SMARTS

(Supporting Me About Rights to Sexuality)

Guidelines on Supported Decision Making in the field of sexuality for service managers.

Co-funded by the European Union

AGREEMENT NUMBER
2020-1-ES01-KA204-082783

Partners:

FUNDACIÓ ASTRES

ARCIL
Associação para a Recuperação de Cidadãos Inadaptados da Lousã

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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.**

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- **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**

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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),
  - Associaçao para a recuperaçao de cidadaos inadaptados da lousa (A.R.C.I.L) (Portugal),
  - Theotokos Foundation (Greece).

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- **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 *I 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.

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Section 1

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

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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)	» 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)	» 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)	» 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)	» 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.

United Nations Convention on the Rights of Persons with Disabilities (2006)	» International human rights treaty. » Protect and promote the human rights, dignity, fundamental freedoms and full equality of PwD.
International Planned Parenthood Foundation’s Declaration to Sexuality (2008)	» Collection of human rights instruments. » Related to sexual and reproductive health and rights.
United Nations 2030 Agenda for Sustainable Development (2015)	» International strategy. » 17 goals set by the United Nations for 2030. » One of the goals: empowering girls and women.
Yogyakarta Principles relating to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics (2017)	» 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.
EU Strategy for the Rights of persons with disabilities 2021-2030 (2021)	» 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.

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- 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:

- 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).

FUN FACT
WHY HUMANS HAVE SEX

A study found that there are over 237 reasons why people participate in sexual activities.

Can you think of reasons why to have sex? And reasons why not to have sex?

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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.

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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.

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Section 2

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).

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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.

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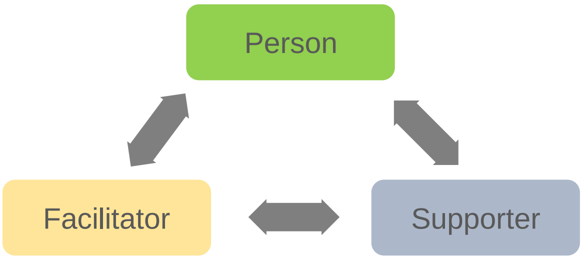

The SDM Agreement: a 3-way relationship

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.

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Roles in the SDM Agreement

Roles in the SDM Agreement

The three main roles in the SDM Agreement are:

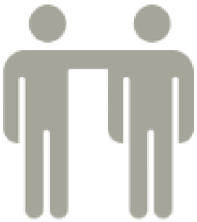
1) The supported person;
2) The supporter;
3) The facilitator.

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.

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- 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.

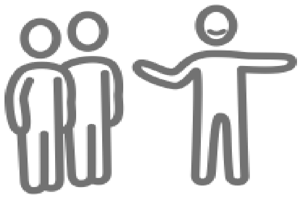
- To assess the skills of the supported person in relation to decision-making in the specific areas listed in the SDM Agreement.
- To explore with the supported person those areas where the supported person might want help with decision making.
- To build and implement, jointly with the supported person, 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.

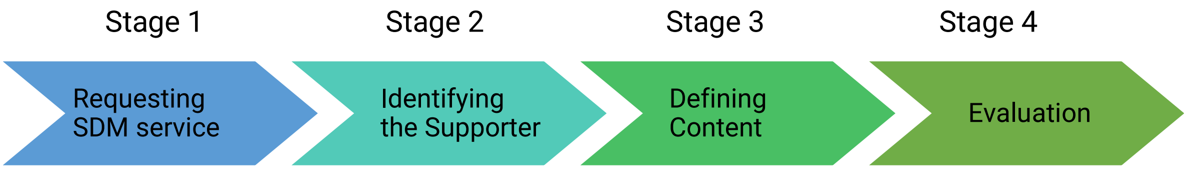
The facilitator needs to have a complete understanding of the SDM process and the terms of the SDM Agreement and should be able to communicate, using suitable language, both with the supported person and the supporter, using mediation strategies and soft skills such as assertiveness.

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

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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

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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.

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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.

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Section 3

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:	» Identifying and addressing the need of the SP, » Communicating about sexuality, » Reflective listening about sexuality, » Myths, » Growth Mindset.

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.

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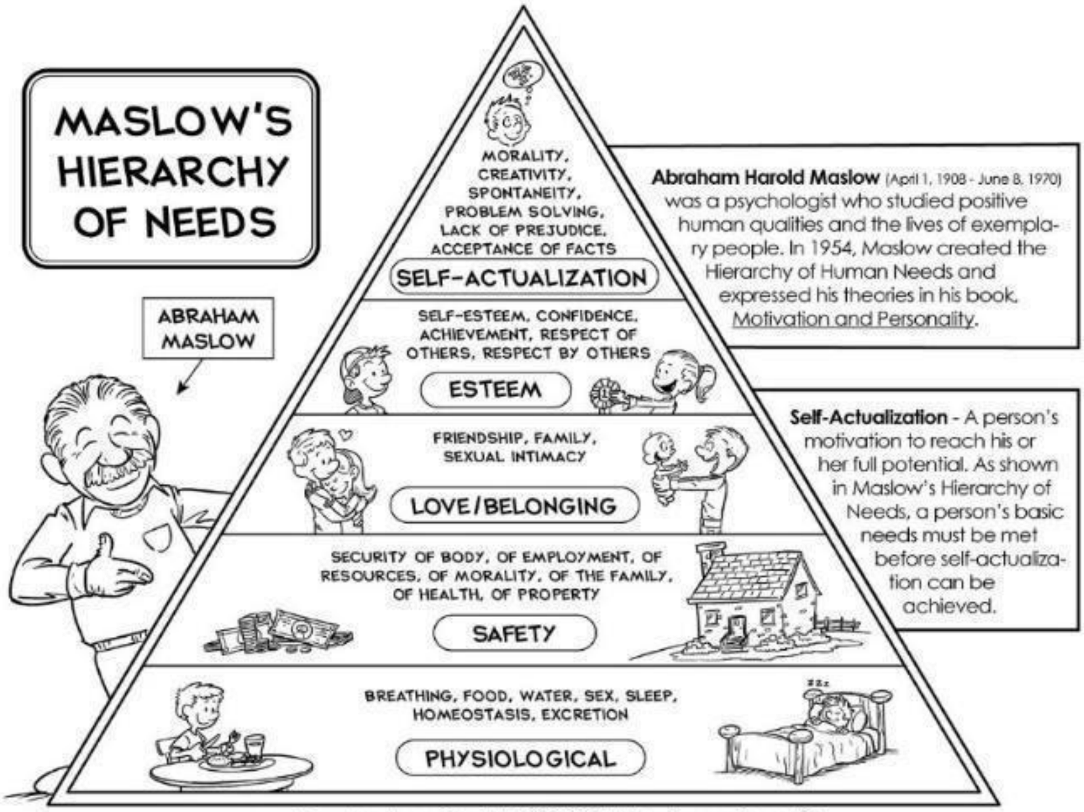

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Self-awareness of PwD of their own needs is a starting point for needs identification and support

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.

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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

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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.

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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.

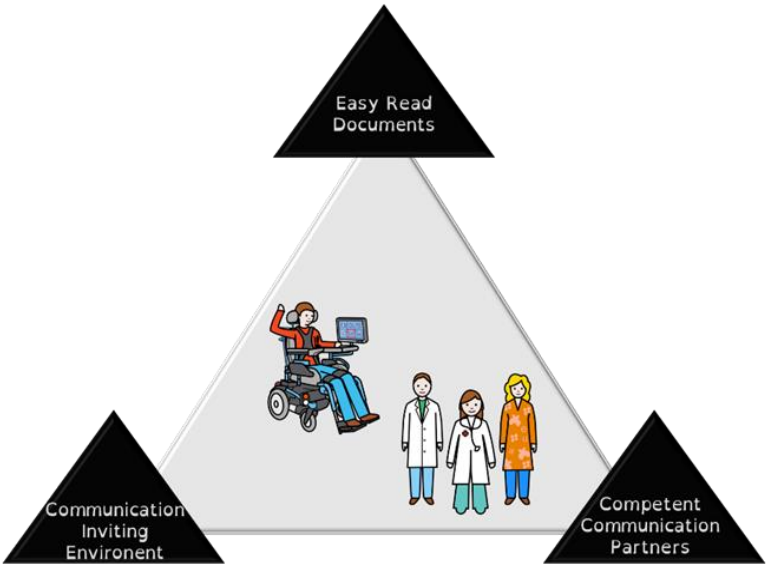
In order to communicate with PwD about sexuality and intimacy, it is important not to feel afraid of addressing the issue, since it is a subject with similar importance to many others (e.g. sleeping and eating).

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

	**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.
	**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.
	**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.
	**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.
	**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.
	**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.

Communication Access and… How to improve it?

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



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.

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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.

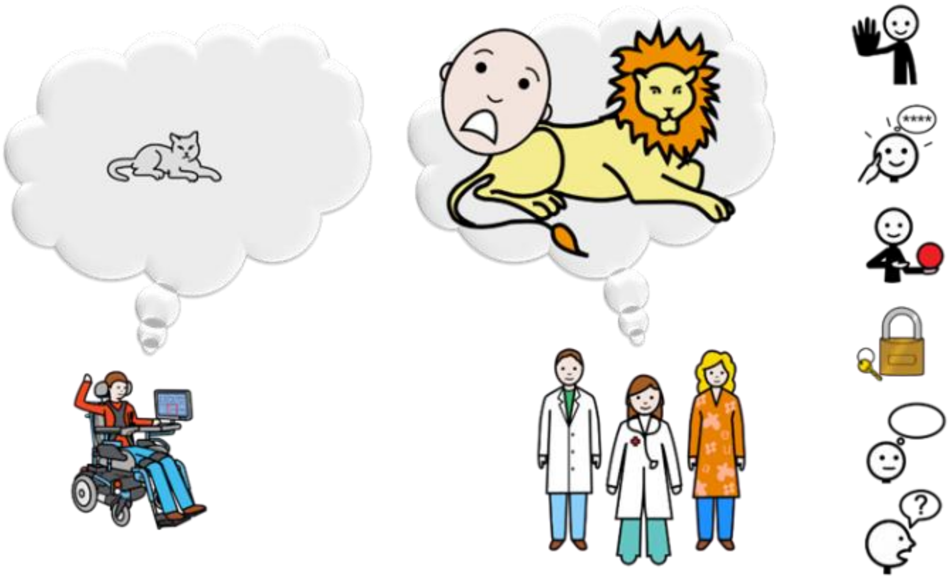
Here are some ideas to improve your role as a Competent Communication partner:

- 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)
- 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)

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: Unclarified 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.

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- *"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

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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?

