: none"> ▪ <i>“Information may provoke curiosity on sexuality. Better leave those things unspoken”</i> ▪ <i>“He/she is not interested in these kinds of things...He/she is still immature...”</i> ▪ <i>“I don’t know how to speak to him/her so that he/she understands”</i>
<p>“Protection is the only thing I should talk about...”</p> <p>You may think that talking about sexuality should be all about being safe. Sexual safety is a very important issue... but not the only one!</p>	<ul style="list-style-type: none"> ▪ <i>You are afraid that the supported person may fall victim to exploitation or abuse.</i> ▪ <i>You feel the need to protect the supported person. Sometimes over protection seems better than the possibility that something bad may happen.</i> 	<ul style="list-style-type: none"> ▪ <i>“He/she may be easily abused or mistreated”.</i> ▪ <i>“He/she is vulnerable and cannot protect him/herself”.</i> ▪ <i>“Maybe it is better not to go out on his/her own. He/she is safer at home”.</i>
<p>“I don’t know how to do it” ...</p> <p>You may have questions about how to approach sexual matters.</p>	<ul style="list-style-type: none"> ▪ <i>You may feel unprepared or unready to talk about sexual matters.</i> ▪ <i>You may need guidance and support from professionals.</i> 	<ul style="list-style-type: none"> ▪ <i>“Where do I begin? What should I talk about?”</i> ▪ <i>“What if I say something wrong?”</i>
<p>“I am concerned about the future...”</p> <p>As a caregiver, you may be concerned about the future of the supported person, as he/she discovers his/her sexuality.</p>	<ul style="list-style-type: none"> ▪ <i>You may be afraid of a bad consequence from sexual encounters (ex. a pregnancy)</i> ▪ <i>You may have concerns about the ability of the supported person to raise children and care for a family.</i> ▪ <i>You may be concerned about the possibility of a genetically transmitted disability.</i> 	<ul style="list-style-type: none"> ▪ <i>“He/she won’t be able to care for a child”.</i> ▪ <i>“He/she won’t be able to make it with family duties”.</i> ▪ <i>“What if his/her child ends up with a disability as well?”</i>

<p>“There is only one possible sexual identity (heterosexuality) for the supported person”</p>	<ul style="list-style-type: none"> ▪ <i>You may think that homosexuality or bisexuality is not an option for people with disability.</i> ▪ <i>You may think that homosexuality and bisexuality are just “problematic behaviours”, not a choice.</i> 	<ul style="list-style-type: none"> ▪ <i>“My son/daughter cannot be homosexual. He/she is just mixed up”.</i> ▪ <i>“He/she is confused. I have to explain who he/she can date”.</i>
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After looking at the table above, you may want to take some time to ponder:

- *Did you find any of your attitudes and thoughts on the table above?*
- *Take a minute and try to access what you believe is right for the supported person around sexual matters: what thoughts and feelings can you identify? What actions do you take or think it is right to take?*

Can my attitudes affect SDM?

As we already discussed, attitudes are reflected in our behaviour. This means that your attitudes about the sexuality of the supported person may - even when you have the best of intentions - become an obstacle to implementing the SDM process and letting them decide for themselves:

- Attitudes leading to the belief that the supported person will not make the “right” decisions and safe choices may lead you to act overprotectively (for example, forcing your preferred way of contraception). This limits the opportunities for SDM, as you are guiding your son/daughter towards “your” decision for him/her.
- Attitudes leading to the belief that talks around sexuality are “too difficult” and better left unspoken, may lead to limited or incorrect knowledge of the supported person around sex, contraception etc. However, offering complete information is an integral part of SDM, and one of your central roles as a caregiver in the SDM process.
- Your attitudes as a family caregiver are communicated, verbally or non-verbally, to the supported person. If you think that sexuality is something immoral or inappropriate, there is a good chance that the supported person will view sexuality as something embarrassing or shameful that “should not be discussed”. In that way, the communication door about sexuality is shut, and so is the chance for SDM.

Is there another way to see things? Alternative attitudes:

Attitudes do not change overnight. They are, most of the time, something we carry for many years of our lives, and that makes them resistant to change. However, we can always keep an open mind, reflect on ourselves and our attitudes, and let ourselves explore different ways of seeing things. In the table below, you can find some alternative attitudes towards the sexuality of your son/daughter that you can experiment with as a caregiver. Have a look:

Alternative attitude	When you stand as a caregiver	Alternative thoughts
<p>Sexuality is something natural for everyone.</p> <p>The supported person is your son/daughter, but he/she is also an adult, with adult needs.</p>	<ul style="list-style-type: none"> You acknowledge that the supported person is an adult. You acknowledge that the supported person has sexual needs and sexual rights. 	<ul style="list-style-type: none"> <i>“My son/daughter is an adult. It is normal that he/she wants to explore his/her sexuality.</i> <i>“My son/daughter is an adult. It is his/her right to have sex”</i>
<p>Sexuality is something that families can talk about.</p> <p>You are open and comfortable with listening and providing information.</p>	<ul style="list-style-type: none"> You acknowledge that sexuality is an important issue for the supported person. You have created an open channel of communication for matters of sexuality. 	<ul style="list-style-type: none"> <i>“I am open to discuss sexual matters with my son/daughter”. I am available for providing information.</i> <i>“I want him/her to come to me to discuss about sexual matters”</i>
<p>Sexual education is about protection and appropriate sexual expression, but also about pleasure and emotions.</p> <p>It is often our tendency to focus on the dangers of sexuality with the supported person. Of course, this is a very important issue. But sexuality is also about pleasure, and about creating meaningful, adult relationships.</p>	<ul style="list-style-type: none"> You acknowledge the different aspects of sexuality. You educate the supported person about the dangers and appropriate sexual expression, but also about the pleasure of sexuality. You acknowledge that sexuality may be a part of an intimate adult relationship for the supported person. 	<ul style="list-style-type: none"> <i>“My son/daughter should be informed about how to protect him/herself, but also about how to have fun with sex”.</i> <i>“My son/daughter can have an intimate adult relationship, and sexuality may be a part of it, if he/she wishes so”.</i>
<p>The supported person has the right to make choices about his/her sexual preferences.</p> <p>The sexuality of the supported person can take many forms, as there are many options available.</p>	<ul style="list-style-type: none"> You acknowledge that sexuality can take many forms other than the male/female relationship. You have in mind that the supported person may choose a different sexual orientation than yours, or the one you expect from him/her. 	<ul style="list-style-type: none"> <i>“My son/daughter may not choose the sexual orientation I expect from him/her, and that is ok.”</i> <i>“My son/ daughter is free to make his/her choices about his/her sexuality”.</i>

You may already see that those alternative attitudes are quite different from the way that caregivers often think and behave. You may notice that it gives much attention to personal freedom of choice and personal rights of the supported person. **This view is aligned with the United Nations Convention on the rights of persons with disabilities (CRPD), which is the theoretical basis of SDM. It promotes equality and non – discrimination for PwD, with respect for the fundamental human right of social inclusion and self-development.** (For a more detailed approach on the UNCRPD, you can check Section 2 in this Guidance).

It is understandable if this way of thinking is something new to you as a caregiver. This is a good time to reflect: *What are your thoughts? What are your feelings? How close or far is the way of thinking below, compared to your current attitudes?*

What can I do about my attitudes?

After finishing this chapter, you may ask yourself:

- What are my attitudes as a family around the sexuality of the supported person?
- How much do my attitudes guide my behaviour?
- How much is my behaviour an obstacle for SDM?
- Would I like to change something in my attitudes (or behaviour)? What would that be?

It is perfectly normal to feel challenged or in need of support. If so, do not hesitate to seek help from a trained professional.

► **When choices clash: a matter of personal rights**

Decisions are based on our value system. So, our choices, as well as our values, can sometimes clash. This is something that happens to the majority of families. The goal is not to avoid an inevitable clash of decisions and values, but to properly handle it in your role as a family carer.

- **Your rights as a family carer:** Of course, as a family carer, you have the right to hold your personal choices and values. You have the right to talk about your values, act upon your values, and communicate your values to the supported person. The best way to communicate your values is not to preach about it and try to convince the supported person about it, but rather behaving in line with your values in your everyday life, acting as a living example of what you believe in.
- **The rights of the supported person:** On the other hand, family carers should keep in mind that the supported person has the exact same right of keeping their personal values, forming decisions based on them, talking about them, and acting upon them. Although it is your right, as a family carer, to present your values to your son/daughter, it is the right of your son/daughter to not be convinced by your values and to make a different choice. After all, it all comes down to a matter of personal freedom.

“What do I do when choices and values clash?”

When choices between a family carer and a supported person clash, the first thing to do is ask yourself some questions. Recall a clash of choices around sexuality between yourself and the supported person, and try to think:

- “What are my personal choices, opinions and beliefs around sexuality?”
- “Where do they come from?”
- “What does my value system tell about this choice?”
- “Why is it so important to me that I hold on to my choice/value?”
- “Am I certain that my set of values and choices is the one and only “correct” set of values and choices?”
- “Do the supported person’s different values and choices have a specific and practical consequence on me/others/ themselves?”
- “Are the supported person’s different values and choices flexible enough to change? Are mine?”

The next step after giving yourself these answers, is to think of where you stand on the continuum between acceptance and change: **Is your value and choice flexible enough to allow you to accept a value or choice that is maybe way different than yours? Is your value or choice so important that you cannot see yourself accepting anything different? Do you lie somewhere in between?**

There are three scenarios in a clash of values and choices:

- **My value and choice are flexible enough to allow me to accept a value or choice that maybe is way different than mine:** After answering the questions above, you may have come to the conclusion that you are able to accept a different value, or that you are able to accept a difference in choices between you and the supported person. This may be the case where the supported person’s different values and choices do not have a specific and practical consequence for them or others.

For example, you may be willing to accept that your son/daughter may choose to have sexual relationships before marriage, although in your life you followed a different path.

- **My value and choice is so important to me that I cannot see myself accepting anything different:** Some values may be central to you, or may seem right to you. In that case, you may want to share your concern about the specific and practical consequences that the different choice may have for yourself, the supported person and others, by presenting realistic facts and concrete information (for example, the STDs related to sexual contact without the use of condom). Presenting your choice, your concern and your facts, is what you can do to help the supported person consider other options. However, the final choice and responsibility for any shift remains in the hands of the supported person.

For example, the idea of your son/daughter visiting a prostitute may be way out of your moral zone. In that case, what you, as a family carer, can do, is to present your concerns and realistic potential dangers (ex. financial difficulty, health dangers) of such a choice.

- **I lie somewhere in between:** In many cases, you may find yourself somewhere in the middle. You may feel flexible enough to take some steps towards acceptance, but not willing to

completely abandon your value or choice. That is a great starting point for a conversation focused on reflection, problem-solving and generating alternatives, if your son/daughter wishes to.

For example, you may be comfortable with the idea of your son/daughter having sexual relationships, but not with the idea of creating a family. In that case, you could think about what your concern actually is, and work on possible solutions with your son/daughter and other professionals that could support you both (see also shopping list item on creating a family).

► SDM on sexuality: special considerations for families.

Sexuality: a matter of privacy within the family

Sexuality is something intimate. We are all inclined to keep it to ourselves. However, within the family, and within the context of SDM, issues of privacy may arise. As a family carer, you may be eager to know the sexual status of your son/daughter, to make sure he/she stays safe and happy. An inner conflict that may arise is: *What information should I know to help my son/daughter decide for themselves and protect them? What information should I not know to protect my son's/daughter's privacy? How do I find balance?*

The following section hopes to clarify some of these concerns.

What about SDM and privacy?

To help your son/daughter make a decision, of course he/she must share some related information. However, how much is too much when it comes to sharing information about your son's/daughter's sexuality?

- What is my son/daughter willing to tell me? The first step towards respecting privacy is respecting the right of your son/daughter to keep some of the details regarding his/her sexual life for themselves. As a caregiver, this scenario may come with lots of thoughts: thoughts that your son/daughter “does not trust you enough”, or that “something bad will happen if you don't know everything”. However, wanting to keep things for oneself is both a personal right, and an adult request.
- What information do I need to support decision making? In the process of SDM, you will need to gather information in order to support your son/daughter to make their own decisions. In that process, the balance between supporting and respecting privacy may be difficult to sustain. When you ask questions, reflect with yourself – how will this question help me with SDM? If it does not serve your goal, could it be that it comes from another place (maybe your need to know what is going on in your son's/daughter's life, or your desire to protect him/her from any harm?)?
- How do I get my son/daughter to open up? As family carers, it is natural to wish that you are the ones your son/daughter turns to when he/she needs support with sexual matters. However, there is no way to “make someone open up”. What you can do is to maintain an open communication channel with your son/daughter, so that you can be there for them when they decide to come to you.

(For more information for communicating about sexuality, see section 3 earlier in this Guidance).

Respecting privacy in the family: how to do it?

Privacy around sexual matters is an important thing to keep in mind within families. If you wonder what you can do to protect and promote privacy as a family carer, here are some suggestions:

- **Talk in privacy:** Help your son/daughter distinguish between private and public. This can be done by talking about public and private body parts, public and private places, and public and private topics of discussion. Help your son/daughter understand that sexuality is something private- it includes private body parts, it is performed in private places, and it is a private topic to talk about with people he/she feels comfortable with.
- **Create private places-and respect them:** Does your son/daughter have a private space for him/her, where he/she can engage in sexual activities? If not, help your son/daughter understand the idea of privacy by creating his/her private space (a personal drawer to keep condoms or contraceptive pills, closing the door of his/her room when he/she wishes to etc). It is important that you, as family carers, respect this private space and help your son/daughter set his/her personal boundaries.
- **Be a role model:** Your son/daughter many times replicates the behaviour that he/she sees inside the family. So, ask yourself: How do you yourself handle privacy? Do people in your family acknowledge the need for privacy? Do you respect each-others' private space? In case the answer is no, the need of your son/daughter for privacy may be a good opportunity of setting healthy boundaries within the family.
- **Discuss when private matters need to be communicated:** Explain to your son/daughter the situations that demand the rule of privacy to be broken, for their own safety and well- being. Whenever he/she feels uncomfortable, pushed beyond their limits, forced against their will, or physically and/or emotionally hurt, the wise thing to do is to communicate with a trusted supporter, no matter how private the subject may be (for more information about safeguarding and sexual abuse, see section 4 earlier in this Guidance.

What about creating a family circle of support?

If caregivers (parents, siblings, close trustworthy relatives) feel that they are willing to act as a Supporter for their son/daughters, this is something that SDM is willing to encourage. It may be that a caregiver of the same sex as the Supported Person, would feel more comfortable to discuss private information with him/ her, but this issue should be discussed with the persons involved.

In any case, if most or all of the caregivers feel uncomfortable to undertake the role of the supporter, or even to be involved in the whole process, the supporting network of specialists will be more than willing to provide other resources and ideas for helping the PwD.



SDM and love, emotional attachment and relationship conflicts

► General considerations about love, emotional attachment and relationship conflicts

The need to love and belong is one of the fundamental human needs. Every person has, from the moment they are born, a tendency to create and maintain bonds with others. As we mature and evolve, we tend to form different kinds of relationships, and explore different kinds of love: from the love towards our parents, to friendship and love towards peers, to romantic relationships and the love towards a chosen partner.