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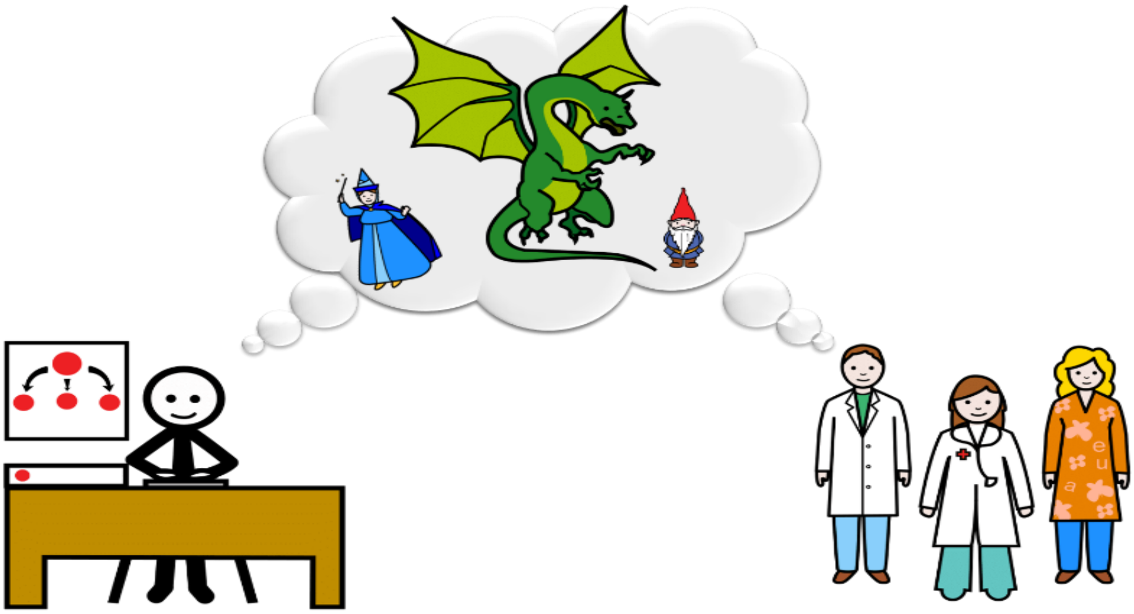
Myths or Facts – What do you choose to believe in?



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:

PwD are asexual	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. 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.
PwD are hypersexual	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.

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The sexuality of PwD is different	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 pleasurably. 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.
Sexuality of PwD is dysfunctional	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?
Sexuality of PwD is secondary	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?
PwD are not at risk of sexual harassment/ abuse	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!
PwD are not capable of becoming parents	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.
PwD can't make good choices regarding family planning	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.

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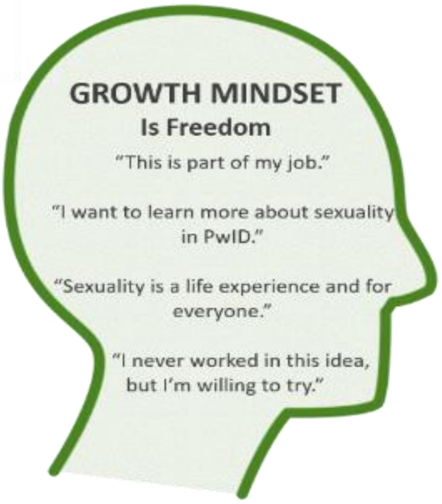
PwD are always heterosexual and their gender matches their sex	As with any part of the community, PwD can and do identify as Lesbian, Gay, Bisexual, Transgender, Transsexual, Queer and/or Intersex (LGBTQI). However, as sometimes people with a disability are incorrectly seen as being asexual, people without disability may forget this fact. 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.

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.



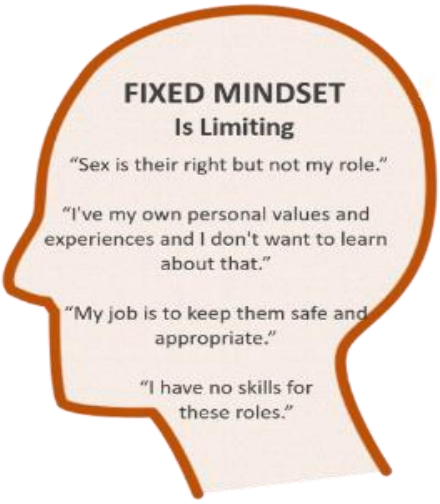
GROWTH MINDSET
Is Freedom

"This is part of my job."

"I want to learn more about sexuality in PwID."

"Sexuality is a life experience and for everyone."

"I never worked in this idea, but I'm willing to try."



FIXED MINDSET
Is Limiting

"Sex is their right but not my role."

"I've my own personal values and experiences and I don't want to learn about that."

"My job is to keep them safe and appropriate."

"I have no skills for these roles."

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.

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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

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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.

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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 abuse.
- 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.

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- ***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.

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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.

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- *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).

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Section 5

SDM in the field of sexuality specifically addressed to service managers

These guidelines are for Service Managers

Preliminary issues for Service Managers

There are many issues to consider when a service intends to implement SDM processes in any field. Regarding the topic of intimacy and sexuality, more specific questions and challenges may exist. This section presents some of the preliminary issues the service managers should explore while attempting to use SDM in the field of sexuality.

These recommendations are for Service Managers

This manual was created to support Service Managers in the implementation of the process of SDM regarding sexuality and intimacy. This will help PwD on their way to a self-determined life course.

The Service Manager is the person responsible for planning, implementing and evaluating the activities and interventions implemented in a specific service. This is a professional with a fundamental role: managing the staff members, involving them in a service embedded in a culture of Inclusion, Self-advocacy and Human Rights. He/she is also the one who may support the service users in whatever issues they may face when accessing the service, as well as the person who communicates with the family and friends of the PwD regarding the service organisation and delivery. Because of the relevance of teamwork and positive relationships between service providers and service users, a communicative and co-creative attitude is fundamental for the manager of the services. Are you this kind of open-minded and inclusive service manager?

The important role of the service manager in creating a culture of communication and inclusion.

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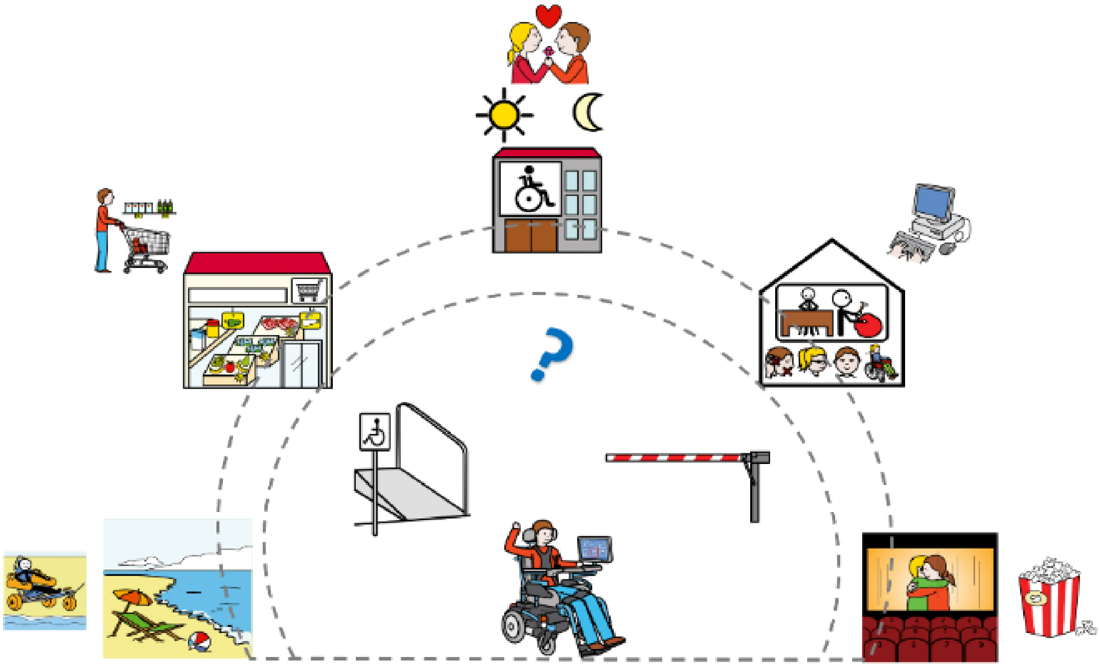
The SMARTS' Guidance provides orientation to ensure that PwD will have the support they need in order to fully participate and exercise their right to an important area in the life of many of us: intimacy and sexuality. This means that service managers should be able to provide the necessary support (e.g., sometimes physical resources, but other times accessible information) to allow PwD to exercise such rights. This also means that barriers (e.g., disbelief and negative attitudes towards the sexuality of the person with a disability) will have to be removed and the person with intellectual disability should be enabled to make individual and informed choices regarding their sexuality and intimacy.



Barriers and facilitators may enhance or hinder the PWD's active participation in life.

- How do you see yourself as a Service Manager?
- As a barrier, or as a facilitator?
- As a "follower of the status quo" or as a "manager of change"?

What are the fundamental principles of the SMARTS' manual?

As explored in the previous chapters, Supported Decision Making (SDM) is all about creating the right conditions for a person with an impairment or disability to make informed decisions on his or her own, so that all and every relevant choice related to the person's life is made by the person him/herself. Important decisions, even if about simple aspects of one's life, should not be made by others on their behalf, even if it is in their best interest. This is the difference between SDM and Substitute Decision Making! In some situations, Substitute Decision Making may be a necessity.

However, this should be seen very much as a last resort, many of the times taking place as a result of legal implications and requirements. These situations may have to be settled in Court, in special situations where the law provides that someone else has to decide for the person on specific topics.

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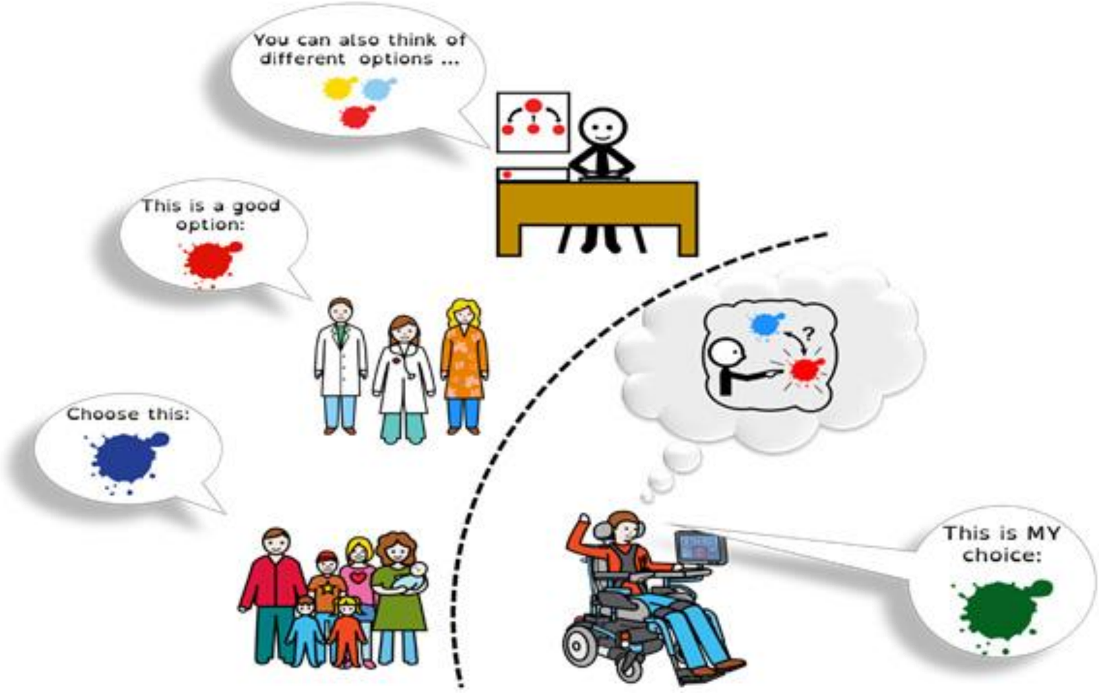
By supporting informed decision making, there is the risk that the person with a disability may not follow what the supporters – either family or professional caregivers – consider the best available option; there is the risk of making mistakes! Acknowledging this right of the PwD to make mistakes and unwise decisions, is an important part of the SDM process. Of course, a duty of care may need to take precedence in some very particular circumstances (such as a wish to commit suicide, self-harm, harm others or perform an illegal act). You can read more about the duty of care in Section 2 of this Guidance.