But what does romantic love mean? Do we all experience it the same way? That is a tricky question, and the answer may not be the same for every person. However, it seems that romantic love consists of three main components: Intimacy, the component of emotional warmth, closeness and mutual understanding; Commitment, the decision that one has chosen to love a “certain” other, and only him/her; Passion, the arousal component of love that motivates towards physical union and may lead to sexual expression between partners. All those “ingredients” interact with each other in different “amounts”, creating different combinations and resulting in different experiences of love and romantic relationships. Love is also a dynamic process: it is developed, maintained, and sometimes terminated, if conflicts occur or feelings fade away. In other words, in the world of relationships- especially romantic ones, one should be prepared to form bonds, make these bonds last, but also quite possibly let these bonds fade or even decide to break them.

► General considerations on love, emotional attachment and relationship conflicts for PwD

Good and close human relationships, love and friendship, interaction with other people, and social needs are in general fundamental sources of well-being, and it couldn't be any different for PwD. However, there are some special considerations when approaching love and romantic relationships for PwD. First, “love” is quite an abstract concept, whereas PwD usually have a more concrete way of thinking. For PwD, “love” tends to focus more on actions than emotions. Second, relationships are guided by complex social rules that vary according to the nature and stage of the relationship - and this can be quite confusing.

The social skills needed to approach a romantic partner, to form a relationship and to navigate this relationship are often a challenge. The same goes with relationship conflicts that also require a variety of skills to resolve effectively. For example, it is important for the PwD to learn how to recognise his/her emotions and how to protect him/herself from being hurt. Due to all these social requirements, PwD often have trouble in one or more parts of the process of being in a relationship, and many times end up in one-sided, short-lived, or non-exclusive relationships, even though they would hope for something else.

► **What does the legal framework say about this?**

GENERAL EUROPEAN LEGISLATION

Friendship and emotional attachment are not the kind of topics which legal systems deal with easily. There are many 'unequal' relationships between all kinds of people (not just PwD!) which we may often recognise and observe. Friends/family often giving advice to someone with a 'broken heart' over a failed relationship is a common action (eg: 'He's just not worth it' - 'Never mind, there are lots of good fish in the sea!')

Some professions have professional standards of behaviour which regulate such relationships and breaking those professional codes can lead to sanctions by the profession's regulatory body. For example, the professional codes affecting doctors, nurses, psychologists, teachers and social workers often set limits about how close the professional should become to their client. This is not an easy borderline to maintain and this is often a situation where actions speak louder than words. A professional who allows a friendship with a client to develop into a sexual relationship is often seen as a reason for regulatory sanction of some sort.

In relationships involving staff and pwd legal controls are likely to be quite rare, with the most clear guidance coming from professional codes of practice and/or organisational guidance. Relationships involving pwd and others are, in general, like any other relationship between friends in the general population, not a matter that the law usually can effectively deal with. So, like any other person, a pwd may suffer the pain of a lost friendship or the anguish of unrequited love and the law will say nothing about it.

► **Questions for supporters on this topic**

Key topics around the SDM process for supporters to consider when framing their support.

<u>Topic</u>	<u>Questions for Supporters</u>	<u>Smart Approach</u>
"Love" is an abstract notion that can be challenging for the Supported Person to grasp, especially when we consider how unrealistically love is often portrayed (in television, books, social media, novels etc.)	How can the Supporter establish the SP's understanding of love and emotional attachment?	<p>In order to clarify what "love" means to the SP, the steps below could be followed:</p> <ul style="list-style-type: none"> » Listen to what they already know: what knowledge or experience does the SP already have about love and romantic relationships? Create a discussion with open questions, to understand what love means to him/her. » Explore love through actions and emotions: try to explain love both through actions (eg; offering flowers), but also through emotions (eg. feeling happy when our favourite person is around). » Compare their idea of "love" with what love really is: what are the examples of love that the SP has from movies, social media etc.? What are the examples of love that he/she has encountered in real life? What are their similarities and differences? What does love in the "real world" look like?

		<ul style="list-style-type: none"> » Does the SP understand/distinguish different types of love e.g., loving a parent/sibling, loving a pop star, loving a pet, loving a girl/boyfriend?
<p>“Reciprocity” is also a challenging term to grasp. Just because X loves Y - it does not mean that Y loves X! The SP may not be able to recognise that his/her wishes and feelings may differ from the wishes /feelings of others. This may lead to unstable, one-sided romantic relationships.</p>	<p>If the SP is in love or in an emotional relationship, how can the Supporter explore with the SP the extent to which it is reciprocal and at the same level?</p>	<p>In order to clarify what “reciprocity” means to the SP, the steps below could be followed:</p> <ul style="list-style-type: none"> » Listen to what they already know: what knowledge does the SP already have about reciprocity? Create a discussion with open questions, to understand what reciprocity means to him/her. » Explore reciprocity through actions: how can the SP understand reciprocity through concrete behaviours? (eg. Does the SP only call his / her favourite person, or do they call each other? Does the SP only express feelings to his/her favourite person, or are those feelings mutually expressed?). The goal for the SP is to understand that in a reciprocal relationship both partners “give and take”. » Let the SP explore the romantic relationships around him. What examples of reciprocity can he/she find? What examples of a one-sided relationship can s/he see or recall?
<p>Discussing with the SP about love and emotional attachment can be challenging, as it requires the ability of grasping abstract concepts and complex social rules.</p>	<p>How can the Supporter support the SP’s understanding in these areas?</p>	<p>It is important that the Supporter pays attention in ensuring the understanding of the SP. Some ways to do that is to adapt your communication style to the preferred communication way of the SP, use communication aids (eg. pictures), explain by offering concrete examples and focusing on observable behaviour, and frequently check the SP’s understanding.</p>
<p>Discussing with the SP about love and emotional attachment / friendship demands clear thinking and emotional maturity on the part of the supporter.</p>	<p>How well equipped is the Supporter to explore such matters with the SP?</p>	<p>It would be natural for the SP to choose a supporter on this issue who was similar to them in age and with whom they felt comfortable to talk about this. That places a big responsibility on the supporter to fulfil the SP’s expectations of being given sound advice and a sympathetic understanding ear. The supporter must not only feel able to do this but must also in fact be able to do it. This might require the supporter asking a more senior staff member for advice, whilst respecting the confidence placed in him/her of the SP. It would not be unreasonable for a SP already established and working effectively in other areas of SDM to say ‘I am not the best person to deal with this - someone else must be found.’</p>

► **Supporting the Supported Person (SP) to make informed decisions**

 <p>TOPICS FOR THE SP TO KNOW & UNDERSTAND</p>	 <p>TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP</p>
<p>Love consists of both acts and emotions. Romantic relationships need us to behave in a certain way, that depends on the nature and stage of our relationship. Emotions also grow depending on the stage of the relationship (eg. an acquaintance may become a friendship, and a friendship may become a romantic relationship).</p>	<p>How does the SP understand the concept of love? Is he/she aware of the emotions that can be defined as “love”? How can someone show that he/she loves someone through their actions?</p>
<p>Conflicts are something normal when we have a close relationship with someone. Again, there is a certain way to behave during a conflict, if we want the problem to be solved without damaging the relationship.</p>	<p>How do we understand that we have entered a conflict? What are the appropriate (eg: discussing about the problem) and inappropriate ways (eg: shouting, pushing, etc) of handling the conflict? What are the consequences of each way?</p>
<p>Love can take many forms, and for every form, there is a different relationship. We may choose to be friends with someone, we may choose to be a couple, and if we choose to be a couple, we may choose to have a sexual relationship or not.</p>	<p>What forms of love has the SP noticed around him/her? Does he/she know about the different kinds of love and the different emotions and behaviours they consist of?</p>
<p>Sometimes the SP may feel confused with the different kinds of love. (S)he may develop romantic feelings for a relative or a teacher</p>	<p>Is the SP aware of the social rules regarding close relationships? Is there way that (s)he could be informed without being hurt?</p>
<p>The idea of the SP about love and sexual relationships may come from non-realistic sources (ex. books, movies etc.). It should be clarified what love and romance in the real world looks like.</p>	<p>Is the SP’s idea of love realistic? What is he/she looking for? Is he/she willing to compromise?</p>
<p>Relationships should be reciprocal. That is a challenging concept for PWD, as it has to do with gaining insight about the wishes and behaviour of the others, and separating those wishes and behaviours from one’s personal wishes and behaviours.</p>	<p>Does the SP understand that relationships are about equality, and about two people giving to each other and taking from each other? Where does the SP stand on the giving-taking continuum?</p>
<p>Another major topic about being in a relationship is learning to protect personal boundaries and respect the boundaries of others. The concept of consent is a challenging concept that should be introduced to the SP. The SP should know that the supporter will be willing to hear about anything that happens without the SP’s consent, but only if the SP wishes to tell them”.</p>	<p>Does the SP know what his/her personal boundaries are? Has he/she learnt when and how to say “no”? Has the SP learnt to respect the boundaries of others? How does the SP react when someone says “no”?</p>

Romantic relationships may last long, but most of them don't last forever. The SP should understand that breaking up and feeling disappointed and sad after the end of a relationship, is something normal.

What are the SP's expectations of a potential relationship? Is he/she aware that many relationships end? Is he/she emotionally prepared to go through heartbreak?

► **Questions for Family Carers on this topic**

<u>Topic</u>	<u>Questions for Family carers</u>	<u>Smarts Approach</u>
<p>Family carers often do not see their son/daughter with disabilities as one who could be in 'love' or in a relationship or form an emotional attachment.</p>	<p>Is my son/daughter ready to become involved in a romantic relationship?</p>	<p>As a family carer, you may have the tendency to protect your son/daughter with disability from all potential harm, not seeing them as mature enough to care for themselves. However, the SDM framework proposes that your son/daughter is an adult who can make informed choices about him/herself.</p> <p>What you can do as a family carer, is to offer your son/daughter information about what it actually means to be in love and in a relationship: help him/her understand what love means, what kinds of love exist, how they are expressed through emotions and behaviour. You can include your son/daughter in social occasions that focus on expressing love and set a realistic view of what relationships look like.</p> <p>After understanding what love and being in a relationship is, will your son/daughter be able to decide what he/she wants for him/herself? The Supporter and the Facilitator are responsible to ensure that your son/daughter makes an informed choice and can help you with any fears or doubts you may have.</p>
<p>As a family carer, it is natural to have expectations of how you wish your son's/daughter's life to be. You may see being in a relationship as a source of happiness, and as a safety that your son/daughter will "have someone". However, this is your personal interpretation of happiness.</p>	<p>What if my son/daughter does not want to form a romantic relationship? I want him/her to be happy!</p>	<p>As a family carer, you may wish to see your son/daughter in a loving romantic relationship. However, this may not be the wish of your son/daughter. According to the SDM framework, your son/daughter is free to choose the kind of relationship that suits him/her best.</p> <p>What you can do is your son/daughter discover the types of relationships he/she can form (friendship, platonic relationship, sexual relationship etc.). Explore the pros and cons of each type of relationship with your son/daughter and the possible consequences of each of them (eg, a platonic relationship will not end up in having children, a sexual encounter will not cover the need for emotional intimacy etc.), so that your son/daughter can make his/her informed choice.</p>

<p>As family carers, it is understandable that you may have fears and concerns about your son/daughter entering a romantic relationship. It would be useful to reflect on how much these fears and anxieties guide your behaviour and make you impose your personal views.</p>	<p>What if the relationship ends and breaks my son's/daughter's heart? Maybe it is better if he/she does not enter a relationship at all...</p>	<p>It is natural for you to have the tendency to protect your son/daughter from potential harm. When he/she enters the world of relationships, you may feel afraid of the possibility of a break up that will cost your son's/daughter's happiness.</p> <p>However, the SDM framework suggests that this should not pose an obstacle if your son/daughter wants to enter a relationship. Your role is to inform your son/daughter about the natural course of relationships, the fact that a breakup is often a possibility, and what a breakup actually means practically and emotionally. After that, your son/ daughter should be free to make the choice to enter a relationship with the risk that comes along – as we all do.</p>
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SDM and Contraception, retaining fertility and forming a family

► General considerations about contraception, retaining fertility and forming a family

Contraception is the deliberate use of artificial methods or other techniques to prevent pregnancy as a consequence of sexual intercourse. The major forms of artificial contraception are:

- » barrier methods, of which the commonest is the condom or sheath.
- » the contraceptive pill, which contains synthetic hormones which prevent ovulation in the female.
- » intrauterine devices, such as the coil, which prevent the fertilised ovum from implanting in the uterus.
- » male or female sterilisation.
- » inserting an implant that inhibits ovulation, that is, prevents eggs from being released from the ovaries.
- » using a sticker that prevents ovulation (egg release).
- » using a vaginal ring that works by inhibiting ovulation, that is, it prevents eggs from being released from the ovaries.
- » using a diaphragm that prevents sperm from coming into contact with the cervix; injectable hormonal contraception that inhibits ovulation and alters cervical mucus.

The topic of contraception has strong links to and overlaps with other areas such as taking care of one's own body, retaining fertility, founding a family and forming sexual and/or emotional relationships. Contraception cannot be seen in isolation from these. Contraception also needs to be understood in the context of knowledge about reproductive processes, pregnancy and childbirth and parenthood.

► General considerations on contraception, retaining fertility & forming a family for PWD

There are certainly numerous forms of disability that do not prevent citizens from having a full and integrated life and from making important decisions - such as getting married and having children.

People with disabilities are not homogeneous groups, so they demand the definition of specific responses that meet their differentiated and identifiable needs.

The matter of sexual and reproductive health of these people must be seen simultaneously not only in a broad overall context that strengthens their personal autonomy and allows them to be properly integrated into society, but also in a single specific context, considering each situation individually, since every person is a different unique individual.

The process of assessing the implications of sexuality and risk of pregnancy and the consequent choice of contraceptive method should involve the person with a disability and the family planning consultation team plus, if requested by the supported person or legally required, family members or guardians, the institutions that welcome or support them, other relevant health professionals. It is necessary to assess the degree of self-sufficiency and sexual risk, the collaboration of family and supporting institutions, giving priority to the most effective contraceptive methods.

Retaining fertility and forming a family are inherent rights for all persons, including PwD. Furthermore, everyone has the right to decide whether or not to have children and the number and spacing between them. To exercise this right requires access to the conditions that influence and determine health and well-being, including sexual and reproductive health services related to pregnancy, contraception, fertility, termination of pregnancy and adoption.

With regards to persons with disabilities, the use and regulation of contraception has wide implications in the field of planned parenthood and on the interests of the different parties implied: those of the person with disability (freedom, information, privacy...), those of their parents or guardians (who may have a legal and/or moral responsibility to take care of them) and those of any possible future baby.

Contraception, when well used, is highly effective against undesired pregnancies. In many contraceptive methods, their effects are reversible. Contraception can also be used to treat many menstrual related symptoms and disorders. On the other hand, some contraception might not protect against STD, so users must know well how to correctly apply them. Some contraception methods might require minor surgery and/or insertion of devices underneath the skin. Some can cause side effects such as irregular menstrual periods, depression, nervousness, and weight gain. The contraceptive pill has also been known to carry risks related to cardiovascular diseases and nervous thromboembolism.

► What does the legal framework say about this?

GENERAL EUROPEAN LEGISLATION

At the European Union level, there is no specific legislation on contraceptives, besides of their recognition as part of sexual and reproductive health and rights (SRHR) and their inclusion in the EU's most recent [Strategy for the Rights of Persons with Disabilities \(2021\)](#). This Strategy is embedded in the European Pillar of Social Rights targeted at the year 2030, and explicitly calls for improvements in access for persons with disabilities to sexual and reproductive healthcare and prevention services. In the same vein, citing human rights, as well as public health, social policy and economic grounds, several countries in the European Union aim to make affordable contraceptives and contraceptive information available, [with Belgium and France being ahead of the curve in this matter](#).

However, in other Member States, access contraceptive methods remain an issue. Since in several countries a comprehensive legal and policy framework on reproductive health and rights is not in place or still highly restrictive. Most importantly, and perhaps as a result, contraceptives are not subsidised under public health insurance schemes, which put them out of reach for many women. In this context, the [European Parliament has called on Member States](#) to ensure universal access to sexual and reproductive health in the EU, by ensuring the availability of affordable, high-

quality contraception, family planning and information on contraception without discrimination on the basis of sex, gender, sexual orientation, health, disability or marital status.

► **Questions for supporters on this topic**

Key topics around the SDM process for supporters to consider when framing their support

<u>Topic</u>	<u>Questions for Supporters</u>	<u>Smart Approach</u>
<p>Understanding the reasons for contraception.</p> <p>Supporting decisions about contraception assumes a wish by the SP for sexual relationships and the avoidance of pregnancy and childbirth and parenthood. These assumptions should be fully tested.</p>	<p>How can I make sure that I understand the wishes of the SP with regards to contraception and parenthood?</p>	<p>The supporter should clarify with the SP the reasons behind wanting to choose contraceptive measures.</p> <p>The SP should then be aware that each contraception option has different and direct implications on family planning outcomes and therefore contraception should be aligned with the wishes of the SP in this matter.</p> <p>Contraceptive options should be discussed respecting the wishes of the SP with regards to parenthood.</p>
<p>Choosing the best contraception method.</p> <p>There is a wide variety of contraception methods: some are permanent, some last a long time. Some types need to be taken every day. There are many ways to apply them: swallowed as a pill every day, put into the vagina by the woman, injected into the arm or buttock, implanted under the skin, put into the uterus by a nurse or doctor. Some types of contraception cost more than others. Not all contraception methods help prevent STD.</p>	<p>How can I best support the SP to choose the contraception method that best applies to him/her?</p>	<p>First start assessing the needs of the SP with regards to contraception. Afterwards discuss in detail the remaining types of contraception in relation to:</p> <ol style="list-style-type: none"> 1) how they are taken, 2) procedures needed, 3) cost, 4) level of effectiveness, 5) reversibility, 6) additional non contraceptive benefits/ side effects. Show samples and demonstrate using diagrams and models. Eliminate those that the SP does not want to use. <p>Discuss whether there is a need to use condoms for STI protection.</p> <p>The supporter will need detailed knowledge of such matters and might also (with the SP's consent) draw on the help of a suitably qualified health professional.</p>

<p>Addressing informed consent.</p> <p>In some cases, families/legal guardians are afraid that their daughters with disabilities might become pregnant and, in some cases, might support the application of contraceptive methods without their awareness.</p>	<p>Can I support the provision of contraceptive methods to the SP without their awareness and consent?</p>	<p>The Convention on the Rights of Persons with Disabilities of 13 December 2006, ratified by Spain/Greece/Portugal, establishes the obligation of States Parties to respect "the right of persons with disabilities to decide freely and responsibly the number of children who wish to have [...] access to information, education on reproduction and family planning appropriate to their age, as long as the necessary means are provided to enable them to exercise those rights ", as well as to equal conditions with others. '</p> <p>The use of contraceptive methods without the awareness and consent of the SP should not happen. Supporters should help families/legal guardians find the right way to inform the SP of the reasons supporting the use of contraception and achieve a shared agreement with the SP on this.</p>
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► **Supporting the Supported Person (SP) to make informed decisions**

 <p>TOPICS FOR THE SP TO KNOW & UNDERSTAND</p>	 <p>TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP</p>
<p>Regarding contraception methods:</p>	

The SP should know that the best method of birth control is the one that is safe, that he/she is comfortable using, and is able to use consistently and correctly. The SP should know and understand the following:

- » Differences between birth control methods. There are many different contraceptive methods. You must get to know about them!
- » Am I aware of how the different contraception options (permanent/temporary) are linked to creating a family?
- » What are the side effects and your tolerance to them? Consider your tolerance for the possible side effects associated with a particular birth control method, your age and health history.
- » Cost of the different birth control alternatives. Which ones can you afford?

- » Why do I need contraception? Do I actually want a sexual relationship?
- » Do I want to avoid pregnancy, childbirth and parenthood?
- » Do I want this to be permanent or do I want to keep my options regarding parenthood open for the future?
- » Do I want to share this information with my family or friends? Could they help me think about the issues or will they want to decide what they think is best for me?
- » Do I have a health/medical professional who I trust who could support me to make and implement my decisions? Could I find one?
- » Do I have enough accessible information about the different options, their pros and cons and their implications?

- » Protection against sexually transmitted infections? Male and female condoms are the only methods of birth control that offer reliable protection from STD. Unless you are in a mutually monogamous relationship and have been tested for sexually transmitted infections, it is important to use a new condom every time you have sex, in addition to any other method of birth control you use.
- » Additional benefits. In addition to preventing pregnancy, some contraceptives provide benefits such as more predictable, lighter menstrual cycles.
- » Do I know what to do if contraception goes wrong (e.g. if the condom breaks or if I forget to take my contraceptive pill?)
- » Is the chosen contraception option acceptable to your sexual partner? Your partner may have birth control preferences that are similar to or different from your own. Discuss birth control options with your partner to help determine which method is acceptable to both of you.

Regarding planned parenthood

- » Some women will want to be a mother, others not. It is important to decide for yourself on whether you want to be a mother or not. Also, is my partner 'on the same page' as me regarding parenthood? If not, what is my plan?
- » It is important for a woman to look after her health if she wants to have a baby. Being pregnant will mean a woman goes through a lot of physical changes.
- » Being a parent can be very enjoyable, but it is also hard work and a big change in lifestyle
- » It's very important to be able to care for the child. A child needs to be looked after, fed, bathed, dressed and needs a safe home to live in.
- » The baby will grow up. He or she will become a child, then a teenager, then an adult. They will need different things at different ages.
- » What are my reproductive goals, such as the number of children I want and how soon do I want to get pregnant?
- » Discuss the good things and difficult things about being a mother or a father. Am I aware what it means to be a parent? What will my duties be?
- » Can I take care of my child on my own or do I need support? Who can support me If I decide to become a parent?
- » Discuss pre-conception and pregnancy care, including ensuring vitamin B levels, folic acid, diet and exercise, alcohol, smoking, medication.
- » Discuss choices of contraception until making a decision to be a parent.

► **Questions for Family Carers on this topic**

<u>Topic</u>	<u>Questions for Family carers</u>	<u>Smarts Approach</u>
<p>Introducing SDM on contraception and creating a family</p> <p>» Using contraception and creating a family are two inter-related topics. Decisions on one topic can also have an impact on decisions about the other.</p>	<p>What are the reasons I feel that the SP should/shouldn't use contraception? Are my reasons linked to the possibility of the SP creating a family? Are my views an obstacle for SDM?</p>	<ul style="list-style-type: none"> » It is normal to hold your own views on contraception and creating a family. However, SDM relies on the concept that the SP makes decisions for him/herself. » It is essential to identify your personal opinions, beliefs and values. Can you see and accept the SP as a sexually active person? Can you see the SP as a potential parent? Is it possible that you are trying to guide the SP towards a certain direction, regarding decisions on contraception and creating a family? In that case, your views could be an obstacle for SDM. » If you feel that your personal beliefs might come out too strongly, the Supporter, Facilitator or a trained professional could offer the help you need.
<p>Reflecting on yourself: your feelings and opinions</p> <p>» Contraception and creating a family are topics that evoke strong emotions in family carers, as they have to do with the SP's present and future well-being.</p> <p>It is a topic that awakens many fears, concerns, but also wishes for the family carers. It is important that family carers reflect on them and recognise them.</p>	<p>What are the main reasons for family carers objecting / supporting contraception? How could this affect SDM and how can I get support to understand and accept whatever s/he might decide?</p>	<p>There are many reasons that form family carers' opinions on contraception and creating a family. Some of the most common are:</p> <ul style="list-style-type: none"> » Moral/ethical reasons. Your moral code may dictate that the use of contraception, or in general intercourse for pleasure/ without marriage, is not permitted. » Fear. You may fear that if you are not in control of the SPs' contraceptive plan, the consequences will be STDs or an unwanted pregnancy. » Concerns about the future. You may have concerns about the ability of the SP to create a family, be a parent/ take on family duties, as well as your ability to offer support. » Difficulty to see the SP as a sexual being: you may have difficulty accepting that the SP is a person with sexual needs, or a potential parent. You may still see him/her as immature, instead of a person with the needs of an adult.

		<p>As previously said, it is normal to have those views, but one should be careful not to impose them on the SP. As a family carer, what you can do is make all the information clear and accessible for the SP, as well as make the SP aware of the potential consequences of each decision. However, the final choice is for the SP to make.</p> <p>If you feel that your personal beliefs, come out too strongly, the Supporter, Facilitator or a trained professional could offer the help you need.</p>
<p>Practically implementing SDM on contraception and creating a family</p> <ul style="list-style-type: none"> » - Even if you support SDM as a concept, it may be difficult for you, as a family carer, to take steps towards practical implementation. » The Supporter and Facilitator should be available to help you if you are facing challenges in practically supporting the SP with his/her decisions. 	<p>Do I understand all the contraceptive options? Will I understand if my son/daughter wants to keep information /decisions private from me?</p> <p>Am I willing to practically support the SP in using contraception and creating a family (eg. offering financial support, offering parenting guidance if asked to etc.)?</p>	<p>As a family carer, there are many things to consider when practically implementing SDM about contraception and creating a family:</p> <ul style="list-style-type: none"> » Your role in the SDM procedure is to make sure that correct information is offered to the SP. This begins with yourself being adequately informed. Don't hesitate to contact professionals who can provide you and/or the SP directly with knowledge about different contraceptive options, pregnancy, taking care of a baby, family duties etc. (ex. medical staff, social workers etc.). » Think about what practical supports for the SP you feel comfortable with giving and which seem feasible to you. Are you willing to support the SP financially in creating a family? Are you willing to monitor the use of contraception by the SP? <p>It is important to create a family circle of support in collaboration with the SP, where each family member participates in a way that is agreed upon (for instance, a male SP may choose the father to support him over using contraception). If the SP chooses someone outside the family circle as a Supporter, it is important to respect this decision, as the SP may keep some information private.</p>

SDM and taking care of your own body and sexually transmitted diseases (STDs)

► General considerations about taking care of your own body and STD

Everyone has a duty to take responsibility for their own health. Universal health coverage means that all people and communities receive the health services they need. It covers the entire spectrum of quality essential health services, from health promotion to prevention, treatment, rehabilitation and palliative care.

Similarly, everyone is free to make decisions regarding their own body. Laws clearly define their rights and duties on this matter and provide for mechanisms for obtaining information about their health.

This also applies to sexual health. In this regard, people are entitled to receive information and support to experience the sexual aspects of their lives in a comprehensive, autonomous, egalitarian, satisfactory and respectful way, with the guarantee of their sexual and reproductive rights.

► General considerations about taking care of one's own body and STD for PwD

People with disabilities need health care and health programs for the same reasons anyone else does – to stay well, active, and a part of the community. That means having the tools and information to make healthy choices and knowing how to prevent illness. This includes the area of health related to sexuality.

Everyone has a body which is used to drive and express their sexuality. For this reason, it is essential that PwD know and learn about their body and their sexuality and know how to take appropriate self-care on these issues. In summary, there is the need to understand how people respond sexually to each other and how the body changes throughout life. This includes knowing and addressing aspects related to reproduction and pleasure (such as arousal, lubrication, erection, ...) sensations and learning to develop the senses, as well as specific phases such as the period or menopause.

Some sexual behaviour may also carry the risk of sexually transmitted diseases (STD) with clear potential effects on the body and its functions. Little is known about the incidence of STDs within the group of PwD because of the lack of data and studies in this area. In order to reduce risky behaviours, it is essential to include STDs in sexual education programmes that are designed and applied within the framework of support services for PwD.

► **What does the legal framework say about this?**

GENERAL EUROPEAN LEGISLATION

The right to health is well established in international human rights law, including in the International Covenant on Economic, Social and Cultural Rights which recognises the right of all persons to the highest attainable standard of health (Art. 12). The Constitution of the World Health Organization (WHO) also enshrines the highest attainable standard of health as a fundamental right of every human being. The right to health includes access to timely, acceptable, and affordable health care of appropriate quality. The right to health means that States must generate conditions in which everyone can be as healthy as possible, including persons with disabilities.

The Convention on the Rights of Persons with Disabilities reinforces and strengthens protection for persons with disabilities in relation to health and rehabilitation. It recognises that persons with disabilities have the right to the highest attainable standard of health and that State parties must recognise that right without discrimination on the basis of disability (Art. 25) and further guarantees the right of persons with disabilities to access rehabilitation services of all kinds (Art. 26). Moreover, the Convention recognises the right of persons with disabilities to access, within their communities, a range of home, residential and other support services (Art. 19.)

WHO/Europe developed a regional framework for implementing the global strategy for the prevention and control of Sexually Transmitted Infections 2006–2015 in the WHO European Region. The WHO has also developed a global health sector strategy on Sexually Transmitted Infections, 2016-2021.

The ESSTI (European Surveillance of Sexually Transmitted Infections) Network promoted by the European Centre for Disease Prevention and Control was first established in 2001 and was funded by DG SANCO. The aim of the network was to develop and coordinate epidemiological and laboratory surveillance of STIs in the European region in order to better inform STI prevention, care and control.

► **Questions for Supporters on this topic supporting the SP to make informed decisions**

<i>Topic</i>	<i>Questions for supporters</i>	<i>Smart Approach</i>
Working on health aspects related to knowing and caring for one's own body or STD, requires a close relationship between the supporter and the SP.	<p>As a supporter, do you feel comfortable in offering support in sexual health issues and STD?</p> <p>Do you feel you have sufficient knowledge to offer such support?</p>	<p>As a supporter you should be comfortable talking to the SP about these issues and should be honest enough to talk openly about the difficulties you might experience addressing them. Also, offering support in aspects related to self-care and STDs, will require you to have sufficient knowledge on the issue (Do you know enough about STDs? Can you provide clear explanations and answer the questions of the SP? Do you know the procedure to follow if there are suspicions that the SP may carry a STD? Do you know the procedures to support the SP to care for him/herself?)</p> <p>If you feel you do not have sufficient information, you might consider getting the support from a health professional who can solve your doubts before addressing the topic with the SP. Alternatively, you can accompany the SP to discuss topics directly with a health professional - if the SP agrees to it. Written or visual information to support explanations either by you or the professionals can be prepared.</p>
Getting tested for STD. Any person that is sexually active, should be aware of the risks of STD and have awareness on how to protect themselves and use available STD testing, if necessary.	As a supporter, should I encourage the SP to get STD testing?	As a supporter it is advisable to inform a SP who is sexually active about the risk of STD and suggest a visit to a health practitioner to be tested if risky practices have already taken place, or for prevention purposes. After providing all necessary information and explaining the processes involved, the supporter should understand that the SP can make their own decision about getting tested or decide to be tested later. The SP can even decide not to have a test.
If someone has an STD it is strongly advisable to let past sex partners know. They should get tested too. It may be awkward, but telling former partners about STD's is the right thing to do.	If the SP is positive in STD testing, what are the limits of confidentiality?	If the SP is positive in STD testing the supporter should explain to the SP that if there is an infection, according to widespread health guidelines, sexual partners may need to be told so that they can protect their health as well. However, the supporter should avoid sharing this private information beyond those directly concerned, in accordance with the wishes of the SP.