Decision making is an important part of our everyday typical life… it for all of us, regardless of our disability status. Besides that, with or without support, we all make mistakes and unwise decisions every now and then! We just need adequate support in order to manage our decisions and their consequences.



Supporting the decision-making process as a service manager

How are decisions made in your services?

What kind of decisions are made with and without consulting the most important stakeholder: the service user?

Services designed for and with PwD should support the use of SDM in all subjects of the persons' lives. That means that regarding sexuality and intimacy, SDM should also be used. Some issues may be particularly challenging, others may require additional reflection with the service user and the decisions on specific issues may be influenced by the legal context of each country. Check Sections 6-14 to explore some of the commonly challenging themes in the field of intimacy and sexuality of PwD:

- Are you, as a Service Manager, prepared to improve your services according to the voice of those with a disability?

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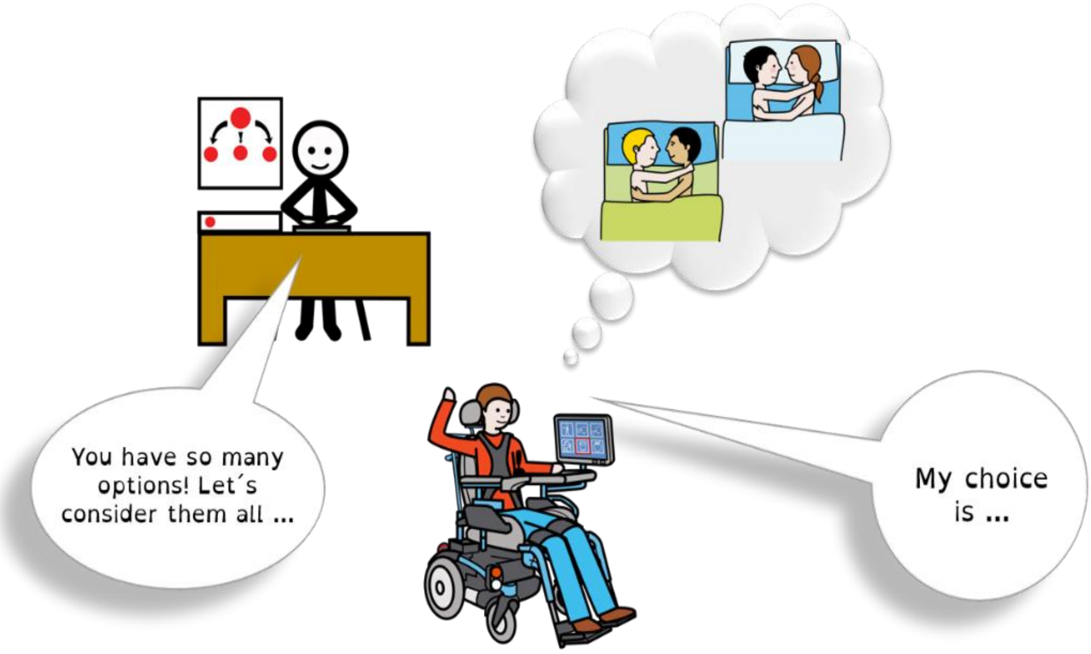
- Are you, as a Service Manager, curious about the interesting process of supporting decision making on such an important topic in everybody's life?
- Are you, as a Service Manager, up for the challenge?



Informing the PWD to consider all the different options, even about sexuality.

What are the Rights of PwD regarding Sexuality?

Sexual rights are Human Rights related to sexuality. The International Planned Parenthood Federation (IPPF) designates ten fundamental sexual rights that are universal, interrelated, interdependent and indivisible as a component of Human Rights. Recognising these rights will improve the world as a place where women, men and young people have control over their own bodies, are free to make choices about parenthood, and are enabled to pursue healthy sexual lives without fear of unwanted pregnancies and sexually transmitted diseases. A world where gender or sexuality are no longer a source of inequality or stigma.

As designated by the IPPF, the ten sexual rights are:

- **Article 1**: Right to equality, equal protection of the law and freedom from all forms of discrimination based on sex, sexuality or gender.
- **Article 2**: The right to participation for all persons, regardless of sex, sexuality, or gender.
- **Article 3**: The rights to life, liberty, security of the person and bodily integrity.
- **Article 4**: Right to privacy.
- **Article 5**: Right to personal autonomy and recognition before the law.
- **Article 6**: Right to freedom of thought, opinion, and expression; right to association.
- **Article 7**: Right to health and to the benefits of scientific progress.

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- **Article 8**: Right to education and information.
- **Article 9**: Right to choose whether or not to marry and to found and plan a family, and to decide whether or not, how and when, to have children.
- **Article 10**: Right to accountability and redress.

Source: Sexual Rights: an IPPF declaration

Another very important reference regarding the Right to Sexuality, specifically of persons with disability, is the United Nations Convention of the Rights of Persons with Disability (UN-CRPD). According to this Convention, efforts must be made in each country in order to make sure that people with disabilities have equal rights to having relationships, getting married and creating a family and raising their children in a healthy and supportive environment. If you wish to know more about this topic, it is thoroughly explored in Section 2 and a reference to an easy read version can be found there.

Reflections and Recommendations for Service Managers

Once the service has assimilated a culture of self-determination and SDM, the PwD will be able to choose and make decisions by him/herself and/or with the support of someone else.

Besides the implementation of SDM in the field of intimacy and sexuality, it is important to ensure that the PwD will actually have the opportunity to experience intimacy and sexuality according to his/her decisions. SDM is only relevant if services are available to create the opportunity for the person to access the experience, he/she chooses to have. This Section presents a series of reflections, scenarios, and questions to guide the service managers in improving, if not ensuring, that the service users may experience intimacy and sexuality with quality, dignity and autonomy.

In many organisations, however, the service delivery is planned thinking of a group of service users and not of each individual in particular. There may be the need to balance the expectations of every individual user with the available resources and the need to implement an intervention that targets a group, rather than one person by him/herself. While exploring the questions and scenarios for reflection, do consider that each organisation will have its own limitations in creating person-centred and individualised responses to each individual service user. Even so, all efforts should be made in order to guarantee the best possible experience of intimacy and sexuality, under circumstances that prioritise self-determination and SDM.

How to (re)organise services to ensure access to the Right to sexuality?

1. Organisation of Spaces:

“Sexuality is an energy that motivates us to find love, contact, tenderness, and intimacy; it integrates in the way we feel, move, touch and are touched. Sexuality influences thoughts, feelings, actions and interactions and, therefore, also influences our physical and mental health."

World Health Organisation

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Based on this premise, the spaces related to love, intimacy and sexual experiences should be welcoming, transmitting an environment of tranquillity in which the service users can experience and express their intimacy and sexuality in a natural and pleasurable way.

☐ Some **reflections** you may want to consider …

It might be positive to create spaces within the service's facilities - be it a residential service, an occupational centre or other suitable service - for private events, such as a romantic dinner, meeting a new friend, having a drink with a new potential partner or eventually sexual intercourse. These spaces would preferably be in a more isolated space, not so close to the common areas, so that its users may benefit from the privacy the moment calls for.

For obvious reasons, it's important to ensure that the spaces where these social and/or romantic activities take place guarantee the maximum privacy and confidentiality. For this same reason, a staff member should be responsible for keeping the information, such as who is using this space, for how long, with whom, private and unknown to the rest of the service users, unless the PwD him/herself wishes to share with someone else.

Whenever there are couples in a relationship using the service, and especially in residential services, it is important to support the service users in the creation of their own intimate spaces. This support should be provided in case of need and, naturally, according to the needs identified and/or raised by the persons themselves. It is particularly important to provide the possibility of couples in long-term relationships to share a room in residential services, enjoying the necessary freedom and autonomy for their life as a couple.

If in need of more practical ideas and recommendations, here is a checklist to support the creation of a … **Romantic Spaces in 10 Simple Steps**:

Questions for Reflection:	Verification		
	No ✗	No. However… ⚠ What adaptations are possible?	Yes ✓
1. Are there private spaces that may be used for romantic events (e.g., sharing a meal, inviting someone for a date, having sexual relations …)?			
2. Is there private access to the spaces that are intended to be used for romantic events?			
3. Are the spaces designated for use in romantic events accessible - physical, sensory and communication wise?			
4. Are there defined rules regarding the use of the spaces designated for romantic events?			

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5. Is there the possibility of scheduling the use of the spaces designated for romantic events, privately?			
6. Are there staff members available to provide support and individual assistance (e.g., providing specific materials, positioning someone with a motor impairment…) in case of need when using the spaces designated for romantic events?			
7. Are the spaces designated for romantic events prepared with all the necessary materials and equipment? ▪ adequate furniture. ▪ assistive technologies. ▪ contraceptive resources. ▪ pornographic resources. ▪ access to communication with staff members. ▪ first aid kit. ▪ specific additional resources.			
8. Is there a possibility for romantic visitors to stay overnight in privacy with their partner?			
9. Is there IT equipment accessible around the facilities for the service users to use the internet to access sexual content?			
10. Is there IT equipment accessible around the facilities for the service users to use the internet to connect with new friends and potential partners?			

Use the checklist to evaluate how prepared are your services' spaces to guarantee SDM and a pleasurable and self-determinate experience of sexuality and intimacy and, if possible, find new ways to improve how you work in this field. Remember… Supported Decision Making about intimacy and sexuality can only become a reality, if there are spaces in the service to make it happen!

Case History - Rosa

Rosa is a 37 years old woman with intellectual disability and a mild mental health condition who lives in a residential care unit. As she finished her vocational training program as a laundry service worker, she quickly got a professional placement and started to work at a laundry nearby her residence. She is very independent, likes to go shopping and to take care of her own things, even though she lives in the residence together with a group of 10 service users.

Rosa met her boyfriend, Manuel, a couple of years ago at a self-advocacy event organised between service providers. Although they live in different cities, they visit each other's residence, go out on dates in the community and wish to have the opportunity to spend the night together, as a couple. However, they both share their rooms with a roommate. How could the services (re)organise to provide the opportunity for Rosa and Manuel to spend the night together, privately?

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The supported decision…

After having a conversation with Rosa and Manuel, separately, and understanding they both wish the same opportunity, the staff members from both service providers presented two available options:

- to spend the night at Manuel's residence, during the weekends in which his roommate is away to visit his relatives, with his consent.
- to spend the night in a hotel room, close to Rosa's residence, considering the need to pay for the accommodation from the couple's budget.

Informed about both possibilities, Rosa and Manuel decided that every other month, they would like to spend one night together at the hotel. Due to budget restrictions, however, they both thought it would be a good idea to take advantage of Manuel's free room, twice a month. Manuel's roommate was consulted about this idea and was comfortable with Maria spending the night whenever he was not there.

2. Organisation of Time and Schedules:

"Even though I think I am not shy and really want to meet someone, it's not been easy to meet a girlfriend (…) I can meet people more easily by texting, than by being with a girl in person. I've had some difficult situations because of text messages sent to girls. I now know they have to be older than 18 and not in a relationship."

Carlos, Service user with intellectual disability

When services have control over the daily activities of PwD, finding time to explore the sexual dimension of oneself may, sometimes, be forgotten. It shouldn't be and it should actually be considered a priority, as any other basic need.