► **Supporting the Supported Person (SP) to make informed decisions**



TOPICS FOR THE SP TO KNOW & UNDERSTAND



TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP

Regarding knowing and taking care of your own body

- » Do you know how your genitals and other erogenous parts of your body work and how to take care of them?
- » Do you know how the genitals and other erogenous areas of the opposite sex work?
- » Do you understand how babies are made?
- » Do you understand how the body shows signs of sexual pleasure: excitement, erection, etc.?
- » Do you know about the bodily changes throughout the life cycle, such as menarche (first menstrual cycles), climacteric (decline in fertility) or menopause (menstruation ceases) and how to address each of the different phases?
- »
- » Clarify with the SP in what areas they need support in order to clearly define them and so avoid violating their privacy with inappropriate questions that are out of scope of the topic of concern.
- » Agree with the SP if they wish to get the support from an external professional to offer a more tailored and/or complementary support. Explain that a person can ask for a female or male doctor or nurse according to their preferences.
- » Explain to the SP that, especially when addressing STD, the support of a health professional might be needed. If that is the case, the doctor or nurse might need to ask private questions about the SP's sexual activity.

Regarding STD

- » Do you know There are STDs caused by bacteria (e.g., gonorrhoea, syphilis), by viruses (HIV, herpes, hepatitis) by fungi (candidiasis, scabies)...?
- » Do you know the risky sexual practices through which STDs can be transmitted (e.g., vaginal intercourse or anal penetration without a condom, oral contact with semen ...)
- » Learn about the main measures to protect yourself from STDs (use of condoms,)
- » Do you know that tests can detect infections and that infections can be treated?
- » Do you know the main tests to identify the presence of STDs?
- » Do you know the main processes to implement STD tests? (e.g., how to self-swab, clinician collected swab, urine sample, blood tests with needles...)
- » Agree with the SP what information they want to share (or not) with their family. Discuss potential support from family and/or friends and explain the possibility for them to attend medical appointments together with the SP.
- » Explain that if there is an infection, sexual partners may need to be told so that they can be tested as well.
- » Be clear with the SP how his/her personal and confidential information will be treated and who will have access to it. Explain what policy will be followed by staff on this matter and what kind of supervision is in place to avoid situations of abuse.

► **Questions for Family carers about this topic**

<u>Topic</u>	<u>Questions for Family carers</u>	<u>Smarts Approach</u>
<p>Communicating with the SP about ST diseases and taking care of your own body</p> <ul style="list-style-type: none"> » Every decision-making process starts with understanding the needs of the SP. » As a family carer, your role is to try to clarify, understand, and respond to the SP's needs. 	<p>In what areas do I think the SP needs support in making decisions about STDs and taking care of his/her own body?</p> <p>Are there going to be challenges for me, being a Supporter and a family carer at the same time?</p> <p>How do I feel about the idea of my son/daughter not wanting to share some information about STDs and taking care of their own body with me?</p>	<p>As a family carer, the first step on the SDM process would be for you to try and clarify:</p> <ul style="list-style-type: none"> » In what area does the SP need my support in making decisions? » Am I the right person to support the SP in these kinds of decisions? Will I be able to offer my support when my son/daughter asks me to, but also respect his/her privacy and not ask "too much"? <p>Matters relating to one's body and sexuality are some of our most private information. As a family carer, it is possible to get carried away by your need to ensure safety and ask questions beyond the SP's personal boundaries. During the SDM process, make sure you reflect on your ability to maintain the balance between supporting and respecting the SP's privacy. Also, reflect on your family's boundaries and privacy (eg. are there private places in your house? Is your son/daughter free to close his/her bedroom door? Are you involved in your son's / daughter's personal hygiene? etc)</p>
<p>Reflecting on yourself: your feelings and opinions</p> <ul style="list-style-type: none"> » It is very normal for you, as a family carer, to hold your own opinions and feelings on STDs and taking care of your own body. » STDs may make you scared and afraid for the SP's wellbeing. They may make you uncomfortable, if you are not very familiar with talking about sexuality related topics. It may be a stress-provoking discussion 	<p>What are my views on ST Diseases? To what degree are my views interfering with the SDM process?</p> <p>What are my views on the SP taking care of his/her own body? Are my views interfering with the SDM process?</p>	<p>Taking care of one's own body is a very important step in adulthood and independence. As a family carer, you may have the tendency to get involved in the SP's self-care, in order to ensure your son's/daughter's health. It would be good to reflect on how the SP feels about your involvement and think whether it would be challenging for you to step back during the SDM process.</p> <p>Many times, those delicate, personal topics are difficult for a parent/ family member to discuss with the SP, without imposing their view or becoming over-involved. You may always ask for help from professionals, the Supporter or the Facilitator during the SDM process.</p>

<p>for you, or you may consider it shameful.</p> <ul style="list-style-type: none"> » As a family carer who is involved in SDM, it is a good idea to reflect on how all these feelings may affect your ability to inform the SP in an objective way, and then let your son/daughter make their own decisions. » It is important that you gain understanding of these feelings and opinions so you can help to implement SDM. 		
<p><i>From theory to practice- practically supporting SDM about STDs and taking care of his/her own body</i></p>	<p>What kind of information may the SP need when making decisions about STD and taking care of their own body?</p>	<ul style="list-style-type: none"> » During the SDM process, information about STDs and taking care of your own body should be available to your son/daughter, so that he/she can make informed choices. Topics of information may include types of STDs, ways of transmission and protection, awareness of one's own body and body parts, taking care of private body parts etc. <p>It is very normal that you, as a family carer, may not have all the answers or knowledge. Don't hesitate to seek help from professionals (ex. doctor) who can help you with providing information.</p>

SDM and the use of internet and social media for romantic and sexual purposes

Important note

The fact that SMARTS is discussing *this topic does not mean that SMARTS is supporting the use of the internet to find a sexual partner*. What follows is a dispassionate examination of the serious issues raised if the Supported Person in SDM asks for help to use the internet to find a sexual partner - and that it is legal to do so. Supporting sexual rights does not mean enabling illegalities to take place, but it should involve a clear understanding of the law and consequences for all concerned. The text below attempts to do this.

► **General considerations about the use of internet and social media for romantic and sexual purposes**

The internet and social media have become key to access information and content and are crucial to connect with others. In this regard, the internet and social media have changed the way people communicate, interact and develop personal relationships with others.

There are currently well established and hugely varied services to put people in contact with one another (Facebook, Twitter, Instagram, Linked In, Vibe etc.).

The use of the internet to find friendships, love and for sexual purposes, is also very common. Content-wise, 30% of the internet is porn and sexual content counts for between 5-15% of all web activity. Searches about sex are estimated to be about 20% of all searches.

► **General considerations for PwD**

As with all users, the benefits for PwD of connecting with others through the internet and social media are often regarded as a good strategy to reduce isolation and stigma. Such activities also promote the development of social relationships, thus contributing to overcoming isolation/marginalisation, so as to allow them to be heard by others. Connecting through the internet has also some inherent risks for everyone, including PwD, that need to be taken into consideration: there are the risks of connecting with persons with bad intentions (e.g., willing to scam others, tell lies, etc), inadvertently accessing violent and harmful websites or the arrival of unsolicited and/or sexually explicit emails, contacts or links to web-pages.

► **What does the legal framework say about this?**

GENERAL (EUROPEAN) LEGISLATION

Persons with disabilities using new internet media and social networks, like any other EU citizen, are subject to several overarching laws, such as the [General Data Protection Regulation \(EU\)](#)

[2016/679 \(GDPR\)](#), which focuses on privacy and data protection, and whose main objective is to give individuals control over their personal data, prohibiting its commercialisation by companies without the users' consent.

The EU has been developing legislation that promotes improved accessibility to the digital world for the benefit of all citizens, especially PwD. In this context, the [EU Web Accessibility Directive 2016/2102](#) aims to harmonise common accessibility requirements to increase inclusion by adapting the websites and mobile applications of public sector bodies to make them more accessible to users, based on the needs of PwD. Additionally, the [European Accessibility Act \(EAA\)](#) aims to improve the functioning of the internal market regarding the accessibility of products and services, such as smartphones, computers, online shops, mobile apps, ATMs, among others.

Furthermore, the UNCRPD has also conceptualised ICT accessibility as a precondition for equality and the enjoyment of rights, in line with Article 9. According to Article 21, States Parties shall take all appropriate measures to ensure that PwD can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, which includes through the internet and social media.

► **Questions for supporters on this topic**

Key topics around the SDM process for supporters to consider when framing their support

<u>Topic</u>	<u>Questions for supporters</u>	<u>Smart Approach</u>
<p>Facilitating (or not) access to the Internet and social media.</p> <p>Using the internet and social media to find love or sexual partners only becomes a live issue if:</p> <ul style="list-style-type: none"> » the SP has access to suitable devices (this could be on a computer or a smart phone/tablet which could be their own - or someone else's (e.g., from a colleague, a relative...), » understands how to use the internet, the design and functionality of the various applications. » Has sufficient literacy skills to use the device 	<p>How should I decide if it is better to encourage or discourage/ access to the Internet?</p>	<p>Because we agree that, on balance, access to the internet and social media can bring far greater benefits than drawbacks (e.g. the opportunity to make friends over the web is generally regarded as a good thing for PwD), then we must accept that facilitating access to devices and 'educating' SP's about the issue of 'sex on the web' is important and beneficial for the SP. Also, according to the SDM principles and Human Rights approach, access to things should not be denied based on the reason of disabilities.</p>

<p>Addressing the risks that the internet and social media activities might pose</p> <ul style="list-style-type: none"> » The 'open' nature of the web and social media experience means that it is difficult to predict or control what a person sees, how he/she interacts with it and any other related risks it may involve. » Contacts and relations forged in the web and social media might evolve in a wide variety of ways and it all depends on the capabilities and intentions of those involved, e.g: a 'pen friend' over the web may remain as such (or not). 	<p>How can we best deal with potential risks associated with the use of the internet and social media?</p>	<ul style="list-style-type: none"> » Activities on the web and social media are in principle a matter of personal privacy. Supporters, when addressing potential risks, should avoid imposing unilateral control on activities but based on mutual agreement with the SP. » For the SP, using the web might be a progressive developmental experience. Their expertise might grow with use. This might require regular reviews with the SP of potential risky or harmful situations. » In some cases, we might need to challenge the option to set controls since others with 'full access' to online and social media contents may show the SP what she/he is missing out on. » Means of control to address risks should be considered only based on the duty of care.
<p>Setting limits to access and use of the internet and social media.</p> <p>There are many different ways of using the internet and social media, ranging from just accessing information, communicating online and actively interacting with others (for friendships, love and for sexual purposes) which may result in a face-to-face meeting.</p>	<p>Should I set limits to the access and use of the internet and social media?</p>	<p>The access and use of the internet and social media is a matter of personal choice and privacy. The personal views of the supporter do not provide a reason for setting any limits to usage.</p> <p>However, if the level of usage affects others (eg. denying them equal access to the internet), then that must be addressed. If illegal materials are being accessed (e.g., child abuse videos), then the supporter (and the organisation) do have a duty of care to prevent this. (See more on the duty of care in Section 2).</p>

► **Supporting the Supported Person (SP) to make informed decisions**



TOPICS FOR THE SP TO KNOW & UNDERSTAND

That the website allows a wide variety of contacts.

You can use the web just to make friends, but people also use it to find love or for sexual purposes.

Fake profiles. Are you aware that what you see on screen might not correspond to reality? People tell lies about themselves and their circumstances and might be willing to take advantage of you (e.g through scams asking for money to address fake financial/difficulties).

Financial risks.

- » When connecting with others, you should be wary of people asking for money.
- » Do you know that there are many 'dating' sites online that often require payment to access them?

Building relationships with others is sometimes complex and not always easy for anyone.

- » Relationships might evolve in many different ways. Initially meeting online can be a stress free and "safe" way to meet new people without being too exposed, but afterwards relationships might progress in a variety of ways, for example friendships might evolve into more intimate relationships?
- » Building relationships with others might involve disappointments, rejections and heartache.

Safety risks

- » If it ever comes to the point that you would like to meet face to face with someone you have met online, you should be aware that meeting someone for the first time might always entail risks and therefore you should agree on a safe way to do so.
- » Explicitly looking for a sexual partner on the web might attract dubious offers from persons willing to take advantage of you.
- » People might ask you to do things you may not be comfortable with (e.g take nude photos or videos doing sex acts)
- » You should be aware of the risk of others spreading and sharing personal and private information (e.g personal data, compromising pictures etc).



TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP

- » Why do you want to have access to the internet and social media? Is it because you feel lonely and want to meet friends? Or are you searching for love? Or is lust driving this search? Or is it a mix of two or all three?
- » What and which are your expectations when meeting somebody through the internet? Are those expectations realistic?
- » Do you want to keep these contacts at a virtual/online level or would you like eventually to meet the other person face to face?
- » Are you worried about what others might think if they find out about this activity? If so, why/why not?
- » Are there other alternatives which could satisfy your needs for meeting people/a romantic/ sexual relationship that you would like to explore?
- » Have you thought about the potential consequences of using the internet to meet people? What are the possible outcomes, what are the *probable outcomes*?

► **Questions for Family carers about this topic**

<i>Topic</i>	<i>Questions for Family carers</i>	<i>Smarts Approach</i>
<p>Communicating with the SP about using the web to find a romantic/sexual partner</p> <ul style="list-style-type: none"> » Every decision-making process starts with understanding a wish expressed by the SP. » As a family carer, your role is to try to clarify, understand, and respond to the SP's wish. 	<p>Have you talked to the SP about this and understood his/her wishes clearly?</p> <ul style="list-style-type: none"> » Is s/he looking for a romantic partner or a sexual partner? Then ask yourself - are you thinking "a romantic partner is OK, but I'm not so happy with the idea of a sexual one?" If so, why do you think this? Will you help with either quest or just the one? » What will you do about the quest you have 'rejected'? Will you allow/propose that someone else help him/her with this? 	<p>"Understanding" can be tricky and includes two levels of decoding a message:</p> <ul style="list-style-type: none"> » Clarifying the actual content of the message: what does the SP know about using the web to find a sexual partner, and what information does s/he still lack to make an informed decision? » Clarifying the needs behind this wish (eg. does using the web to find a sexual partner seem less threatening than face-to face communication? Does the SP feel that it is the "only way" to find a sexual partner?) <p>Both these levels are important for helping the SP to make an informed decision about themselves.</p>
<p>Reflecting on yourself: your feelings and opinions</p> <ul style="list-style-type: none"> » Both the SP and yourself, as a family carer, hold your own opinions and feelings on using the web to find a sexual partner. » It is important that you gain understanding of these feelings and opinions to implement SDM. 	<p>What are your fears about the SP using the web to find a sexual partner?</p> <p>A lot of thoughts may cross your mind regarding the use of the internet by your son/daughter. For example</p> <ul style="list-style-type: none"> » If he/she will be able to detect a fraud » What kind of people may he /she meet through the internet? » All possibilities are open, how can he/she detect who is sincere and trustworthy? » He/she may easily be abused or taken advantage of. » What may the other person ask from him/her? » Without proper support through this search, he/she may end up confused and hurt, rather than happy and content. » He/she may build lots of expectations and be really disappointed in the long run 	<p>The SDM process suggests that the SP should have all the necessary information available before making a choice.</p> <p>He is free to make his personal choice, as long as he is aware of the possible outcomes and pros and cons, regardless of the feelings and opinions of his family and/ or caregivers.</p> <p>In case you feel, or you discover during your discussion with the SP, that you shall be overwhelmed by your fears and thus influence the decisions of your son / daughter, maybe it would be better to seek help from professionals that know him/her and are willing to give him/her accurate information.</p> <p>If you are not the Supporter during the SDM process, the Supporter will be available if you ask him for his /her help. If you are the Supporter, then the Facilitator may be available to guide you.</p>

	<p><i>If you approve or disapprove about the SP using the web to find a sexual partner - how influential will this be with the SP? For example; will your 'disapproval' actually prevent this from happening?</i></p>	<p>The SDM protocol suggests that you allow the SP to make their own informed decisions. However, how easy is it for you to set your personal views aside?</p> <ul style="list-style-type: none"> » SDM requires reflecting on your approval or disapproval, and deciding how important it is to you that you hold on to your opinion and how much it will affect the SP. » You should always keep in mind that the SP has the right to hold their own opinions and views, and that those opinions and views may sometimes be opposite to yours. » If you find yourself strongly guided by your opinion in a way that hinders the decision of the SP, maybe it is time to team up with the SP and problem solve together, evaluate your options, and generate alternatives. If you feel you are imposing your views to the SP, do not hesitate to seek support from professionals.
	<p><i>If you disapprove, what alternatives have you suggested?</i></p>	<p>As the SDM methodology proposes, the SP should have all the information available before making his/her choice. You may want to discuss alternatives for finding a sexual partner with the SP, for example it would be useful to know if s/he is interested in one of his/her friends or acquaintances. The pros and cons of each choice should be clearly stated. Of course, many times this delicate, personal topic is difficult for a parent / family member to discuss with the SP. You may always ask for help from the professionals/ the person who is the Supporter during the SDM process.</p>

From theory to practice - practically supporting using the web to find a sexual partner

Think about how you can practically help your son/ daughter access the internet.

IT equipment will be needed - will this be shared use or private - just for one person?

IT equipment often fails/ becomes obsolete over time. Who will update/pay for it?

A lot of modern IT equipment, especially mobile/ smart phones, is very easily lost or stolen.

What are your thoughts and availability on practically supporting the SP on implementing this decision?

'Access is power' - are you willing to hand over that power of access to your son/daughter?

Allowing/enabling the loss of access is also a form of power.

Your simple inaction might result in a loss of access too.

There are often many practical problems with the web (e.g., 'downtime' by provider networks, communication glitches, software updates which then make old equipment less useful etc).

Are you prepared to be actively involved in keeping your son/daughter sufficiently 'up to date' i.e., not using the very latest gizmo every time it launches but still able to stay in touch online? This may take time and money (and some careful negotiation too!)

Are you willing/able to replace/ update lost, broken or obsolete equipment even if this means this allows them to carry on contacting people in a way you disapprove of?

- » Making sure that a pc/laptop/tablet is available as well as a private room-space within the house when the SP has decided to do his online search.
- » It would be useful if the SP (with the appropriate help if necessary) creates a personal/private account in order to keep his activities and communications private. If agreed so by the SP, a second person (the supporter or a family member) may also have access to this account.
- » The same person or the supporter should be available, in case the SP has some questions or feels he needs some help nearby in handling his online communications.
- » Maybe you and/or the supporter may provide him/her with some suggestions about relatively "safer" sites and chats?
- » If the SP decides to meet somebody in person and asks for your support, you should first make sure the SP knows and understands the risks of meeting someone. You could be available for him/her that day either by actually accompanying him/her, or by remaining available on call or physically nearby if s/he would like to ask something or needs any kind of support.



SDM and Pornography

IMPORTANT NOTE!

The fact that SMARTS is discussing this topic does not mean that SMARTS is supporting the use of pornography. What follows is a dispassionate examination of the serious issues raised if the Supported Person in SDM asks for help to find and / or use pornography - and that it is legal to do so. Supporting sexual rights does not mean enabling illegalities to take place, but it should involve a clear understanding of the law and consequences for all concerned. The text below attempts to do this.

► **General considerations about pornography**

Pornography is any medium that depicts erotic behaviour for the sake of sexual arousal. This controversial subject is most often associated with magazines and movies but also includes other topics such as art, cartoons, and other media. With the advent of Internet-based media and commerce, the pornography industry has expanded into cyberspace, thus allowing for greater product accessibility while maintaining relative user anonymity.

► **General considerations on pornography for PwD**

Some PwD are interested in pornography, but often their access to it is limited, given their difficulties in acquiring it on their own. However, the internet is changing this state of affairs very quickly and substantially, given the ease with which information on the network can be accessed.

Many people watch and enjoy porn. People of all abilities may also watch and enjoy porn. As long as it is ethical, shows consent and doesn't interfere with other life activities, pornography may be a way for someone who is unable to engage in sexual activity with another person (whether physically, emotionally or cognitively), to experience sexual arousal and release on their own. Regardless of their abilities, most people experience sexual desires, attractions and feelings. Pornography can be a helpful tool for a person who may not have other avenues for sexual experience that meets those needs.

Nevertheless, there is evidence to suggest that pornography can portray unrealistic ideas about men and women, the body and sex. These messages can be damaging, affecting confidence and self-esteem (Wallmyr & Welin, 2006). Young people and PwD may be particularly vulnerable to such harmful messages. It is also important to note that in many countries the presentation of pornography to PwD, without their informed consent, is considered a form of sexual abuse.

Viewing porn in public is illegal. It is fundamental to help the young person or adult with a disability to understand that searching and viewing pornography is a private behaviour; something that should only be done in a private place, where no one else can see or hear the person.

Having a conversation about pornography may be a stressful topic for caregivers, therefore it is often a topic that is avoided at all costs, or it is addressed in a way that is shaming or hurtful to

the PwD. However, more than ever, all the available information on this topic makes the unsupervised access to pornographic content very probable, therefore it is fundamental to be an available and approachable caregiver when it comes to this subject.

► **What does the legal framework say about this?**

GENERAL EUROPEAN LEGISLATION

Access to and possession of pornography is legal in all EU Member States (MS), the legal framework for the production of pornographic content varies from country to country (being completely illegal in Bulgaria), but all MS have strict laws condemning the production, distribution, access to and possession of child pornography. In the same vein, the EU has adopted the [Directive 2011/92/EU](#) aimed at deepening the fight against sexual offences against children, with particular provisions specifically targeting child pornography on the Internet. However, there is no general legal framework at EU level on pornography with regard to persons with disabilities.



► **Questions for supporters on this topic**

Key topics around the SDM process for supporters to consider when framing their support

<u>Topic</u>	<u>Questions for supporters</u>	<u>Smart Approach</u>
There are risks in the use of pornography: in particular, there is the risk that people without any sexual education deduce that pornography is a reflection of real life, when the truth is that these materials tend to reflect languages and attitudes based on discrimination and on the consideration of people – most often women - as simple sexual objects. This can lead to a reinforcement, in the person with disabilities, of behaviours that are intended to be eliminated.	Should access to pornography be facilitated to PwD?	Supporters should not prevent access and private use of pornographic material when the person with a disability requires it. However, it should always be done within the framework of previous sex education training and focused planning on the SP. Pornographic material is NOT educational material.
There are risks that PwD may access pornographic content without supervision or guidance. The risk here being that not all pornographic material is legal and not all the sources of pornographic material are secure and licit.	How to ensure safety and legality when the PwD accesses and uses pornographic content?	Supporters should provide information on legal and secure sources of pornographic content and educate potential users with disability on what is and what is not ethical and legal pornography, according to the country's legislation and promoting a healthy socio-emotional development for the person with disability.

<p>There is the possibility that caregivers, being family members or professionals, do not feel comfortable with supporting the use of pornography in practice, being an issue that may be out of their comfort zone and against individual values. There is also the possibility of not understanding how to support the use of pornography, should the person with disability need guidance.</p>	<p>What, when and where is adequate to support the use of pornography by the PwD?</p>	<p>Supporters should be supported and feel comfortable to ask for help in case they do not feel prepared to address this topic; if feeling unprepared and/or unavailable, this should be reported and the conversation about pornography should be guaranteed by someone else.</p> <p>If the supporter is willing to support the access and use of pornography, (s)he should explain that this is a private behaviour to be adopted in private settings and, if involving any other person, with expressed and informed consent. All accessed pornographic material should be considered ethical and legal, according to the country's legislation.</p>
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► **Supporting the Supported Person (SP) to make informed decisions**

 <p>TOPICS FOR THE SP TO KNOW & UNDERSTAND</p>	 <p>TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP</p>
<ul style="list-style-type: none"> » What is pornography and what are the pro's and con's regarding the use of pornography? » What are the reasons why people would wish to access pornography? » Why some people may not feel comfortable or may be against the use of pornography. » What are the risks of pornography interfering with a healthy socioemotional and sexual development and lifestyle? » What are the different types of pornographic material and what are legal and illegal materials and sources of information? » How to access pornographic content, ensuring the fulfilment of legal requirements? » Which are the safety issues when accessing pornographic material? » Where, when and how to use pornographic material? 	<ul style="list-style-type: none"> » Why do you want to have access to pornographic contents? » What are your expectations when using pornography? Are those expectations realistic? » Are you worried about what others might think if they find out about this activity? if so, why/why not? » Are there other alternatives which could satisfy your needs for sexual arousal that you would like to explore? » Have you thought about the potential consequences for you of using pornographic material? » What kind of support do you think you would need when accessing pornographic material?

► **Questions for Family Carers about this topic**

<u>Topic</u>	<u>Questions for Family carers</u>	<u>Smarts Approach</u>
<p>Communicating with the SP about pornography</p> <p>Every decision-making process starts with understanding a wish expressed by the SP.</p> <p>As a family carer, your role is to try to clarify, understand, and respond to the SP’s wish through communication.</p> <p>» However, some topics, such as pornography, may be challenging for you to talk about: you may feel that this topic is out of your moral or comfort zone, or may not know “how to talk about” it and “what to say”.</p>	<p>What can I do if I find it hard to communicate about pornography with my son/daughter? Will that affect the SDM process?</p>	<p>Clear and open communication is a vital component of the SDM process. The SDM process suggests that the SP should have all the necessary information available to make an informed choice.</p> <p>Information may revolve around understanding:</p> <ul style="list-style-type: none"> » What exactly pornography is, what types of pornography are there, and how can the SP have access to pornography, if he/she wishes to. » What example/expectations does pornography set about sex and relationships, and how realistic are these examples. » What legal implications are there concerning pornography, and what forms of pornography are considered illegal. » Where and how can the SP watch pornographic content. » What dangers should the SP be aware of when using the internet to access pornographic content. » That other people may have strong views about pornography and may object strongly to it. So, talking openly to others about it may cause offence. <p>If you feel that you do not know how to approach those subjects with the SP, the Supporter or the Facilitator should be available to guide you. If, nevertheless, you feel that this topic makes you uncomfortable, maybe another family member or a trusted professional could support the SP on this specific topic.</p>

<p>Reflecting on yourself: your feelings and opinions</p> <p>Both the SP and yourself, as a family carer, hold your own opinions and feelings on using the web to watch intimate intercourse between adults.</p> <p>It is important that you gain understanding of these feelings and opinions to implement SDM.</p> <p>Pornography is a topic that can raise many feelings for family carers: shame, a sense of “inappropriateness” or even fear that your son/daughter may be “carried away.”</p>	<p>If you approve or disapprove about the SP using pornography- how influential will this be with the SP?</p> <p>For example; will your 'disapproval' actually prevent this from happening?</p> <p>If your son/daughter watches pornography regularly and this is his only sexual experience, (s)he may end up believing this is the way people are being intimate, which is not always realistic.</p>	<p>The SDM process suggests that the SP should have all the necessary information available before making a choice. The SP is free to make a personal choice, as long as (s)he is aware of the possible outcomes and pros and cons, regardless of the feelings and opinions of family and/ or caregivers.</p> <p>If you feel, or you discover during your discussion with the SP, that you may be overwhelmed by your own fears and thus influence the decisions of your son/daughter, maybe it would be better to seek help from professionals?</p> <p>» The important thing is not who explains pornography, what really matters is that the SP knows what it is, understands how it affects him/her and recognises that it is often a fantasy with one aim in mind - to stimulate a sexual response in those who use it. It is most certainly not a guide on how relationships between people should be carried out! It is also big business, found all over the world, often linked to crime and prostitution/abuse. Only you can decide on the extent to which you feel, as a family carer, that you can dispassionately explain all this to the SP.</p>
<p>From theory to practice- practically supporting SDM on the use of pornography</p>	<p>What are your thoughts and availability on practically supporting the SP on implementing his/her decision?</p>	<p>Of course, the SP’s privacy and his/her choice on sexual issues should be respected, but we should never neglect the idea of safeguarding.</p> <p>As nowadays most of the pornographic material is circulated through the Internet, a lot of frauds also find their way through sites that have to do with sex. People may ask the SP for money, credit card use, “promising” meetings with strangers etc. Maybe a good idea would be to check in advance some sites that would seem safer for the SP to use and recommend them.</p> <p>Also, to encourage the SP to talk to his/her supporter or a family member if he feels something weird is going on and people ask things from him/her</p> <p>In order for the SP to watch pornographic material, (s)he needs some privacy and a laptop/pc/tablet that (s)he may need. Is the family ready/prepared to offer this privacy? Maybe, if this is not available in the family’s home, is there another safe place the SP may use?</p> <p>» In general, the SP should be properly informed about the possible dangers (s)he may face when dealing with pornographic material.</p>

SDM and commercial sex

Important note

The fact that SMARTS is discussing this *topic does not mean that SMARTS is supporting/recommending SDM* and the use of commercial sex.

What follows is a dispassionate examination of the serious issues raised if the Supported Person in SDM asks for help to access some form of commercial sex. Supporting sexual rights does not mean enabling illegalities to take place, but it must involve a clear understanding of the freedoms and limits to action under the law as well as the potential consequences for all concerned of using commercial sex.

The text below attempts to do this.

► SDM & commercial sex

Some important definition of terms:

Sexual assistance is the range of services provided by trained professionals to PwD, in order to help them to achieve sexual expression.

Sexual assistants (SA's) are the professionals trained in efficient communication, relaxation and sexual (penetrative and non-penetrative) techniques, in order to enhance the sexuality of PwD.

Prostitutes/prostitution is the provision of any form of sexual service to another person for monetary gain. Most prostitutes are female and prostitution is found in every country in the world.

We use the collective term '**sex worker**' to cover both these groups offering commercial sex.

There are varying definitions of sexual assistance. One way of looking at it (Centeno 2013) sees it as simply helping someone to access their own body in sexual matters. So, the sexual assistant would, for example, help the person before, during and / or after sexual practices with other people in everything he/she cannot do without support, or masturbate the person if he/she is unable to do so on his/her own. Some organisations (eg: Tandem Team) have gone further and eliminated the word "Assistant" and instead use the concept of Intimate & Erotic Accompaniment, seeing this as another resource to develop eroticism, just another way of helping someone within the actions needed for the satisfactory development of sexuality."

There are some approaches that consider sexual assistance as a therapy, learning and managing their sexuality, since the objective of the Assistance is not "the immediate satisfaction of desire, but the application of a therapy established by a professional of sexology". (ISESUS.)