Routines are part of everyone's life and should incorporate, as much as possible, meaningful activities for each individual. This means activities in all spheres of life should be considering, including daily life activities (e.g., getting dressed, taking care of your own body…), domestic life activities (e.g., preparing a meal, shopping for groceries …), work activities and/or learning and education projects (e.g., having a job, taking a course), leisure activities (e.g., going to the cinema, physical exercise) and social interaction (e.g., meeting friends, contacting with new people…). Within a balanced routine of activities in diverse dimensions of life, it is important to ensure time to access and enjoy the exploration of sexuality and intimacy, alone or with someone else. This is also a way to promote self-knowledge and individual growth.

☐ Some **reflections** you may want to consider …

At the same level as other areas of one's life, it is important to help the service users decide on a reasonable number of activities or events in the field of intimacy and sexuality that each may wish to access on a regular basis. Having this in mind, it may be useful to allocate the responsibility of selecting and scheduling the activities with each service staff member who may suggest ideas and negotiate possibilities with the group users, according to the needs and expectations of each one and of the whole group.

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Following the same premise, holding regular meetings with each service user and with the group will be important, in order to understand how satisfied they are with the service's routines and schedules regarding sexuality and intimacy and to support decision making on the topic of sexuality, balancing the needs of all the users with the available resources and with a healthy experimentation of sexuality and intimacy.

If your service supports several service users in one location and activities tend to be collective/group activities, it will be essential to consider how couples can share intimate moments away from the group. Ideally, this should not prevent them from taking part in the group's usual activities.

If in need of more practical ideas and recommendations, here is a checklist to support the creation of a … **Sensible Schedules in 10 Simple Steps**:

Questions for Reflection:	Verification		
	No ✗	No. However … ⚠ What adaptations are possible?	Yes ✓
1. Does the daily routine for service users allow opportunity for individual activities of a private nature (e.g., spending time alone, taking care of one's own body)?			
2. Does the daily routine for service users allow opportunity for social activities of a private nature (e.g., going on a date with a boyfriend/girlfriend)?			
3. Does the daily routine for service users allow opportunity for activities of a private nature with individuals that are external to the group of service users (e.g., going out alone or in a group to meet new friends and potential partners)?			
4. Is there a procedure to schedule and reschedule activities of a private nature, maintaining the confidentiality and privacy of all the service users?			
5. Are the service users encouraged to manage their time and individual activities, including those of a private nature, in a balanced and healthy way (e.g., balancing time by oneself and time interacting with other persons)?			
6. Is there a professional with responsibility of checking regularly if the service users are satisfied with the opportunities for activities to meet their sexual and intimate needs?			
7. Is there a professional with responsibility of checking regularly if the service users are satisfied with the opportunities for activities to meet their sexual and intimate needs?			

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Use the checklist to evaluate how prepared are your services' schedules to guarantee SDM and a pleasurable and self-determinate experience of sexuality and intimacy and, if possible, find new ways to improve how you work in this field. Remember, SDM about intimacy and sexuality can only become a reality, if there is time in the service to make it happen!

Case History - Alex

Alex is a 29 years old man with moderate intellectual difficulties, accommodated in an independent living service within a small community. He is shy and has difficulty in creating and maintaining new friends and, therefore, has been having difficulties in finding a partner for the long-term romantic relationship he wishes to have in his life.

Alex shares his accommodation with three other housemates. With the help of a support worker, the group manages ways to share the available resources in an equitable way. The use of the computer with internet access is, however, a reason for disagreement very frequently, since Alex prefers to meet new friends and create connections using the social networks and ends up spending most of the evenings and nights with this activity, stopping others from using the computer for this or other purposes.

The supported decision …

The support worker engaged Alex in a conversation about the advantages and disadvantages of only meeting new friends online and about the need to allow others to use the technology shared at home. Since Alex may meet his girlfriend online, because it would be easier for him, he decided that it would be a good option for him to buy a smartphone, in order to reduce the tension between him and his housemates. Nevertheless, due to the encouragement of the support worker, after a discussion about the advantages and disadvantages of going out, Alex decided to take two evenings of the week to go out and actually engage with people in physical environments and in a selection of leisure activities that would include soccer practice, going to the library and taking part in the cultural activities from the local social centre.

3. Management of materials and equipment

- "***What, for you, is sexuality?"***
- It's the physical contact, but not only sex. The cuddling. At the moment, sexuality doesn't mean much to me; it's been a long time since I've felt the desire of having sexual relations. I think it is because of the sterilisation I went through. But I do feel jealous of my husband."

Paula, Service user with intellectual disability

To deprive someone of the possibility of expressing his/her sexuality is to limit his/her possibilities to communicate and completely express who he/she is. It matters not only to arrange space and time to ensure an autonomous and self-determined practice of sexuality and intimacy, but also to manage the equipment and materials necessary for these experiences to take place with comfort and safety.

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Managing materials and equipment, including needed accessories and assistive technology, should be the responsibility of a professional, enabling him/her to guarantee all the safety standards and the acquisition of the necessary items. A regular monitoring process is important, as well as a close communication with the service users, in order to clarify and meet their needs.

☐ Some **reflections** you may want to consider …

In order to ensure that supported and informed decisions are made, it is essential to reflect with the service users about the kinds of materials available in the market which may be useful for the needs of different service users. For more specific information and materials, arranging occasional meetings with experts in the field is a good idea, to update the staff and service users with new developments in materials, technologies and equipment that may support the experience of sexuality.

Once the service is provided with adequate materials and equipment, one of the staff members should have the responsibility of filling in regular requisitions of the materials to use in the future (e.g., for the following week or month), taking into account different preferences and the types of material and equipment required for each service user. There should be a professional responsible, as well, for the evaluation of the satisfaction of the service users with the options that the service is providing.

If in need of more practical ideas and recommendations, here is a checklist to support the creation of a… **Sexuality toolbox in 10 Simple Steps**:

Questions for Reflection:	Verification		
	No ✗	No. However … ⚠ What adaptations are possible?	Yes ✓
1. Is there information about materials and equipment that may be used to support the sexual experience available for the service users to consult?			
2. Is the available information about materials and equipment that may be used to support the sexual experience accessible and easy to read?			
3. Is there a professional responsible for creating an inventory of the available materials, equipment and assistive technology to support the sexual experience?			
4. Is there a professional responsible for filling in regular (e.g., every other week) requisitions for the maintenance and/or acquisition of materials, equipment and assistive technology to support the sexual experience?			

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5. Is there a professional responsible for supporting the use of materials and equipment and clarify any doubts and questions from the service users?			
6. Is there IT equipment to be used by the service users to access sexual content, meet potential partners or other activities related to intimacy and sexuality?			
7. Is there a procedure for all the service users who wish to, to use the available materials, equipment and assistive technology safely and with confidentiality?			
8. Are the service users regularly (e.g., monthly) consulted regarding their needs and wishes in terms of materials, equipment and assistive technology to support the sexual experience?			
9. Are there opportunities to meet professionals and experts in the field of sexuality to provide advice about available materials, equipment and assistive technology?			
10. Are there opportunities to participate in events and visit places (e.g., sex shops) where materials, equipment and assistive technology to support the sexual experience are available?			

Use the checklist to evaluate how prepared are your services' schedules to guarantee SDM and a pleasurable and self-determinate experience of sexuality and intimacy and, if possible, find new ways to improve how you work in this field. Remember, SDM about intimacy and sexuality can only become a reality, if there are materials, equipment, and assistive technology in the service to make it happen!

Case History - Alice

Alice is a 21 years old woman with intellectual difficulties who lives with her mother and younger sister, receiving visits from a support worker twice a week. She is very sociable and enjoys meeting new people.

Although she is still single, she has an active sexual life and has had diverse sexual partners over the last year. This situation is concerning her mother, considering the recent episode of a sexually transmitted disease (STD). However, Alice does not want to change her behaviour, arguing that she is already taking the birth control pill. The conversations about this topic tend to end up as arguments that create discomfort within the family.

The supported decision …

After having a conversation about her mother's concerns, the support worker discussed with Alice the reasons for the arguments. Alice agreed that she did not want to have another episode of STD and would be interested in finding ways of avoiding that.

As a first step Alice agreed to schedule an appointment with the general practitioner, in order to explore the best available contraceptive methods and solutions to prevent a new infection *from a STD. After exploring diverse possibilities, Alice decided on the use of condoms, besides the birth control pill that she had already been taking and went and checked different brands with the support worker. Together with the physician, the support worker explained to Alice that there are other ways of exploring sexuality and her own body and gave her some brochures with information about sex toys from a local sex shop; Alice agreed to read this information and to have another conversation about this topic in the next consultation.*

In a conversation between Alice and her mother, it was decided that the caregiver would provide a pack of condoms every month and Alice would be encouraged to manage her sexual activities responsibly, not having sexual relationships with new partners without using the condom.

4. Management of Budget and Expenses:

- ***"What do you value in a romantic relationship?"***
- *That we can make love and share a life, in sickness and in health, as they say.*
- *To have someone that helps me and supports me.*
- *To trust my partner, spend time together and be able to share a future.*
- *To go out on dates."*

Group of service users with intellectual disability

Projects require resources in order for activities to take place. It's not realistic to think of a diversity of activities in the field of sexuality and intimacy if there is no input to make them possible. It is, therefore, important to draw up a budget which establishes the minimum and maximum amount that should be used for the management and maintenance of space and dynamic activities in the field of sexuality and intimacy: romantic dinners, contraceptive methods, couple dates etc…

The budget allocated to this field, as well as with others, should be made known to the service users and its use decided with the group and/or individually. Sometimes, the budget to be used in this activity comes from the service's resources (e.g., if it is a residential service, it is expected for the service to provide for materials and equipment for the users to take care of their own body). Other times, or in specific situations, the budget may have to be provided by the service user him/herself and/or by his/her relatives and caregivers.

Budget restrictions are, in general, a challenge in the social services' field. It might so happen that the field of intimacy and sexuality is underestimated and not seen as a priority. In order for the PwD to access experiences in this field and to have the opportunity to make informed and supported decisions, services should reorganise and establish partnerships, in order for resources to be made available.

☐ Some **reflections** you may want to consider.

Depending on the type of service, it may be possible and useful to establish a monthly ceiling for the service to use in activities related to sexuality and intimacy. Define, individually, what are the regular needs and distribute the budget accordingly and throughout time.

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If there is no funding available because the usual funding of the service does not cover this important area of everyone's life, establishing partnerships and finding sponsors may be an option to cover this gap. Using public mainstream services (e.g., family planning consultations at the local Health service) may be an efficient solution for some of the needs (e.g., contraceptive resources).

In any of the above-mentioned situations, it is fundamental to reflect with the service users about the issue of funding of resources and activities in this field and to make adjustments over time.

If in need of more practical ideas and recommendations, here is a checklist to support the creation of a… **Sensible budget in 10 Simple Steps**:

Questions for Reflection:	Verification		
	No ✗	No. However … ⚠ What adaptations are possible?	Yes ✓
1. Is there a monthly budget available for the service to spend in intimacy and sexuality related activities (e.g., health and safety materials, contraceptive methods, pornography…)?			
2. If there is no budget allocated to this area, is there a procedure to look for families and friends who could support the service users?			
3. If there is no budget allocated to this area, is there a procedure to look for partners and sponsors who could support these costs?			
4. Is there a professional responsible for analysing the individual and/or service the budget allocation, together with the service users?			
5. Do service users participate in decisions on how the service's budget allocated to this area is distributed regularly (e.g., monthly or every other month)?			
6. Do service users participate in decisions on how their individual budget allocated to this area is distributed (e.g., monthly or every other month)?			
7. Are health expenses related to intimacy and sexuality (e.g., family planning) considered in the individual's and/or service's budget?			
8. Are there regular (e.g., every six months) revisions about the budget management related to intimacy and sexuality?			
9. Is there accessible and easy to read information about options on how the budget can be spent and distributed on activities related to intimacy and sexuality?			