The dividing line between Sexual Assistance and prostitution can be difficult to assess. Before suggesting using the services of a SA, the Supporter/ Manager should check the training and past experience of the SA in supporting PwD to use their services. Not all SA's and not all countries offer such training.

The training is considered necessary, since without it, the Assistant cannot carry out his/her work properly. For example, she/he will not know how to react to a rise in tension of the user, she will not know how to place a person from a wheelchair to the bed, etc in a safe manner. And most importantly, she will not know how to teach the user to have sensations and learn from their sexuality (Sánchez, 2014).

Although sexual assistants are also considered to be commercial sex workers as well as prostitutes, there are some critical differences between the two kinds of services. Both are rewarded by monetary exchange. Sexual assistants have freely chosen to offer these kinds of services and are not exploited or taken advantage of. They are expected to provide several choices and levels of support for addressing different aspects and expressions of sexuality, whereas prostitutes mainly offer sexual services.

Sexual assistants	Prostitutes
Offer their services to persons with special needs (mobility needs, intellectual disabilities...).	Offer their services to anybody willing to pay.
The service is Implemented freely and the sexual assistant is chosen by the supported person.	Many (but not all) prostitutes are not doing it out of choice but out of necessity. Many are exploited / controlled by men (pimps) often using force. Some prostitutes have alcohol or drug addiction and need money for that.
Provision of support for a range of sexual experiences such as autoeroticism, masturbation, and sexual practices with others.	Usually, any sexual practices agreed between client and the prostitute
Monetary exchange	Monetary exchange
May have had some training/ qualification relating to sexuality and disability and will have had experience of sexual issues and disability, which will be all the sex work that they do.	Will not have had any training specific to disability & their sexual needs. Also, any past experience they have had of sexuality and disability will have been unplanned, irregular and form only a small part of their commercial sexual activities.

► **General considerations on commercial sex (prostitutes and sexual assistants) for PwD**

If the supported PwD chooses and is able to pay in order to meet with a potential sexual partner, in countries and places where these two ‘professions’ are legal, this may prove an easy task, a quick and targeted solution.

However, there is a higher risk involved for PwD, especially when choosing to find and meet with a prostitute, than for the general population. Sex workers are often linked to/controlled by criminal

gangs and work in places that are definitely unsafe for PwD to approach. Also, if the supported person likes this experience, he (it almost always is a 'he', but it could rarely be a 'she') may choose to meet with a prostitute often. Then the family will be obliged to significantly raise the monthly budget needed for the Supported Person. The health risk of being contaminated with a Sexually Transmitted Disease (STD) also increases. A further complication, with potentially emotionally painful consequences, is that the SP might fall in love with the prostitute.

Choosing to use the services of a sexual assistant may prove to be a less risky choice for PwD. As these professionals are trained to respond to each person's specific needs, the supported person probably will feel fulfilled and satisfied with this choice. The assistant is able to provide support for sexual touches, caresses, autoeroticism, masturbation, and sexual practices with others, so the range of potential sexual experiences is wide and may be easily individualised. Again, there is the risk that the SP might fall in love with the sexual assistant.

To find and use the services of a sexual assistant for PwD, could turn out to be an easier and more trustworthy solution than hiring the services of a prostitute, but this depends a lot on the situation and legislation currently in force in each country. In some European countries, sexual assistants may not officially exist yet.

Also here again, probably the moral, financial and emotional issues which arise for PwD, and their caregivers and service providers may prove to be equally difficult to resolve to everyone's satisfaction.

► **What does the legal framework say about this?**

GENERAL (EUROPEAN) LEGISLATION

Sexual assistance, like prostitution, falls directly into the debate on the legality or illegality of the provision of sexual services, which varies from country to country and still lacks a general framework at the EU level. However, the European Commission has shown interest in studying and analysing experiences in this area by funding the study: [Commercial Sex, 'Sexual Assistance' and People with Disabilities: A Qualitative Inquiry on Sweden, Britain, and Switzerland](#).



► **Questions for supporters on this topic**

Key topics around the SDM process for supporters to consider when framing their support on commercial sex

<u>Topic</u>	<u>Questions for supporters</u>	<u>Smarts Approach</u>
<p>Addressing the level of influence of the supporter in shaping the opinion of the SP on whether to 'commercial sex' use or not.</p> <p>The Supporter's and the Facilitator's personalities and values may, even unconsciously, influence the</p>	<p>How is it possible for the supporter and / facilitator to keep their 'procedural neutrality' when the SP chooses to use the services of a SA or prostitute?</p>	<p>The Supporter and Facilitator are expected to leave aside their personal moral dilemmas and explain / communicate neutrally with the SP about the pros and cons of choosing a sex worker. If the SP is legally permitted to use a sex worker, then like anyone else making that decision, it is their right to do so. SMARTS is all about supporting people's rights in the area of sexuality.</p>

<p>SP's choice, if s/he wants to meet with a sex worker of any kind.</p>		<p>The legal framework and the emotional issues related to this topic, as well as health and hygiene precautions, should be covered in detail in this discussion.</p>
<p>What level of support should the Supporter and Facilitator provide to the SP who wants to use the services of a Sex Worker?</p> <p>Should they just explain to him/ her the pros and cons? Or should they also be engaged in actually providing the SP with specific information on where to search and how?</p>	<p>Is it fair/reasonable/ realistic to expect supporters to support PwD to meet with a sex professional if they feel such actions are fundamentally wrong/ dangerous?</p>	<p>Engaging in commercial sex encounters is usually a complex issue. Once the SP has decided to use a sex worker, the service should find ways to help the SP to find a Sexual Assistant who is officially allowed to do this job (for example to search through the local and accredited providers) and who is especially trained to work with PwD and strictly follows all the hygiene-health precautions. In some countries such a service is not yet legally recognised. The Supporter should make sure the SP is well informed and all the process is legally and professionally corrected. The supporter might not be involved any more once the SP has made a supported decision, because the SDM process stops at that point. Responsibility for <i>implementing</i> that decision rests with the service as a whole and the manager in particular to work out how to move forward and to support the SP's decision.</p>
<p>The SP's choice to explore the choice of a sex worker may affect third parties, eg: family members, other residents sharing the SP's accommodation, the manager of the place etc.</p> <p>The decision to allow or even encourage paid sex services to engage with the SP 'on-site' (see above on managers and condoning/ providing the use of accommodation /rooms), may affect legally and socially the SP's residential environment and the SP him/herself.</p>	<p>Should potential consequences for supporters and/or third parties related to the SP be taken into consideration in the decision on whether to use services of a sex worker?</p>	<p>Both the supporter and the supported person should take into consideration and discuss the possible consequences for the third parties and maybe address them in order to prepare the ground for the SP's choice.</p> <p>It would be sensible to assume that, as some stage, even with strict confidentiality rules in place, the nature of the SP's activities with a sex worker 'on site' will become known to others. Plan ahead on how you will deal with it.</p>

► Supporting the Supported Person (SP) to make informed decisions

 TOPICS FOR THE SP TO KNOW & UNDERSTAND	 TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP
<p>Does the SP understand the legal aspects of choosing the services of a sex worker?</p> <ul style="list-style-type: none"> » Does the SP understand that this is not a relationship of love or even affection between the two adults, but a transaction based on money alone? » Have the costs of using sex worker's services been fully explained to him/her? » Have the risks –at different levels- been fully explained to the SP? eg: health, social, legal? » At a medical level: the risk of STD? » At a legal level: is the sexual assistant really a sexual assistant or a prostitute (contributing to the exploitation of prostitutes might be penalized by the law). » Safety level: the risk of going to unsafe areas, of getting in touch with undesirable people, the risk of losing/being robbed of the money intended to purchase the sexual services. » Social level: is there a risk social stigma for using commercial sex services? 	<ul style="list-style-type: none"> » Are there any other choices less costly and socially more acceptable that could adequately respond to the SP's needs and expectations? » Is the SP person aware of what kinds of services a sex worker provides and how to properly express and explain his needs to him/her? » If the SP has realised that this is a transaction based on money, and other options have been presented to him/her, is the solution of a sex worker really what s/he wants? For what reasons? » Is the SP aware that his choice is sensitive private information and that s/he may have the right not to share it with anybody? » If this is the case, is it possible to keep such a meeting private when living in the family home or together with other residents? » How does the SP feel about the possibility that his social environment may learn that he is meeting with a sex worker of some kind?

► Questions for Family Carers about this topic

<u>Topic</u>	<u>Questions for Family carers</u>	<u>Smarts Approach</u>
<p>Communicating with the SP to clearly understand and clarify his needs, is the first important step for implementing SDM</p> <p>As a family member, you are close to the SP and probably it is easier for you to understand what s/he really wants?</p>	<p>Have you talked to the SP about the option of choosing to meet with a sex worker and understood his wishes related with this particular choice?</p> <p>Is the SP well informed about the kinds of services the two kinds of sex worker offers and the difference between them?</p> <p>Is s/he aware that this is a sexual and commercial interaction and it does not involve any romantic feelings?</p> <p>Does the SP believe this is his only chance to fulfil his sexual desires?</p>	<p>Answering all the above is very important in order for the SP to reach an independent, informed decision.</p> <p>If you feel it is difficult for you to discuss all this delicate information with the SP, do not hesitate to ask for the professional's help.</p>

<p>Reflecting on your own opinion about the matter</p> <p>You hold your own opinion about the possibility that the SP chooses the services of a sex worker</p> <p>It is important to explore your thoughts and fears, in order to carry out SDM effectively.</p>	<p>Do you feel reassured with the fact that sexual assistants are specially trained for working with PwD?</p> <p>Do you prefer this alternative to choosing a prostitute?</p> <p>The danger for STD is still present though. Is the SP adequately informed and ready to implement and demand hygiene and appropriate contraception?</p> <p>Do you fear he/ she may expect a romantic relationship after meeting with the Sexual Assistant or prostitute.</p>	<p>The SDM process suggests that the SP should have all the necessary information available before making a choice.</p> <p>He/ she is free to make his/her personal choice, as long as s/he is aware of the possible outcomes and dangers, regardless of the feelings and opinions of his/her family and/ or caregivers.</p> <p>In case you feel, or you discover during your discussion with the SP, that you may be overwhelmed by your fears and thus influence your son/ daughter's decision, maybe it would be better to seek help from professionals who know your son/daughter and are willing to give him/her accurate information.</p>
<p>If the SP's final choice is to use a sex worker's services, are you willing to provide him/her with some facilities to enable this to happen safely?</p>	<p>For example, if your son/daughter lives in a home &/or shares a room - then the need to find an alternative place to meet is clear.</p> <p>The home may be unwilling/ unable to help. If you have helped him/her, make the decision, are you also willing/able to help him/her implement it?</p>	<p>Does it seem affordable/ acceptable for the family budget to cover the costs of using a sex worker's services?</p> <p>Is there a private room available in order for the encounter to take place?</p>

SDM and masturbation and the use of sex toys

Important note

The fact that SMARTS is discussing this *topic does not mean that SMARTS is supporting/recommending* the unrestricted use of masturbation or of sex toys.

What follows is a dispassionate examination of the serious issues raised if the Supported Person in SDM asks for help to learn how to masturbate and/or does so inappropriately. Supporting sexual rights does not mean enabling actions to take place in a manner or place which damages the public perception of a PwD or causes public offence to others. SMARTS promotes a clear understanding of the sexual freedoms and rights of PwD and the need for PwD to understand the constraints on their behaviour in public and in the company of others.

The text below attempts to do this.

► **General considerations about Masturbation and the use of sex toys**

Masturbation is defined as ‘the erotic stimulation especially of one’s own genital organs commonly resulting in orgasm and achieved by manual or other bodily contact exclusive of sexual intercourse, by instrumental manipulation, occasionally by sexual fantasies, or by various combinations of these agencies.’ (Merriam- Webster Dictionary online).

It is considered to be a timeless, worldwide, self-erotic tactic, traditionally assigned mostly to men. As this seems to have been mostly a cultural perception, in recent years attitudes have changed, so that women do not feel intimidated about admitting they are exercising masturbation or would like to.

Up until the 19th century and even in the beginning of the 20th, several myths and prejudices, with purely religious roots were linked to the idea of masturbation, trying to warn the “potential sinners” about the hypothetical harms of masturbating (eg ‘masturbation will make you blind’). Since then, science has proved that masturbation causes no harm and even seems to have some benefits for people who choose not to be exposed to sexual intercourse.

Sex toys: Objects used to provide or increase sexual pleasure. For example, a vibrator. They can be obtained in specialised, real or online sex shops. They can be used during sexual intercourse and/or during masturbation.

► **General considerations about masturbation and the use of sex toys for PwD**

PwD may practise masturbation and, if they can afford it and are willing to try, make use of sex toys, just like any other person can.

However, there are a couple of issues that should be considered and investigated. Masturbation practices are framed by specific social rules having to do with privacy and confidentiality. Additionally, both for masturbation and for the use of sex toys, health and safety precautions should be explained, before the person decides to experiment with new objects.

Since masturbation is pleasurable there may be a tendency for some PwD to ‘overdo it.’ Specifically for men and women within the autism spectrum, there is the possibility of choosing to repeat masturbation several times during a day. The practical aspects of this and the behavioural/physical consequences should not be overlooked.

► **What does the legal framework say about this?**

GENERAL EUROPEAN LEGISLATION

Despite the fact that the sex toys market has been developing strongly across Europe during the last years, there seem to be no regulations on their use / purchase at a European level. Even though in some countries (eg; India, Malaysia) owning or selling sex toys is forbidden, this is not the case for countries across Europe, where sex toys are distributed and sold freely. Most of the discussion around sex toy regulations in Europe concerns general issues of safety and consumer protection, although there is not yet an official direction or legislation specifically covering them.



► **Questions for supporters on this topic**

Key topics around the SDM process for supporters to consider when framing their support.

<u>Topic</u>	<u>Questions for Supporters</u>	<u>Smarts Approach</u>
Masturbation requires a complex set of skills, such as knowledge of body parts, knowledge of anatomy, experimentation, use of different equipment etc. for the SP to derive pleasure.	How can the supporter help the SP to understand the idea/process of masturbation?	<p>Listen to what they already know: what knowledge does the SP already have about their own anatomy, body parts and sexuality?</p> <p>Create a discussion with open questions, to understand what masturbation means to him/her. Enhance communication with the use of visual aids (ex. anatomically correct images of the body, educational DVDs etc.).</p> <p>Explain to the SP how our body works, and the functionality of sex toys. This knowledge is going to be the basis for making an informed decision!</p> <p>It may be that supporters will not feel willing / able / well enough informed to do this themselves, so their role might well change to that of finding an expert who can do this and supporting the SP to discuss it with the expert.</p>

<p>Masturbation and the use of sex toys is a sensitive matter. Depending on the role of the supporter in the life of the SP, different lines are drawn, and different limits are set. Supporters should be careful and clear about the framework of their role.</p>	<p>Where does my role as a supporter end when opening the topic on masturbation and the use of sex toys?</p>	<p>Different limitations are set according to the role of the supporter in the SP's life (for instance, a professional may be able to inform about masturbation, but helping the SP in acquiring and using sex toys perhaps falls beyond the limits of their role). Supporters should be careful about where their role ends when approaching this topic. Connections can be made to ensure that the SP gets the support that he/she needs, if it falls beyond the limits of the supporter (for example, as physical touch with sexual intention is strictly forbidden to both for professionals and family members, a sexual assistant could offer their services in case the SP needs guidance with masturbating/using sex toys).</p>
<p>Masturbation and the use of sex toys is a topic that may elicit ethical considerations from some supporters. Others may feel uncomfortable about discussing such a topic.</p> <p>On the other hand, the SP may also be reluctant in discussing a topic like that, as it is sometimes seen as "shameful" or wrong.</p>	<p>How do the parties involved in the SDM agreement feel about opening the topic of masturbation and the use of sexual toys?</p>	<p>Masturbation and the use of sex toys is a topic not always easy to discuss. As a supporter, your role is to:</p> <ul style="list-style-type: none"> ▸ Self-reflect on your own values about masturbation, use of sex toys and disability (eg Is there something inside you that tells you that people with disability shouldn't/ can't masturbate/use sex toys? Is there a value inside of you saying that masturbation/use of sex toys is inappropriate?). Another topic of self-reflection is how comfortable you are with discussing such a matter. Are there any feelings of shame or uneasiness? If so, addressing your thoughts and feelings is the best thing you can do. ▸ Pay attention to how the SP feels about opening this topic. Is he/she uncomfortable or ashamed? If so, the SDM process could be slowed down so as to spend some time normalising masturbation/use of sex toys, as something completely natural and fun! <p>In both cases, do not hesitate to seek support from the Facilitator.</p>

► **Supporting the Supported Person (SP) to make informed decisions**

 <p>TOPICS FOR THE SP TO KNOW & UNDERSTAND</p>	 <p>TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP</p>
<ul style="list-style-type: none"> » Masturbation is often seen by some as a deviant sexual behaviour when it occurs in the lives of people with disabilities. The supporter should help the supported person normalise masturbation and the use of sex toys, and then enable the SP to make Supported Decisions about if/how they wish to engage in such activities. 	<ul style="list-style-type: none"> » Masturbation and the use of sex toys is a healthy expression of sexuality, and a normal sexual activity people do. People with disabilities have the right to derive sexual pleasure in the same way if they wish to. There are many ways and aids to achieve this.
<ul style="list-style-type: none"> » In case of masturbation and the use of sex toys, some things are the SP's decisions, but others are not – they fall under the category of social rules. The supporter should help the SP discern what can be his/her personal choices, but also teach the rules around this topic. » Safety always comes first, and this is also the case for masturbation and the use of sex toys. The SP should be informed on how to keep themselves safe and protected. » If assistance is required from a sexual assistant (eg; guidance with masturbation technique, physical help), the supporter should help the SP clarify the nature of this relationship. 	<ul style="list-style-type: none"> » When masturbating, there are some things that are our decisions, but also some rules we should follow. The rules include that masturbation is done in private, behind closed doors, when we are alone. The decisions one can make include: the preferred technique/ way of masturbation, the preferred material (ex. magazines, videos) that he/she uses, the use or not of sex toys as well as the kind of sex toys he/she prefers. » The supporter should inform the SP about the safety rules of masturbation and use of sex toys, for instance: no objects with sharp edges/ objects that can shatter or break should be used for masturbation -only objects that belong to the person should be used for masturbation. Such objects should NOT be shared with others. It is important to maintain bodily health and prevent transmission of diseases. » The supporter should inform the SP that a sexual assistant is a professional who offers services, and this professional relationship is different from a romantic sexual relationship.

► **Questions for Family Carers about this topic**

<u>Topic</u>	<u>Questions for Family Carers</u>	<u>Smarts Approach</u>
<p>As a family carer, you may not know how to approach the subject of masturbation with the SP - you may not know what to say, how to say it, or where your limit lies. You may as well have concerns about the social rules around masturbation, especially if they interfere with your family life, or the social life of the SP.</p>	<p>Who is going to explain/show to my son/ daughter how to masturbate?</p>	<p>As a family carer, there are things that lie within your responsibilities, but also things that are beyond your role and limits:</p> <ul style="list-style-type: none"> ▪ You are responsible for providing the SP with information on masturbation in a clear, comprehensive way (you can use visual aids, videos created for PwD etc). If you feel uncomfortable or uncertain on how to do it, do not hesitate to reach out for help (eg; seeking consultation from a psychologist/social worker trained in sexual education). ▪ Keep in mind that any kind of touching with sexual intention or any kind of touching leading to arousal is to be avoided, both for ethical and legal reasons, and lies beyond your role as a family carer. In case the SP needs physical assistance, think of the possibility of reaching out to a sex worker (a prostitute or a sexual assistant).
	<p>Shall I be able to make him/ her understand the social rules about masturbation?</p>	<p>Masturbation has a set of personal choices (eg. the material one prefers to masturbate to), but also has rules that need to be followed. As a family carer, you can:</p> <ul style="list-style-type: none"> ▪ Set a clear set of rules around masturbation (eg; in private / in my bedroom/ with the door shut), and talk about the concrete social consequences of these rules not being followed. Inform the SP about what he/she can't and can do, remind them about the rules in a clear, specific manner and model the desired behaviour (for example, lead the SP to his/her bedroom explaining this is the appropriate place to masturbate, and close the door). ▪ Incorporate these rules into your daily family routine (for example, prompt the SP to close the door when he/she is showering, to promote the idea of "privacy").

<p>Many family carers agree upon the fact that most young people with PwD after learning how and where to masturbate, seem more relaxed and less agitated.</p> <p>However, there are reports of PwD who seclude themselves in their rooms for many hours each day, in order to be able to practise self-arousal repeatedly.</p>	<p style="text-align: center;">What if he/she becomes obsessed with masturbating and chooses to practise it several times during each day?</p>	<p>Although no direct health danger has been connected with masturbation practices, cases of repeated multiple daily orgasms, especially for persons who have been diagnosed with heart – and/or neurological health issues, may result in physical exhaustion.</p> <p>Additionally, any kind of obsession deprives a person from socialising, meeting new people and learning new things. If the PwD wishes to search for a potential partner, (s)he cannot find him/her easily if (s)he spends most of the day closed up in a room.</p> <p>Especially designed and agreed with the PwD “time deals” about masturbation could work, in order for him/ her to limit the time (s)he spends in self-erotic arousal.</p> <p>Suggest that the person engages him/herself with other activities that motivate him/ her, maybe could take his/her mind off masturbation.</p>
<p>The use of sex toys is a personal choice for every adult. The difficult part of this choice is to use them safely and keep them really clean. Their use should not involve bodily harm and they must be thoroughly sterilised after each use. The difficult part of this choice is to use them safely.</p>	<p style="text-align: center;">I am not comfortable with the thought that my son/ daughter may choose to use sex toys.</p> <p style="text-align: center;">I have no idea where to find sex toys and how my son/ daughter can use them.</p>	<ul style="list-style-type: none"> ▪ Discussing with the PwD about the reason why (s)he wants to use sex toys and the way (s)he is thinking to use them, may help to limit your worries. However this kind of discussion is rarely comfortable between two family members. ▪ As this is purely a personal choice, a suggestion would be that the SP could be encouraged to discuss these issues with his/ her supporter, a specialised therapist, or a sex worker.

SDM and inappropriate sexual behaviour

Important note

What follows is a dispassionate examination of the serious issues raised if the Supported Person in SDM asks for help about inappropriate sexual behaviour, eg; what it is, how different situations can change behaviour etc. Supporting sexual rights does not mean enabling inappropriate behaviour to occur, but it should involve a clear understanding of the law and of any potential consequences for all concerned. The text below attempts to do this.

► General considerations about inappropriate sexual behaviour

Behaviour is defined as the reflection of a whole set of feelings, thoughts, emotions, attitudes, and values that can bring out a certain type of behaviour. Aberrations from normal behaviour are referred to as conduct disorders, which are often diagnosed during childhood and are characterised by anti-social traits that violate the rights of other people and fail to follow socially established norms and rules.

Inappropriate sexual behaviour or behavioural problems in the field of sexuality is a category of conduct disorder that affects the behaviour of a person in the field of sexuality. Such behaviours are not a simple entity but are the result of the interaction of different types of psychobiological vulnerabilities and many different types of environmental stress.

From the biochemistry perspective, inappropriate sexual behaviours might be caused by issues in the self-regulation of the autonomous nervous system and/or metabolism problems. Environmental factors such as abuse, severe affective deficiencies and mistreatment and inadequate role models are also considered key risk factors leading to these types of conduct disorder. It is therefore necessary to address this issue in a person-centred, comprehensive and systematic way.

Inappropriate sexual behaviour does not always need to be directed at anyone in particular. In this regard it would imply the person acting in a way that is not considered 'correct' according to the established norms (e.g. a couple touching or kissing each other in a form that is considered inappropriate, people practising sex in visible/semi-public places).

Inappropriate sexual behaviour directed towards a specific person or people can be also considered harassment.

We understand by sexual harassment the situation in which any unwanted verbal, non-verbal or physical behaviour occurs, of a sexual nature, with the purpose or effect of attacking a person's dignity, especially when it creates an intimidating, hostile, degrading, humiliating or offensive environment.

Some examples are the following:

- Verbal: Making obscene sexual comments, making sexually offensive jokes, making derogatory or obscene forms of address, spreading rumours about a person's sex life, asking or explaining fantasies or sexual preferences, making rude comments about the body or physical appearance, talking about one's own sexual skills/abilities, exerting pressure to set up committed dates or sexual encounters, demand for sexual favours.
- Nonverbal: Lewd glances at the body, obscene gestures, use of graphics, cartoons, drawings, photographs or internet images of sexually explicit content, letters, notes or e-mail messages with sexually offensive content.
- Physical: excessive physical closeness, cornering or deliberately seeking to be alone with the person, deliberate and unsolicited physical contact (pinching, touching, unwanted massages, Intentionally or "accidentally" touching the sexual parts of the body).

► General considerations about inappropriate sexual behaviour by PwD

The integral development of a human being includes the acceptance of the human being as a sexual being, and therefore, sexuality must be considered as an important part of the development of a person. This affirmation must also be recognised for PwD; a group about which there have been and still are prejudices and attitudes in wider society that hinder their exercise of the right to and the enjoyment of sexual freedom.

When we consider offering sex-affective education to PwD, we have to keep in mind that they already have many previous influences about their way of seeing things and acting and relating to people and situations. When this 'education' is transmitted from the families, professionals, specialised centres or in the society in general, different and sometimes conflicting values and messages are clear.

Normally, sex education is an area of someone's life that has not been addressed or simply it has been left alone so that someone's behaviour has been inhibited or not taken into account. This patchwork of accidental learning distorts and magnifies anything that hasn't been solved/ explained, or that has been denied.

PwD do not have sexual particularities different from other people without disabilities, but we do observe differential aspects that can influence their erotic manifestation and that are important when dealing with socially inappropriate behaviours:

- Poor sexual socialisation.
- Having no capacity on building their own intimacy.

In order to go deeper into these two aspects, we can use the guide *Intellectual disabilities and sexuality: socially inappropriate sexual behaviour*. Ricardo de Dios del Valle, Mercedes García y Oscar Suárez (2006) Gobierno del Principado de Asturias.

► What does the legal framework say about this?

GENERAL EUROPEAN LEGISLATION

When it comes to inappropriate sexual behaviour, there is no legal framework at European level. There are however directives about violence and exploitation, especially as regards women, in the field of sexuality: eg. sexual harassment and sexual exploitation. See for eg: Directive (2006/54/EC) <<https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32006L0054>> on equal opportunities and equal treatment of women and men in employment and occupation brings about requests to implement the prohibition of direct and indirect sex discrimination, harassment and sexual harassment in pay.

EU law distinguishes between sex-based harassment and sexual harassment. While the former is about unwanted behaviour directed to someone based on their gender, the latter involves unwanted conduct of sexual nature.

Sexual harassment is illegal under several EU directives and prohibited under the Council of Europe Convention on Preventing and Combating Violence against Women and Domestic Violence - the Istanbul Convention <<https://www.coe.int/en/web/istanbul-convention/text-of-the-convention>>. The Convention defines acts of gender-based violence as resulting in “physical, sexual, psychological or economic harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or private life”. Sexual exploitation of women is recognised as a Eurocrime <<https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A12008E083>> for which the European Parliament and the Council have defined sanctions, within the meaning of Article 83 (1) TFEU. The Gender Equality Strategy <<https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52020DC0152>> (2020-2025) reinforces this latter point by mentioning that the Commission will propose additional measures to prevent and counter specific forms of gender-based violence, including sexual harassment, abuse of women and female genital mutilation.

The strategy further identifies key steps:

- * Member States are encouraged to ratify the International Labour Organisation (ILO) Convention which combats violence and harassment at work.
- * In order to tackle sexual exploitation, the Commission will present a new EU strategy on the eradication of trafficking in human beings.

The Charter of Fundamental Rights of the European Union <<https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:12012P/TXT>> (2000/C 364/01) states that human dignity is inviolable. It must be respected and protected (Article 1).



► **Questions for supporters on this topic**

Key topics around the SDM process for supporters to consider when framing their support.

<u>Topic</u>	<u>Questions for Supporters</u>	<u>Smarts Approach</u>
<p>What should the general attitude of supporters towards inappropriate sexual behaviour be? Inappropriate behaviour is that which breaks with established social norms e.g. Masturbation in public, touching the genitals, exhibitionism...</p>	<p>How does displayed Inappropriate sexual behaviour make us feel?</p>	<p>Supporters should be aware that some of these behaviours may clash directly with their values. Supporters should leave personal beliefs aside and be open minded to understand the roots and motivations of these unlike behaviours.</p>
<p>General approach of supporters to address the display of inappropriate sexual behaviour towards others. How should supporters address situations in which a PwD displays inappropriate sexual behaviour towards others and/or receives complaints in relation to his/her conduct?</p>	<p>Is it necessary for the supporter to adopt a punitive attitude in these cases?</p>	<p>The display of inappropriate sexual behaviour should not be penalised but addressed at several educative levels with the SP, using methods and materials consistent with the SP's abilities:</p> <p>On the one hand the supporter should try to understand the origin of the disruptive behaviour shown by the SP in a comprehensive manner and thus try to find what motivated it. Eg. Was it a relaxation strategy? A consequence of not having a partner? A consequence of not having an intimate space? Plain boredom?</p> <p>On the other hand, the supporter should propose educative actions aiming to inform the SP of the potential consequences on himself and others of such disruptive behaviours.</p> <p>Last, but not least, the supporter and SP should discuss any available alternative and socially accepted behavioural options. Within this process it is key to introduce concepts such as respect of others, intimacy, the use of public space vs intimate spaces, etc.</p>
<p>General approach of supporters when being the target of inappropriate sexual behaviour? Preventive actions to counteract the direct display of inappropriate sexual behaviour should be taken and noted.</p>	<p>What should supporters do if the SP targets them with inappropriate sexual behaviour?</p>	<p>There are several general recommendations on how to approach daily work by the supporter to prevent such situations as far as possible:</p> <ol style="list-style-type: none"> 1. Establish from the start clear boundaries between the supporter and the SP in terms of what can and cannot be done. 2. Avoid situations or relationships that may cause confusion to the SP. 3. Provide similar interactions and care to all persons without differentiations that could be understood as affective preferences by the SP.