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Use the checklist to evaluate how prepared are your services' budget management procedures to guarantee SDM and a pleasurable and self-determinate experience of sexuality and intimacy and, if possible, find new ways to improve how you work in this field. Remember, SDM about intimacy and sexuality can only become a reality, if there are resources, including funding, in the service to make it happen!

Case History – Rodrigo, Marco, David and Gabriel

Rodrigo, Marco, David and Gabriel all live together at residential service for people with disabilities. Since they don't have a fixed job, their monthly income is not stable and because they have some form of intellectual disability, they struggle with the management of domestic expenses.

During the monthly meeting with the staff members of the residence, the group complained that they miss Wi-Fi access in the apartment in order to use their social networks and access multimedia content. While exploring their budget needs in the field of intimacy and sexuality, the four of them asked for a monthly amount that would allow them to invite their romantic partners for a romantic date, every weekend. The restrictive service's budget, however, would not be able to support both the demands: WI-FI access and weekly dates.

The supported decision …

After reviewing the monthly budget and making all the possible adjustments, the staff workers had to inform the group of young men about the impossibility of supporting all their demands. Individually, each gave his opinion about how they thought the available funds should be spent, coming to the joint decision to reduce the number of romantic dates, in order to be able to afford a Wi-Fi service for the residence.

The staff negotiated that the service management would pay for part of the costs of the Wi-Fi service and agreed to support the service users in reaching out for their families to explore the possibility of a monthly allowance, during the periods in which the boys have no job, to help them have more opportunities for social activities with their girlfriends.

5. Ensuring Privacy and Confidentiality:

- ***"What is, in your point of view, the meaning of privacy?***
- *To keep my own things, what I have and what I do, to myself. To be respected and not to tell others whatever it is I do with my husband. To have my own room and to be comfortable and by myself."*

Maria, Service user with intellectual disability

Even though sexuality is a matter that is common to everyone, it is also something that, individually, only matters to the person and those who are directly involved. People with and without disability generally regard their personal relationships and sexuality as private matters that must be treated with sensitivity and respect.

It is important that all the staff members, service users and visitors to the service understand what privacy and confidentiality mean and learn to be reserved and respectful of themselves

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and others. In that sense, it is recommended that the service has a confidentiality procedure to implement with all the parties involved to ensure the privacy and confidentiality of all users of the service.

☐ Some **reflections** you may want to consider…

Regarding sexuality and intimacy, but also on any other relevant issues, providing an appropriate environment in which privacy can be supported and maintained is fundamental. When individuals external to the service visit the facilities or interact with the service users, preparing a confidentiality agreement, which guarantees this right to all the service users, may be necessary and appropriate. With the same purpose, the spaces which are used for activities related to intimacy and sexuality should be adapted, in order to guarantee the privacy of all the service users and visitors.

Regarding confidential information, all efforts must be made in order to keep private all information about the personal relationships of the service users, unless the person consents to disclosure. For the same reason, services should ensure people with a disability are not encouraged or coerced into revealing personal details, thoughts or feelings that they would prefer to keep private. Additionally, even if they do want to share information, support workers should adopt a pedagogical attitude, helping them reflect about the reasons and (dis)advantages in sharing this kind of information.

There are times, however, when confidentiality and privacy considerations may be overridden by other policy or duty of care requirements … this should always be explained to the PwD.

If in need of more practical ideas and recommendations, here is a checklist to support the creation of a… **Confidential romantic lives in 10 Simple Steps**:

Questions for Reflection:	Verification		
	No ❌	No. However … ⚠ What adaptations are possible?	Yes ✓
1. Is there a confidentiality agreement signed by staff members, service users and visitors to the space?			
2. Is the confidentiality agreement in an accessible and easy to read format?			
3. Are there privacy rules, documented in an accessible format, and available to all service users, visitors and staff members?			
4. Is there a specific staff member that each service user can turn to, to deal with their intimacy and sexuality-related issues?			
5. Can each service user choose the staff member with whom he/she wants to clarify doubts, ask for information and/or request materials and equipment regarding intimacy and sexuality?			

6. Can service users choose with whom to share their room and bathroom?			
7. Do service users have the opportunity to make private calls and receive personal mail/e-mail in privacy?			
8. Is it possible for service users to receive visitors in a private location, without having to go through spaces that are common to other users?			
9. Is it possible for service users to make and receive romantic visits and/or to stay overnight privately?			
10. Does the service enable the service users to use their own budget for expenses related to their sexual and intimate life privately and with no need for accountability?			

Use the checklist to evaluate how prepared is your services' confidentiality procedure to guarantee SDM and a pleasurable and self-determinate experience of sexuality and intimacy and, if possible, find new ways to improve how you work in this field. Remember, Supported Decision Making about intimacy and sexuality can only be respectful, if the service guarantees privacy and confidentiality to make it happen!

Case History – Marlene

Marlene is 37 years of age and lives in a residential service. She has intellectual difficulties and a severe mental health condition and, as a consequence she sometimes has difficulties controlling her emotions and behaviour, especially when interacting socially with others. Marlene has a long-term relationship with Aurora and, most of the time, it's possible and easy to adjust their relationship to the domestic life in a group of 12 residents.

When Marlene's mental health is not well, however, arguments between the couple are frequent and sometimes escalate into aggressive verbal behaviour between the two women. Under these circumstances, it is common that Marlene complains to the staff members and to the other residents about Aurora, disclosing specific details about their intimate and sexual life together. When this happens, some staff members and other service users engage in conversations about this issue, giving rise to comments and gossiping around the house, which leaves Aurora in a very unpleasant situation.

The supported decision …

In a private conversation with Marlene, the service manager and the key support worker had to remind her about the privacy and confidentiality policy and procedures of the service, clarifying the limits of her own life, her relationship with Aurora and Aurora´s life and privacy. Marlene was also reminded of the privacy rules that she has to respect and of the confidentiality agreement that she has signed and agreed to follow, making sure there was a common understanding of what are intimate subjects of each of the involved and that Marlene would only be allowed to share private information of her own.

Lastly, Marlene was informed that it would be ok to talk with someone about the reasons for distress in her relationship, but she was advised to do so in a more private space and only with

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a restricted number of persons she chooses. She then decided she could go to the key support worker case manager that she chose by herself whenever she needed to complain or ask for support.

The service manager also had a meeting with the staff team to clarify the role of each professional in maintaining confidentiality in the service and protecting the users' privacy, even in situations in which the users themselves share confidential information. They were instructed to avoid commenting on any situation shared by Marlene and to discourage other service users from doing so, as well as to invite Marlene for a private conversation about what is upsetting her, instead of leaving her to complain around the residence.

6. Ensuring quality communication about sexuality

- ***"What barriers and facilitators to the Right of Sexuality are there in the service?"***
- *In my opinion, I have the Right to sexuality. They – the staff members – support me, by giving me advice and helping me with the dates with my girlfriend."*

Antonio, Service user with disability

Unless a person is able to access and understand information about this topic, he/she won't be enabled to communicate his/her whole identity, including issues related to intimacy and sexuality. It is fundamental that the service's staff provide accessible information and support the service users if they need assistance in accessing and/or understanding information about this topic. It is also important that the service users know that it is ok to approach the professionals whenever they feel the need to, allowing them to feel heard and understood.

Professionals from the teams should feel comfortable and prepared to communicate about intimacy and sexuality with the PwD and they should, as well, feel supported by the service manager. If they don't feel comfortable having conversations about this theme, it's important that they are aware of their own discomfort and that they know whom to ask for help. There are some suggestions in Section 5 of SMARTS for support professionals to help staff feel more comfortable talking about sex.

☐ Some **reflections** you may want to consider…

It may be necessary to hold regular meetings with the staff members to create awareness and prepare them to have conversations about topics related to intimacy and sexuality whenever the service users express the need to. In the same way, staff members should be prepared to identify the needs from the service users to address the topic, even if unexpressed or subtly demonstrated.

It may naturally happen that some professionals feel unprepared to approach the topic of sexuality and/or to deal with different issues related to this subject. The service manager should create opportunities and allow staff members to express their needs and concerns regarding communication about sexuality and intimacy, encouraging those who feel uncomfortable with the topic to ask for support from other team members, if the need to have a conversation about the issue arises.

Having regular conversations with the service users to let them know that the topic of sexuality is as important as any other physiological need is good practice. In a natural way and as the service users bring up the topic, provide information, explore multiple resources about this topic and have leaflets, brochures and informative websites available for consultation in the service. For specific questions and topics requiring a professional approach, establishing partnerships with specialised services may be an option.

If in need of more practical ideas and recommendations, here is a checklist to support the creation of a… **Quality communication in 10 simple steps**:

Questions for Reflection:	Verification		
	No ❌	No. However … ⚠ What adaptations are possible?	Yes ✓
1. Are there spaces in the service where staff and service users can have a conversation calmly?			
2. Do the service's schedules and routines allow availability of time for staff and service users to enter into a dialogue about intimacy and sexuality?			
3. Are there documents and information about intimacy and sexuality in an accessible and easy to read format?			
4. Are there visual supports and communication aids to enhance communication about intimacy and sexuality for service users with communication support needs?			
5. Are there professionals in the team with additional training and/or information about Communication Access?			
6. Are there professionals in the team with additional training and/or information about Active Listening?			
7. Are there professionals in the team with additional training and/or information about intimacy and sexuality?			
8. When engaged in a conversation about intimacy and sexuality, are the staff members able to approach the topic comfortably and naturally?			
9. When engaged in a conversation about intimacy and sexuality, are the staff members able to use the **6 R's** of Communication: **R**elax - **R**emember - **R**eveal -**R**each Deeper - **R**esearch - **R**eflect? (see section 3 of SMARTS for professionals for further details).			

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10. When having difficulties in a conversation about intimacy and sexuality, is the service manager and/or a specialist available to support the staff member(s)?			

Use the checklist to evaluate how prepared your service is to ensure quality communication about the topic of sexuality and intimacy and, if possible, find new ways to improve how you work in this field. Remember, SDM about intimacy and sexuality can only become a reality, if there is good Communication Access around the topic to make it happen!

Case History – Daniel

Daniel is an 18 years old young man with mild intellectual disability, living with his family and being supported by a staff member from the local independent living project. He is very close to his parents and would like to continue to live with them, at least until he finishes his vocational training programme and finds a professional placement.

For a couple of months, during their daily activities, Daniel had been asking questions of his support worker about the "right" sexual orientation that would allow him to get married and raise a family. During one of the visits the support worker brought an easy-to-read brochure about the Human Right to sexuality and a leaflet from a LGBTQ+ association, explaining different sexual orientation and identity issues and clarifying terminology. The support worker then understood that Daniel felt attracted to other men and would identify as homosexual, although the conservative family had taught him that in order to get married, have kids and raise a family, the "right" sexual orientation would be the heterosexual one, expecting him to find a girlfriend within the next few years.

The supported decision …

After the first conversation about the topic, the support worker did not really know how to deal with this dilemma and understood that professional intervention from a psychologist would be needed, not only to guide Daniel in exploring his sexual orientation and identity, but also to help him to communicate his choice to his parents. Daniel was thoroughly informed that everyone has the right to choose his sexual orientation and to have consensual relationships with anyone else, regardless of their gender or what others consider the right choice about sexual orientation. He was also able to discuss the problems that could arise when/if he decided to tell his rather 'conservative' parents that he was homosexual. He said he needed some time to think through all these things.

Some weeks later, Daniel decided to talk to his parents about his choice to look for a boyfriend and asked the help from the support worker, together with the social worker that ran the vocational training programme where his parents had him registered. At first his parents were quite shocked when Daniel told them he was homosexual.

Over time they came to see that he was much happier now and accepted that this was his choice. They met many of his friends and were pleased to meet his long-term partner and welcome them both to the family home.

Section 6

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.

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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.

Topic	*Questions for Supporters*	*Smart Approach*
“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?	In order to clarify what “love” means to the SP, the steps below could be followed: » 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?

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		» Does the SP understand/distinguish different types of love e.g., loving a parent/sibling, living a pop star, loving a pet, loving a girl/boyfriend?
“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 recognize that his/her wishes and feelings may differ from the wishes/feelings of others. This may lead to unstable, one-sided romantic relationships.	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?	In order to clarify what “reciprocity” means to the SP, the steps below could be followed: » 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?
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.	How can the Supporter support the SP’s understanding in these areas?	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.
Discussing with the SP about love and emotional attachment / friendship demands clear thinking and emotional maturity on the part of the supporter.	How well equipped is the Supporter to explore such matters with the SP?	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.’

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Supporting the SP to make informed decisions

 *TOPICS FOR THE SP TO KNOW & UNDERSTAND*	 *TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP*
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).	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?
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.	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?
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.	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?
Sometimes the SP may feel confused with the different kinds of love. (S}he may develop romantic feelings for a relative or a teacher	Is the SP aware of the social rules regarding close relationships? Is there way that (s)he could be informed without being hurt?
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.	Is the SP’s idea of love realistic? What is he/she looking for? Is he/she willing to compromise?
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.	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?
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".	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”?

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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 Service Managers on this topic

Topic	*Questions for SM*	*Smarts Approach*
Love and emotions within the service It is important to clarify the correct attitudes and responses of the service manager towards the development of feelings by a service user towards him/her or a member of the staff.	What if the service user(s) develops feelings for a staff member?	If the service user(s) develop feelings for a member of the team, it should be clear to the entire team that this feeling should be discouraged. To facilitate the intervention of service managers in these situations, it may be necessary to create a code of ethics and conduct that clarifies the responses/ attitudes to be taken in similar situations. It is important that the manager ensures this code is remembered and known by the entire team.
Love and emotions within the service As in the general population, assaults against people with disabilities are more likely to be perpetrated by someone they know, such as a family member, service manager, co-worker, or someone they live with. Research also shows that sexual assaults on PwD are less likely to be reported.	What if a staff member (somehow) encourages the development of romantic feelings from a service user?	It should be clear to the entire team that some PwD have reduced or non-existent legal capacity, due to a process of interdiction or disqualification, and cannot, by themselves, practise certain duties and rights or be legally coerced into their practice. In the legal context, and with regard to sexual and reproductive rights, PwD can practise, by themselves and by their own will, exactly the same acts compared to people without disabilities, unless otherwise provided by the laws in that country. Indeed, it is often the Court that decides, on a case-by-case basis, which actions the PwD cannot perform by themselves, which then means such actions require the consent of a legal representative or guardian. The UNCRPD says such legal interventions should always be at the minimum level necessary to secure the well-being of the person and seek to maximise their autonomy and decision making in as many areas as possible. Legal systems in almost all European countries have yet to be changed to comply with this requirement.

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Love and emotions between people with and without disability PwD are more dependent and vulnerable to sexual abuse. For some, the perception of signs of abuse can represent an additional effort in understanding this behaviour.	What if a service user with a disability has a relationship with someone without a disability who is not a member of staff? What if a service user with a disability has a relationship with someone who also has a disability? What if this relationship is very 'unequal'?	Service managers must be familiar with the institution's codes of ethics as well as the law that protects people with disabilities from abuse. The staff should also help to model assertive behaviour, supporting and explaining the basic principles of protective behaviour and being aware of any signs of abuse. Care must be taken to respect the right of PwD to explore relationships, even if they are 'unequal' and / or seen to be unstable/ doomed to fail. 'Love can be blind' is a reality that affects us all, including PwD.

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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.

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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 and 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.

Topic	*Questions for Supporters*	*Smart Approach*
Understanding the reasons for contraception. 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.	How can I make sure that I understand the wishes of the SP with regards to contraception and parenthood?	The supporter should clarify with the SP the reasons behind wanting to choose contraceptive measures. 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. Contraceptive options should be discussed respecting the wishes of the SP with regards to parenthood.
Choosing the best contraception method. 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.	How can I best support the SP to choose the contraception method that best applies to him/her?	First start assessing the needs of the SP with regards to contraception. Afterwards discuss in detail the remaining types of contraception in relation to: 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. Discuss whether there is a need to use condoms for STI protection. 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.

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Addressing informed consent. 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.	Can I support the provision of contraceptive methods to the SP without their awareness and consent?	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. ' 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.

Supporting the SP to make informed decisions

 ***TOPICS FOR THE SP TO KNOW & UNDERSTAND***	 ***TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP***
Regarding contraception methods:	
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?

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» 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.

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Questions for Service Managers on this topic

Topic	*Questions for SM*	*Smarts Approach*
Enabling supported decision making about contraception *The PwD may not access adequate information about contraception and/or may not have resources to acquire the best possible alternative for their individual situation.*	Are professionals and visual supports available to provide information about diverse contraceptive methods?	It is fundamental that the person with disability has access to relevant information in easy to read and accessible formats about the diversity of contraceptive methods available in the market. It is important that the service user has the opportunity to consult with a health professional, with the support of any other professionals from the service, in order to ask all the questions, clarify any doubt and receive meaningful information to make an informed decision. The manager must try to ensure this is available as needed.
	Is there a budget available to ensure access to contraceptive methods and related health services?	
Enabling supported-decision making about family planning *Services may not be prepared with human resources to address the complex topic of family planning and the consultation of specialists (e.g., health and legal professionals) may be necessary.*	Are professionals available to provide information and enter into a dialogue about family planning with the service user(s)?	Should the service user(s) decide to plan a family, it is fundamental for a team of professionals to be available to enter into a dialogue with them about all the advantages, demands, risks, costs, etc. of having a family. This conversation should be facilitated by professionals with training in communication access and visual supports to communication. It is important that professionals from the social, health and educational fields are available to discuss the issue with the service user(s) and support their independent decision-making.
	Are professionals available for legal consultation about family planning with the service user(s)?	Should the service user(s) decide to create a family, it is important that the service manager liaises with legal/justice services in order to guarantee the access to legal information and support throughout the process. It is fundamental that a professional from the social service ensures good communication access in every relevant conversation and discussion.

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Ensuring support throughout the process of contraception and family planning If the PWD decides to start a family or even if he/she decides not to, the support of an impartial multidisciplinary team will be necessary in order for the adequate support to be provided over time.	Are impartial and independent professionals available to support the service user(s) throughout time, should he/she/they decide to start a family?	The decision to start a family when one or both of the partners have disability should be analysed from various perspectives and considering the UN Convention of Rights of Persons with Disability. There should be independent and impartial professionals supporting the service user(s) and the family and/or legal guardians. A reflective period should be taken to prevent impulsive decisions and caregivers from different settings should be enquired before the decision is made. The country's legal framework should be taken into consideration.
	Are impartial and independent professionals available to support family and legal guardian(s) if a permanent contraceptive method is considered the best decision for someone, especially in cases of severe or profound disability?	The decision for the use of a permanent contraceptive intervention, even in cases of persons with severe to profound intellectual difficulties, should be analysed from various perspectives and keeping in mind the UN Convention of Rights of the Person with Disability, as well as supported by independent and impartial professionals. A reflective period should be taken to prevent impulsive decisions and caregivers from different settings should be enquired before the decision is made. The country's legal framework should be taken into consideration.
	Are impartial and independent professionals available to support family and legal guardian(s) if a termination of pregnancy is considered the best decision, especially for someone with severe or profound disability?	The decision to terminate pregnancy, even in cases of persons with severe to profound intellectual difficulties, should be analysed from various perspectives and considering the UN Convention of Rights of Persons with Disability, as well as being supported by independent and impartial professionals. A reflective period should be taken to prevent impulsive decisions and caregivers from different settings – family members, legal guardians, key workers, etc. - should be enquired before the decision is made. The country's legal framework should be taken into consideration.

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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.

Addressing the topic of disabilities in the field of health in general and in the field of sexuality in particular implies taking into account the contributions of PwD, in the design, application, monitoring and evaluation of the established health systems. It is also important to put them at the centre of any action and decision that involves them and their bodies. In this context, it is essential to guarantee their freedom and their informed consent when carrying out any treatment that may have an impact on their bodies.

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 recognize 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

Topic	*Questions for supporters*	*Smart Approach*
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.	As a supporter, do you feel comfortable in offering support in sexual health issues and STD? Do you feel you have sufficient knowledge to offer such support?	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?) 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.
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 a 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.

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Supporting the 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.

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Questions for Service Managers about this topic

Topic	*Questions for SM*	*Smarts Approach*
Approach of service managers with regards to the topic of sexual health and STD	As a service manager, how should I address the issue of sexual health and STD within the care facilities I manage?	As a service manager, addressing sexual health and STD among users and staff should be regarded as a top priority, since both have the potential to impact strongly and negatively in the overall health and wellbeing of the PwD. It is for this reason that service managers should ensure the provision of sufficient resources at all levels to address these.
Capacity building for professionals from care services to support PwD	**How can service managers ensure that staff members have sufficient and appropriate training on how to deal with sexual health and STD?**	Facilitating capacity building for professionals in the topics of sexual health and STDs should be a shared responsibility between service managers and health professionals. Service managers should ensure sufficient resources and support to raise awareness and empower among PwD on these issues. In addition to resources and support, staff should also receive training on sexual health and dealing with STDs. For both profiles there are sexual health education materials and programs designed to address the needs of PwD and staff that service managers need to know to implement in their service. Additional and external support with regards to capacity building provided by health professionals is strongly encouraged since they are in the position to provide comprehensive and up to date information and advice on these issues from the health system perspective.
Resources to support the PwD in taking care of their own body. *Service managers must promote quality services, ensuring health and safety to all service users*	Is the service equipped with resources – human resources, materials and equipment and facilities - to guarantee hygiene and safety in the field of sexual health and STD to all the service users?	It is important to have a close connection between health professionals and service managers in order for care services to be up to date and be able to clearly inform both professionals and users on topics relevant to sexual health and about the ways STDs can be transmitted so that the real risks can be understood and identified, including possible contagion/ transmission to others. Resources to support PwD in these topics can have different forms: » Human resources: have professionals trained and access to health practitioners that can provide complementary information. » Materials and equipment: such as training resources, educational publications (adapted for PwD), preventive and testing materials, health products... » Facilities: provision of spaces to discuss and provide support with a high level of confidentiality.

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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)

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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

Topic	*Questions for supporters*	*Smart Approach*
Facilitating (or not) access to the Internet and social media. Using the internet and social media to find love or sexual partners only becomes a live issue if: » 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	How should I decide if it is better to encourage or discourage/ access to the Internet?	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.

Addressing the risks that the internet and social media activities might pose » 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).	How can we best deal with potential risks associated with the use of the internet and social media?	» 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.
Setting limits to access and use of the internet and social media. 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.	Should I set limits to the access and use of the internet and social media?	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. 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).