		<p>If the inappropriate sexual behaviour does occur:</p> <ol style="list-style-type: none"> 4. Verbal instructions should clearly state that the supporter does not tolerate such behaviour. 5. Address the situation using an educative approach (see previous topic)
<p>What should the general attitude of supporters towards inappropriate sexual behaviour be?</p> <p>Inappropriate behaviour is that which breaks with established social norms e.g. Masturbation in public, touching the genitals, exhibitionism.</p>	<p>How does displayed Inappropriate sexual behaviour make us feel?</p>	<p>Supporters should be aware that some of these behaviours may clash directly with their values. Supporters should leave personal beliefs aside and be open minded to understand the roots and motivations of these unlike behaviours.</p>

► **Supporting the Supported Person (SP) to make informed decisions**

 <p>TOPICS FOR THE SP TO KNOW & UNDERSTAND</p>	 <p>TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP</p>
<p>What is inappropriate sexual behaviour?</p> <ul style="list-style-type: none"> » Understanding that some sexual behaviours are not wrong unless displayed in public. E.g. masturbating is not inappropriate, but doing it in public is. » Why do people showcase inappropriate sexual behaviour? » How is inappropriate sexual behaviour perceived by others? » What are the risks of the person's behaviour for himself and others? At legal, emotional, relational levels. » Understanding the need for privacy. 	<p>Can the SP understand that he/she is displaying inappropriate sexual behaviour?</p> <p>Is the SP able to explain the reasons for such a display?</p> <p>What sex education has the SP previously received?</p> <p>What kind of sex-affective socialisation has the SP had?</p> <p>Is the SP aware of the need for privacy?</p> <p>Are private spaces available?</p> <p>Does the SP know how to use them?</p> <p>Does the SP have access to build his/her own privacy?</p> <p>How is his/her inappropriate behaviour affecting people around them? colleagues, family, professionals...</p> <p>Provision of guidelines to differentiate when a normal sexual behaviour becomes inappropriate.</p>

► **Questions for Family Carers about this topic**

<u>Topic</u>	<u>Questions for Family Carers</u>	<u>Smarts Approach</u>
<p>Several PwD tend not to realize, know or pay attention to the social rules and/or specific country laws regarding sexually appropriate/ accepted behaviours. This reality may embarrass their family carers and make them feel reluctant to socialize publicly with the PwD in order not to expose themselves or cause any kind of harm to other people.</p>	<ul style="list-style-type: none"> ▪ I would like to go out for a walk with my son/daughter, but I am afraid (s)he is going to try to flirt with strangers. I feel so embarrassed, what could I do; ▪ My son/daughter tends to touch his/her genitals often, even when we are in public places. People around us stare at him and I am sure they think a lot of awful things about him/her and me. 	<p>For both these situations and any similar ones, the answer is to offer to the PwD appropriate information and guidance. Laws and social “does and don’ts” may be explained orally or through visual aids.</p> <p>For PwD that seem to be interested in exploring their sexuality, the sooner you start explaining them about their rights and appropriate sexual behaviour, everything will seem natural and easy to follow, as for any other teenager and young adult.</p>
<p>Sometimes PwD get mixed up or they really do not have many other options available, so they express their sexual and romantic needs towards relatives or close family friends, regardless of age or availability of the other person (for example towards a mother’s close friend who is married with children).</p>	<p>What if my son/daughter feels (s)he is “in love” with a family member or close family friend? I do not want him/her to get hurt but this is a difficult situation for everybody. How should I handle the situation?</p>	<p>Both the PwD and the person that is being approached should be supported in similar situations.</p> <p>The fact that during the last centuries, an intimate relationship between relatives is forbidden, is a rule that the PwD should be helped to accept and thus differentiate between family and romantic love. The person who is being approached could receive some ideas on how to respond to the PwD’s feelings.</p> <p>If there is a chance to avoid this kind of situations, a prevention idea would be that the family environment is open for their member to explore his/her sexuality and need for a romantic affair, in other, more accepted ways. There are a lot of options. You can find many ideas here in other sections such as the chapter “Love and romantic relationships”.</p> <p>As these seem to be private and delicate issues, it is natural and expected for you to feel self-conscious on how to deal with them. A specialised professional can help you and support the family and the PwD.</p>

<p>In some cases, family carers may find themselves in a difficult situation, as they are called to advocate on behalf of the PwD to another person who may have felt insulted from the PwD's approach.</p>	<p>What could I say to a person who feels insulted by my son's/ daughter's behaviour, especially if this person does not know what is going on and I would prefer not to stigmatise my offspring.</p>	<p>Usually the "discreet" truth is the proposed answer. For example, you try to make the other person understand that the PwD did not insult him/her intentionally but (s)he is not always able to judge the other person's intentions.</p> <p>In any case, you can ask a specialised professional to help you get through these awkward situations.</p>
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SDM and sexual orientation

► General considerations about sexual orientation

A person's sexuality, or sexual orientation, determines whom they do or do not feel attraction toward. This attraction is typically sexual or romantic.

Sexual attraction describes a person's desire to have sex or form a sexual relationship with other people. It often also describes physical attraction, or lack thereof, toward others.

Romantic attraction can describe a person's expression of love within a relationship. This relationship does not have to be sexual, and a person does not have to experience both romantic and sexual attraction to have a sexuality.

Concepts and definitions that refer to sexual orientation and gender identity are an evolving field. Many of the terms used in the past to describe LGBT people, namely in the mental health field, are now considered to be outdated and even offensive.

Sexual orientation refers to the sex of those to whom one is sexually and romantically attracted (American Psychological Association, 2012 cit in Moleiro and Pinto, 2015). Nowadays, the terms 'lesbian' and 'gay' are used to refer to people who experience attraction to members of the same sex, and the term 'bisexual' describe people who experience attraction to members of both sexes. It should be noted that, although these categories continue to be widely used, sexual orientation does not always appear in such definable categories and, instead, occurs on a continuum (American Psychological Association, 2012 cit in Moleiro and Pinto, 2015), and people perceived or described by others as LGB may identify in various ways (D'Augelli, 1994 cit in Moleiro and Pinto, 2015).

The terms for the community of people that encompasses people who are lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTIQ+) are as broad as that community itself: As society's understanding, recognition, and inclusion of diverse sexual identities and gender expressions has grown, so has its collective acronym.

► General considerations about sexual orientation for PwD

Adults with intellectual disabilities are often victims of discrimination simply because they have a disability. PwD who identify as LGBTQ+ face further bullying and harassment simply because of whom they choose to love or how they express their identity.

These individuals need support from their caregivers to ensure that they are able to meaningfully access the LGBTQ+ community and develop positive sexual identities. Without encouragement and support from family members, friends, and professionals who care for and about them, their ability to fully express their sexuality will be inhibited.

People with ID who identify as LGBTQ+ have the same right to express their sexuality as any other person. This fundamental right can be undermined when caregivers are unsure of how to discuss sexuality with the adult PwD. Creating environments where LGBTQ+ adult PwD feel safe to openly

discuss their sexuality is challenging for most care providers. Talking about issues that are central to those in the LGBTQ+ community may make caregivers and family members feel uncomfortable because they do not have the knowledge to discuss these issues in an informed and empathetic manner.

► **What does the legal framework say about this?**

GENERAL EUROPEAN LEGISLATION

The legal aspects of the European Commission's LGBTIQ equality are based on Article 21 of the EU Charter of Fundamental Rights which explicitly prohibits discrimination on the basis of sexual orientation and Article 19 of the Treaty on the Functioning of the European Union which allows for measures to combat such discrimination.

Since the year 2000, discrimination on the basis of - among others - sexual orientation in the fields of employment and occupation has been prohibited by Directive 2000/78/EC. This means that: you are protected by law if, for example, you think you are being treated unfairly when applying for a job because of your sexual orientation; you are protected by law if, for example, you have a job where your colleagues treat you badly - for example by calling you names or making jokes at your expense because of your sexual orientation; you are protected by law if, for example, your boss refuses you promotion or training because of your sexual orientation.

In addition, in 2008 the Commission issued a proposal for a directive that would extend protection against discrimination based on - among others - sexual orientation beyond the workplace into certain key areas of life.



► **Questions for Supporters about this topic**

Key topics around the SDM process for supporters to consider when framing their support.

<u>Topic</u>	<u>Questions for Supporters</u>	<u>Smarts Approach</u>
Sexual Orientation	How to support a service user who needs help in defining his/her sexual orientation?	The role of the supporter is to inform, clarify and support decision-making. The supporter's own values, beliefs, choices should not interfere in the support. <ul style="list-style-type: none"> ▪ Clear, simple and rigorous information should be available. If necessary, other professionals and/or caregivers may help.
Conflict and Prejudice	How to support a service user in dealing with conflict and prejudice related to diversity in sexual orientation?	It is important to provide information and social/emotional support to the service user, if a conflict related to his/her sexual orientation should ever emerge. An important part of supporting decision-making is informing the person of the risks and negative consequences that may rise from making a decision that goes against others' will.

Health and Safety	How to ensure health and safety, regarding sexuality in diverse sexual orientations?	Different people, with diverse sexual orientations, may need to be informed of specific care and health procedures, in order to protect themselves, as well as others. Depending on the experience and training of the service's staff, professional support and additional specialists may be called in, to provide specialised assistance.
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► **Supporting the supported person (SP) to make informed decisions.**

 TOPICS FOR THE SP TO KNOW & UNDERSTAND	 TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP
<ul style="list-style-type: none"> » Diversity in sexual orientation. » Freedom of choice and self-determination in terms of sexual orientation. 	<ul style="list-style-type: none"> » Questions and concerns around sexual orientation choice. » Healthy and safety within diverse sexually oriented couples
<ul style="list-style-type: none"> » Healthy relationships may exist, regardless of sexual orientation. » A family may be raised in couples with diverse sexual orientation. » The free choice of one's sexual orientation may shock and be against others' opinions. 	<ul style="list-style-type: none"> » Conflict with family and friends about sexual orientation » Potential prejudice and stereotyping by society.

► **Questions for Family Carers about this topic**

Key topics around the SDM process for supporters to consider when framing their support.

<u>Topic</u>	<u>Questions for Supporters</u>	<u>Smarts Approach</u>
Family carers sometimes do not see their son/daughter with disability as a person who can choose his/her sexual orientation. Any kind of attraction different than the "traditional" man-woman relationship is often seen as a "problem behaviour"/ "confusion" that needs intervention.	Can my son/daughter have different sexual orientation than the traditional man-woman relationship? Maybe he/she is just "confused"?	As a family carer, you may have a specific idea and expectation of your son's/ daughter's sexual orientation. However, the SDM framework proposes that your son/daughter is an adult who can make informed choices about him/herself. Sexual orientation is a matter of choice, and PwD have the same right as everyone to make decisions about what kind of relationship they wish to have, and with whom. Although it may be different than what you were expecting from your son/daughter, PwD can have different preferences, wishes and needs, that may sometimes be different than monogamous, heterosexual relationships.

		<p>As a family care, your role is to support your son/daughter by providing all the relevant information so that he/she can make an informed choice about his/her sexual orientation.</p>
<p>As a family carer, you may not know how to approach the matter of different sexual orientations – you may not know what to say, or how to talk in a clear and comprehensive way.</p>	<p>How can I help my son/daughter by providing information on different sexual orientations to help him/her with making an informed decision about his/her sexual orientation?</p>	<p>One of the fundamental steps of the SDM process is helping the SP gather all the knowledge necessary in order to make an informed decision. To facilitate this process for sexual orientation, some useful steps could be:</p> <ul style="list-style-type: none"> ▪ Be open: be open and available in discussing about sexuality. Normalise the idea of different choices in sexual orientation and debunk the myth that there is only one way to sexual relationships (being monogamous and heterosexual). ▪ Use reality/facts as a starting point for discussions: different sexual orientations are all around us - on TV shows, movies, on homosexual couples we meet on the streets or have in our social circle, or on big events like Pride. Let your son/daughter observe different orientations, normalise that this is ok, and use it as a starting point for exploring together and explaining the different sexual orientations that exist – as well as the right of choice. ▪ Be realistic about the possible risks/consequences: discuss with your son / daughter the possible consequences and the possible risks of the different sexual orientations, so that he/she can make an informed decision (e.g., he/she won't be able to have children, if they choose a homosexual relationship. His/her partner will also have other partners and will not be exclusive, if they choose polyamory, etc.)
<p>As family carers, it is understandable that you may have your own values around different sexual orientations. It would be useful to reflect on how much your values could make you impose your personal views.</p>	<p>What if my values are against different sexual orientations? What if I believe that there is only one option, that of a monogamous, heterosexual relationship?</p>	<p>It is natural for you to have the tendency to behave according to your values. However, the SDM framework suggests that this should not pose an obstacle if your son/daughter wants to follow a different direction.</p> <p>Self-reflect on your own values about different sexual orientations and disability:</p> <ul style="list-style-type: none"> ▪ Is there something inside you that tells you that people with disability shouldn't/can't choose different sexual orientations?

		<ul style="list-style-type: none">▪ Is there a value inside of you saying that preferring a different sexual orientation is a sign of problematic behaviour/confusion? <p>If so, addressing your thoughts and feelings, as well as the impact they may have on SDM, is the best thing you can do.</p> <p>If you feel that you need support and guidance, do not hesitate to seek support from the Facilitator or a trained professional.</p>
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Annexe 1: The SDM Agreement & supporting documents

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

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:







	<ul style="list-style-type: none"> ▪ Help me get the information relevant to the decision.
	<ul style="list-style-type: none"> ▪ Help me to understand my options so I can make a decision and/or
	<ul style="list-style-type: none"> ▪ Help me to communicate my decisions to other persons.

SDM AGREEMENT (Example) FORM

- 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:

	<ul style="list-style-type: none"> To identify supporters.
	<ul style="list-style-type: none"> To help me on how the Agreement works.
	<ul style="list-style-type: none"> To help me sort out any disagreement with the supporter.
	<ul style="list-style-type: none"> To the check quality and satisfaction within the arrangements.
	<ul style="list-style-type: none"> To help me change the Agreement if needed and
	<ul style="list-style-type: none"> To confirm when the Agreement has ended.

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

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

I consent to act
as a supporter.

(signature of supporter)
(printed name of supporter)

Jenny Jones

I consent to act as a
facilitator.

(signature of supporter)
(printed name of supporter)

Ray Rogers

Signature

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

Sally Smith

Signed at (place): *My house*

Date: *20th February*

Supported Decision Making Agreement

What is supported decision-making?

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

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

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

The 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.

For these reasons:




- I agree the following person be my Supporter:

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

In particular, I want:







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:

	<ul style="list-style-type: none"> ▪ Help me get the information relevant to the decision.
	<ul style="list-style-type: none"> ▪ Help me to understand my options so I can make a decision and/or
	<ul style="list-style-type: none"> ▪ Help me to communicate my decisions to other persons.

- I also appoint the following person as my Facilitator:

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

	<ul style="list-style-type: none"> ▪ To identify supporters.
	<ul style="list-style-type: none"> ▪ To help me on how the Agreement works.
	<ul style="list-style-type: none"> ▪ To help me sort out any disagreement with the supporter.
	<ul style="list-style-type: none"> ▪ To the check quality and satisfaction within the arrangements.
	<ul style="list-style-type: none"> ▪ To help me change the Agreement if needed and
	<ul style="list-style-type: none"> ▪ To confirm when the Agreement has ended.

SDM AGREEMENT (Example) FORM

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)

Signed at (place):

Date:

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

Form for Individualised Supported Decision Making (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 - An Introduction for supporters.

Assessment – who does what?

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

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

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

When does assessment take place?

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

What has to be covered?

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

What is the level of detail required?

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

When does it end?

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

Feedback from the Supported Person

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?

If		ones?
	Some of them	





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

Supported Person Self-Assessment Form

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

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?)

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.





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