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Supporting the 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*?

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Questions for Service Managers about this topic

Topic	*Questions for SM*	*Smarts Approach*
Access to the internet and social media	Are there materials and equipment in the service to ensure service user access to the internet and social media?	Everyone has the right to feel included in society and to actively participate in different aspects of life. In the current world, social life takes part, in a meaningful way for many people, through the internet and social media. An inclusive service should be able to ensure access to the internet and social media by providing the necessary materials and equipment and ensuring access to a quality internet network.
	Is there budget provision for the individual or group to ensure the access to the internet and social media?	To guarantee continuous access to the internet and the possibility to participate in social media, it is essential that the service's budget considers the necessary expense. Each of the service users, especially if it is a residential service or independent living project, should have his/her own budget allocated to this activity, if they find it meaningful and a priority. In order to do so, the support professionals should provide all the necessary information and support decision making regarding the type of service and the amount of individual budget allocated to this resource.
Creating conditions for comfortable and safe use of the internet and social media	Is there a space where service users can use the internet and social media to exercise their right to sexuality and intimacy with privacy and dignity?	Whether it is for social interaction with friends or unfamiliar people or to access dating sites or pornographic content, it is fundamental that the service users have privacy during their 'online time', as well as confidentiality regarding when, how or for what motive he/she has been accessing the internet.
	How would you monitor the safe use of the internet by service users? If the answer is that you would not monitor it, then what would you look for as indications that something was going seriously wrong here?	This is tricky. The privacy of the SP demands that you don't know, but prudence/common sense suggests you should know at least something about what is going on. As in any similar situation, if you don't have any inside knowledge (provided here by the supporter) then you must be alert for other signs that something is going wrong (e.g. emotional outbursts / loss of money/ change in character / signs of anxiety/fear etc) and act if needed.

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Assessing the impact of the use of the internet and social media	Are there policies and practices to evaluate the positive and negative impact of the use of the internet and social media?	Is guidance available to both staff and service users about the use of the internet? How such usage might need to be shared and spread out so as not to overload the connection? As to what the access is used for by services users - are any limitations set? (If so, why?) Is guidance to staff/supporters available about the limits to the help they can/should provide to service users for any reason - e.g., to pay for access to 'adult porn' or join an expensive 'dating service' etc? Are there ways of assessing if an individual is actually harming him/herself by their online activities? What should happen then?

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Section 10

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

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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

Topic	*Questions for supporters*	*Smart Approach*
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.

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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.	**What, when and where is adequate to support the use of pornography by the PwD?**	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. 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.

Supporting the SP to make informed decisions

 *TOPICS FOR THE SP TO KNOW & UNDERSTAND*	 *TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP*
» 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?	» 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?

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Questions for Service Managers about this topic

Topic	*Questions for SM*	*Smarts Approach*
Facilitating access and use to pornography. Some PwD are interested in accessing and using pornography but need support to get this access.	How can service managers support SP in accessing and using pornography?	Service managers that support PwD should facilitate access to pornography. There may be a reference or key worker, in order to maintain privacy, to whom the SP can turn, if necessary, to ask for support in the acquisition of materials (DVD's, magazines, access to websites). It must also be ensured that the SP's budget includes these expenses and that the types and sources of pornography are ethical and legal.
Guaranteeing privacy while accessing pornography For PwD, intimacy is not always a private matter due to lack of privacy, especially when living in shared accommodation.	How can service managers guarantee the privacy of PwD about access to pornography?	Services should arrange spaces and schedules in order for the SP to be allowed to use pornographic material with privacy and guaranteeing confidentiality. Service managers and staff members should explore possibilities within the service and look for support and partnerships with family members and other organisations, e.g., if there is no possibility to access the service's computer to view pornographic content privately, perhaps an individual device should be acquired.
Safeguarding and prevention of abuse related to the use of pornography. People with intellectual disabilities may need support to clearly identify the range of risks associated with using the internet and personal electronic devices to access pornography.	How can staff members guide PwD to securely access pornographic content on the internet?	Staff should guide and assist PwD in accessing safe and legal pornography sites. There may be an adapted, plain language guide to help PWD understand what is legal and illegal on the internet (example: https://www.choicesupport.org.uk/uploads/documents/Online-Pornography-and-Illegal-Content-Web-Version.pdf). The staff should also explain the dangers of the internet (you can use an adapted model to facilitate: https://www.achievetogether.co.uk/wp-content/uploads/2019/09/Keeping-Safe-Online-Easy-Read-Guide-Email-Version.pdf) and can suggest some sites, tv channels, or other sources of material, that are more secure.

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Organisational policy related to the use of pornography Since PwD may need support to access pornography once they have freely decided to do so, it is possible that staff and resources may be used to implement that decision. This may cause disagreements amongst staff, service users and their families and could damage the reputation of your service and/or the whole organisation.	How can Service Managers be confident that actions to implement an SDM decision to use pornography will be supported by staff, families and the organisation?	Service managers need to ensure that the organisation has understood that supporting SDM and implementing SDM decisions could involve matters such as the use of pornography (or sexual assistants or prostitutes etc). So, at a policy making level there must be agreement/acceptance over what this means in practice when supporting the sexual rights of PwD. At a lower level, amongst the staff group, a similar recognition and acceptance must take place, although it may be necessary for the organisation/Manager to accept that some staff may object to taking part in the implementation of some decisions. As a Service manager it is up to you to make sure that the implications of SDM in sexual matters is understood and its implementation supported. You must provide the leadership and intellectual honesty in argument to follow the direct line of thinking from the principles of the UNCRPD to its practical implications for a PwD in your service. This linear connection lies at the heart of the SMARTS project.

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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

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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

Topic	Questions for supporters	Smarts Approach
Addressing the level of influence of the supporter in shaping the opinion of the SP on whether to 'commercial sex' use or not. The Supporter's and the Facilitator's personalities and values may, even unconsciously, influence the	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?	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.

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SP's choice, if s/he wants to meet with a sex worker of any kind.		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.
What level of support should the Supporter and Facilitator provide to the SP who wants to use the services of a Sex Worker? 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?	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?	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 *implementing* 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.
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. 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.	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?	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. 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.

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Supporting the SP to make informed decisions

 *TOPICS FOR THE SP TO KNOW & UNDERSTAND*	 *TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP*
Does the SP understand the legal aspects of choosing the services of a sex worker? » 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?	» 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 Service Managers about this topic

Topic	*Questions for SM*	*Smarts Approach*
Enabling/Disabling access to Sexual Assistants and/or Prostitutes by an SP	Are there opportunities for the service users to access sexual assistants and/or prostitutes?	It is important for the service manager to be well informed about the national legal framework regarding the use of sex workers' services in order to create procedures to ensure access to these opportunities. If legally required, the information about the services should be disseminated to the legal guardians. Meetings with the interested service users should be held, in order to schedule the implementation of this activity over time.

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	Is there a budget for the service users to access sex workers?	If the use of a sex worker requires funding, it is important to ensure a budget for this purpose. According to the legal framework, the funding may be provided by the service and/or by each service user. It is important that every service user understands how their use of a sexual assistant is funded and that any communal funding is fairly shared. If there is no such budget - then how will such services be paid for?
	Are the service's infrastructures and materials appropriate for the service users to access sexual assistants?	If the use of sexual assistance services requires the SP and the sex worker to make use of the service's own facilities and materials, (e.g., using a guest bedroom) managers should recognise that other service users would expect any similar requests they make to be permitted in a similar fashion.
Creating conditions for a *comfortable and safe* access to sex workers' services.	Do the sex workers receive specialised training on a regular basis?	Before using a sexual assistant, the service manager should confirm that there are professionals with adequate training and profile to provide the service. Before using a prostitute, the service manager should be careful to check what past experience the prostitute has of PwD and how s/he would react if the SP became distressed or anxious.
	Is there a professional from the service available to supervise and support the access to sex workers?	**If** a service user decides to arrange a meeting with a sex worker, it is important that a professional from the service's team is available nearby to support the service user and ensure privacy.
Creating legally and ethically correct conditions to access to sex workers.	Is the SP subject to any legal constraints which control what s/he can/cannot do? Does the SP's consent alone provide sufficient legal grounds to go ahead with this?	Is there a procedure to communicate with and obtain informed consent from the service users regarding the access to sex workers? Is there a procedure to inform and, *if necessary*, obtain informed consent from family and/or legal guardians regarding the access to sex workers?

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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.

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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.

Topic	*Questions for Supporters*	*Smarts Approach*
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?**	Listen to what they already know: what knowledge does the SP already have about their own anatomy, body parts and sexuality? 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.). 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! 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.

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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.	**Where does my role as a supporter end when opening the topic on masturbation and the use of sex toys?**	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).
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. 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.	**How do the parties involved in the SDM agreement feel about opening the topic of masturbation and the use of sexual toys?**	Masturbation and the use of sex toys is a topic not always easy to discuss. As a supporter, your role is to: ‣ 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! In both cases, do not hesitate to seek support from the Facilitator.

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Supporting the SP to make informed decisions

 ***TOPICS FOR THE SP TO KNOW & UNDERSTAND***	 ***TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP***
» 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.	» 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.
» 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.	» 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.

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Questions for Service Managers about this topic

Topic	*Questions for SM*	*Smarts Approach*
Staff members may have difficulty in approaching this topic with the service users and their families	**How to support staff members with difficulties in dealing with the topic of masturbation and the use of sex toys?**	The role of the staff members is to inform and support decisions, without making judgements about what the supported person considers to be a good choice. The Service Manager should provide information in accessible formats for the staff members to share with the service users. He/she should also ensure the team has enough information and training to guide the supported persons in making their choices. Should a staff member feel uncomfortable with the topic, it is important for the Service Manager to intervene and support this professional and/or find another team member who is more prepared to support the service users in decision-making about this topic. National legislation and service standards and recommendations have to be respected, regardless of the suggestions here presented.
Services should be prepared and equipped with adequate materials and equipment to use in these kind of sexual activities	**How should the service be organised in order for the service users to be able to engage in masturbation activities?**	The services should be equipped with materials and equipment for a safe and healthy exploration of masturbation practices in case the service users so decide. The Service Manager should ensure a budget for the acquisition of adequate materials and equipment. The budget may come from the personal budget of the service users and/or from the services' budget. This will be dependent on the national legislation. Partnerships with other organisations and private suppliers may help to equip the service. The spaces of the service's facilities should also be organised in ways that ensure safety, comfort and privacy in terms of masturbation practices. National legislation and service standards and recommendations have to be respected, regardless of the suggestions here presented.

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Family members may have difficulties accepting that his/her relative has the need to masturbate and disagree with the service to support this activity.	**How should the service manage a situation of a family member that does not accept that the service now allows and/or supports the service user either in masturbation and/or the use of sex toys?**	If there is conflict about the practice of masturbation by a service user, because family or caregivers do not accept this situation, the Service Manager should support the staff members and, if necessary, the service user, explaining that this is a natural part of human sexuality of people with disability, as it is of persons without disability. He/she should also ensure the family and caregivers that no abusive situation is taking place and that the staff members will mostly provide support in decision-making and respect the service user's will. National legislation and service standards and recommendations have to be respected, regardless of the suggestions here presented.

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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.

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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.

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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).

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Questions for supporters on this topic

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

Topic	*Questions for Supporters*	*Smarts Approach*
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...	How does displayed Inappropriate sexual behaviour make us feel?	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.
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?	Is it necessary for the supporter to adopt a punitive attitude in these cases?	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: 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? 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. 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.
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.	What should supporters do if the SP targets them with inappropriate sexual behaviour?	There are several general recommendations on how to approach daily work by the supporter to prevent such situations as far as possible: 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 differentiation that could be understood as affective preferences by the SP.

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		If the inappropriate sexual behaviour does occur: 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)
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.	How does displayed Inappropriate sexual behaviour make us feel?	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.

Supporting the SP to make informed decisions.

 *TOPICS FOR THE SP TO KNOW & UNDERSTAND*	 *TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP*
What is inappropriate sexual behaviour? » 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.	Can the SP understand that he/she is displaying inappropriate sexual behaviour? Is the SP able to explain the reasons for such a display? What sex education has the SP previously received? What kind of sex-affective socialisation has the SP had? Is the SP aware of the need for privacy? Are private spaces available? Does the SP know how to use them? Does the SP have access to build his/her own privacy? How is his/her inappropriate behaviour affecting people around them? colleagues, family, professionals... Provision of guidelines to differentiate when a normal sexual behaviour becomes inappropriate.

Questions for Service Managers about this topic

Topic	*Questions for SM*	*Smarts Approach*
The need to define limits between service users and staff members.	**What if a service user has inappropriate verbal and/or physical behaviours towards a staff member or another service user?**	The Service manager should define clear and simple rules and a code of conduct that defines what is and what is not appropriate regarding the (sexual) behaviour of the service users, within the service. Any kind of inappropriate behaviour - physical approach, verbal harassment, lack of inhibition, etc. - from a service user, towards a staff member or another service user, should be followed by contingent consequences.
The need to define limits between service users and staff members. It may be necessary to have clear limits set in terms of appropriate and inappropriate behaviour within the Service and between all of those involved.		The rules and code of conduct should be prepared in an Easy-to-Read format and accessible to every service user. The Service Manager should organise regular workshops to explore this topic with all of the involved, making sure the supported persons know about their rights and how to ask for help and protection. If a staff member feels abused or vulnerable to a service user's abusive and/or inappropriate sexual behaviour, the Service Manager should act upon this situation. Additional training for the staff members may be necessary, to help them define clear limits in the relationship with clients, even though sometimes they will assist decision-making and/or support them in the field of intimacy and sexuality. In specific and severe situations, the consequence of repetitive inappropriate sexual behaviour from a service user may result in the cancellation of the service delivery to this person, in order to ensure the rights and wellbeing of all the other service users. National legislation and services' standards should be followed and considered, when dealing with this topic

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	What if a staff member shows inappropriate verbal and/or physical behaviour towards a service user?	The Service manager should define clear and simple rules and a code of conduct that defines what is and what is not appropriate regarding the (sexual) behaviour of the staff members, within the service. Any kind of inappropriate behaviour - physical approach, verbal harassment, lack of inhibition, etc. - from a staff member, towards a service user, should be followed by contingent consequences. Information about abuse and inappropriate behaviours should be available for the service users to access and be informed. The Service Manager should organise regular workshops to explore the topic of abuse with service users, making sure they are aware of the procedures for their own protection. If a service user reports any kind of inappropriate sexual behaviour from a staff member, measures should be taken, following the sexual abuse prevention procedure of the organisation. National legislation and services' standards should be followed and considered, when dealing with this topic.

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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 (LGBTIQA+) 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

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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.

Topic	*Questions for Supporters*	*Smarts Approach*
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. ▪ 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.

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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.

Supporting the SP to make informed decisions.

 ***TOPICS FOR THE SP TO KNOW & UNDERSTAND***	 ***TOPICS FOR DISCUSSION BETWEEN THE SUPPORTER AND THE SP***
» Diversity in sexual orientation. » Freedom of choice and self-determination in terms of sexual orientation.	» Questions and concerns around sexual orientation choice. » Healthy and safety within diverse sexually oriented couples
» 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.	» Conflict with family and friends about sexual orientation » Potential prejudice and stereotyping by society.

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Questions for Service Managers about this topic

Topic	*Questions for SM*	*Smarts Approach*
1) There are different variants of human sexuality, such as heterosexuality, homosexuality, or bisexuality. The awareness that one is homosexual (gay or lesbian), bisexual or other, usually arises in the period of adolescence. The way of discovering it differs from person to person and almost always involves a period of confusion and many doubts, which can be even more marked and difficult in people with disabilities	**How do you support a person with intellectual difficulties who asks for help in identifying their sexual orientation?**	It is important for the service's team to be aware that persons with intellectual disability may have diverse sexual orientations, just like any other person. For this reason, the staff members should not assume the sexual orientation of any service user, nor should they speak or act in ways that would give indications of the sexual orientation of the other person. If a service user asks any of the staff members for help in identifying with a specific sexual orientation, the supporting person should provide information about the diversity in sexual orientation, using plain language and Easy to Read materials. The professional may also provide information about organisations working in this field and ensure the person that there is time to make a decision, based on self-knowledge and own thoughts and feelings. The service manager should support staff members in this process and provide information, materials and, if possible, partnerships to collaborate in this individual reflection.
	How to reorganise the rooms and their occupation considering the different sexual orientations?	If the diversity of sexual orientation within the service creates discomfort between service users, due to prejudice, false beliefs and/or individual bias, the service manager should arrange a meeting with the staff members and with the service users to provide information regarding gender, sexual orientation and sexual health issues; plain language should be used and Easy to Read materials should be provided. With all the information available, the service users should be supported in explaining the sources of any discomfort or unpleasant feelings and make joint decisions, should any reorganisation of the rooms and use of bathrooms be considered relevant.
2) Discrimination and stereotypes associated with sexual orientations other than heterosexuality still mark society's actions and attitudes today. Those who are confronted with this reality, both in their personal and professional lives say	**How do you react when a team member has difficulty accepting different sexual orientations?**	The service manager should provide training opportunities for all the staff members regarding gender and sexual orientation diversity. If, after receiving training and individualised support, a staff member has difficulties in supporting and/or relating to a specific service user, due to his/her sexual orientation, measures should be implemented according to the specific anti-discriminatory legislation of the country.

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prejudice etc still exists. It is therefore important to prepare human resources for these issues that naturally arise in institutional contexts.		No service user should be subject of negative discrimination or prejudice from a staff member for any reason, including sexual orientation.
3) The acceptance of different forms of sexual orientation within families is still a taboo, whether by children or parents. Sex education, even nowadays, is hardly ever carried out within the family. Adolescence is usually a complicated phase, keeping generations away from frank and open dialog, especially those related to sexuality. These difficulties increase when dealing with people with disabilities, so the articulation between the institution and the family caregivers plays a very important role.	**How do you manage a family conflict when one family member does not accept the sexual orientation of the person with a disability?**	If a family member of a supported person does not accept the sexual orientation of his/her relative with disability, the role of the staff and service manager is to support the service user in making an informed decision about his/her sexuality. Informing the service user that a family member may be disappointed and react negatively to his/her option is very important, doing so in a simple and clear way. If and when the supported person feels ready to disclose his/her option of sexual orientation to his/her family, the staff and the service manager may need to support the service user in the communication of his/her decision and in advocating for his/her sexual rights. Additional emotional support may be necessary, if there is a negative reaction from the family's side.
	How do you support the staff and the client when a family member pressures a service user about his sexual orientation and relationships?	The service manager may need to support the service user in exploring and explaining his/her rights to his/her family, having in mind the UN-CRPD and the Sexual and Reproductive Rights. It may be necessary to inform the service user that a family member may be disappointed and react negatively to his/her option. It may be necessary, as well, to support the service user in the communication of his/her decision and in advocating for his/her sexual rights. Additional emotional support may be necessary, if there is a negative reaction from the family's side.

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Annexe 1: The SDM Agreement & supporting documents

SDM AGREEMENT (Example) FORM

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:

	▪ Help me get the information relevant to the decision.
	▪ Help me to understand my options so I can make a decision and/or
	▪ Help me to communicate my decisions to other persons.

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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:

	▪ To identify supporters.
	▪ To help me on how the Agreement works.
	▪ To help me sort out any disagreement with the supporter.
	▪ To the check quality and satisfaction within the arrangements.
	▪ To help me change the Agreement if needed and
	▪ To confirm when the Agreement has ended.

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

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

I consent to act as a supporter. *(signature of supporter)* *(printed name of supporter)*	I consent to act as a facilitator. *(signature of supporter)* *(printed name of supporter)*	Signature *(signature of the person)* *(printed name of the person)*
Jenny Jones	***Ray Rogers***	***Sally Smith***

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

Date: ***20th February***

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SDM Agreement Form (BLANK)

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.

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SDM Agreement Form (BLANK)

Page 2 of 3

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:

	▪ Help me get the information relevant to the decision.
	▪ Help me to understand my options so I can make a decision and/or
	▪ Help me to communicate my decisions to other persons.

- I also appoint the following person as my Facilitator:

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

	▪ To identify supporters.
	▪ To help me on how the Agreement works.
	▪ To help me sort out any disagreement with the supporter.
	▪ To the check quality and satisfaction within the arrangements.
	▪ To help me change the Agreement if needed and
	▪ To confirm when the Agreement has ended.

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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:

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

Name of Supported Person	Name of the Supporter	Name of the Facilitator
Simon	*Chris*	*Erica*

SDM topic(s)	*Health. Simon (the supported person) would like help in deciding how he can lose weight*
Plan of Activities	*We (Simon & Chris) agreed that:* • *we need to find and understand information about what a healthy weight is for Simon's height.* • *Find and understand information about diets and physical exercise as two main ways to lose weight. Think about seeing a person who knows all about food and losing weight (a dietician) for help with how Simon can understand a diet (eg. calories, what is in different foods, things that make you fatter, etc).* *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.*
New Skills involved	*What extra help does Simon need on the computer to be able to search for information through the internet?* *How to monitor and record Simon's weight loss/gain.*

Start date: *10/03/2019*	Predicted End date: *01/05/2019*	Actual end date: *30/05/2019*

How have the activities progressed?	*It has been easy for Simon to understand the dietician and what following a diet means.* *We improved (using tables and pictures) Simon's understanding about what is in different foods and their calorific value. Actually, counting and recording the calories is causing a few problems for Simon.* *Simon likes individual sports (like swimming) and low intensity activities (walking). He has been searching the internet to find a local swimming pool near his house. This required some support to learn how to search such for this. Simon has made a table to record his weight every week, but sometimes he forgets to do this. Simon knows he could choose to visit the dietician regularly if he decided to follow a diet.*

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Form for Individualised Supported Decision Making. Blank Page

Page 1 of 1

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)	

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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

Page 1 of 1

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

Please read the questions carefully and take your time to answer.

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

Today is… ___ /___ /___

1. Can you remember some decision(s) you have taken recently? Please describe up to 3 of them in the box below.

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

😣	🙂	😄	😐
Not really	Some of them	Yes	Don’t know

If not really or if you don’t know,

😣	😐
Not really	Don’t know

Why do you feel this way?

____

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Supported Person Self-Assessment Form

If 🙂 Some of them ones?

Which ones got no support?

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

😣	🙂	😄	😐
Not really good	So so	Good	Don't know

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

😣	🙂	😄	😐
Not really	So so	Yes	Don't know

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Supported Person Self-Assessment Form

Page 2 of 2

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

   What would you like to see change?

   1.
   2.
   3.

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

😣	🙂	😄	😶
Not really	Somehow	Yes	Don’t know

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

😣	🙂	😄	😶
Not really	Sometimes	Yes	Don’t know

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

😣	🙂	😄	😶
Not really good	So so	Good	Don’t know

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

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Supporter Self-Assessment Form

Page 1 of 2

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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