

# Safeguarding and consent in sexual reproductive health services when supporting persons with intellectual and sensory disabilities

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## Acronyms

<b>AAAQ framework</b>	Availability, Accessibility, Acceptability and Quality framework
<b>ARROW</b>	Asian-Pacific Resource and Research Centre for Women
<b>CEDAW</b>	Convention on the Elimination of All Forms of Discrimination against Women
<b>CRC</b>	Convention on the Rights of the Child
<b>CRPD</b>	Convention on the Rights of Persons with Disabilities
<b>FCDO</b>	Foreign, Commonwealth & Development Office
<b>FIGO</b>	International Federation of Gynecology and Obstetrics
<b>GBV</b>	Gender based violence
<b>GDPR</b>	General Data Protection Regulation
<b>HIV</b>	Human Immunodeficiency Viruses
<b>ICCPR</b>	International Covenant on Civil and Political Rights
<b>ICESCR</b>	International Covenant on Economic, Social, and Cultural Rights
<b>IRC</b>	International Rescue Committee
<b>LGBTI</b>	Lesbian, gay, bisexual, transgender and intersex persons
<b>LVCT Health</b>	A Kenyan non-governmental organisation focusing on HIV
<b>OHCHR</b>	Office of the United Nations High Commissioner for Human Rights
<b>OPDs</b>	Organisations of People with Disabilities (sometimes referred to Disabled People's Organisations or DPOs)
<b>PAC</b>	Post Abortion Care
<b>MSI</b>	MSI Reproductive Choices
<b>NHS</b>	National Health Service
<b>SGBV</b>	Sexual and gender based violence
<b>STI</b>	Sexually transmitted infection
<b>SRH</b>	Sexual and Reproductive Health
<b>SRHR</b>	Sexual and Reproductive Health and Rights
<b>UNAIDS</b>	Joint United Nations Programme on HIV and AIDS
<b>UNFPA</b>	United Nations Population Fund
<b>UNICEF</b>	United Nations Children's Fund
<b>WEI</b>	Women Enabled International
<b>WHO</b>	World Health Organisation
<b>WISH</b>	Women's Integrated Sexual Health
<b>WRC</b>	Women's Refugee Commission

# Executive summary

## Introduction:

There are lots of challenges around informed consent and safeguarding for people with disabilities in SRH services. Health service providers can struggle to explain SRH options to clients with intellectual and sensory disabilities. They may not be confident about how to ensure the voluntary and informed consent of their clients. In spite of their efforts, in the end, decisions are often taken by others. Further, SRH service providers may need to support clients who face abuse or coercion from others including care givers and intimate partners, but they may not always have the safeguarding knowledge, skills or confidence to do so effectively.

This guidance aims to help health care workers in SRH services with Informed consent and safeguarding ideas and processes, so that clients with intellectual and sensory disabilities can live their lives with dignity, and are able to exercise choice and freedom in their SRH lives.

## SRH rights of people with disabilities:

In 2006, the United Nations agreed the UN Convention on the Rights of Persons with Disabilities (UN CRPD), a comprehensive and legally binding human rights treaty that promotes the rights and equality of persons with disabilities. Today, the CRPD is one of the most widely ratified human rights treaties in the world. CRPD articles that are particularly important for the SRHR of people with disabilities are:

- Article 6, 9, and 25: The right to accessible health services, including SRH services provided on the basis of informed consent, and equal access to information.
- Article 12: Legal capacity and the right to full autonomy over reproductive health decisions.
- Article 16: Protection from violence and abuse, including gender-based violence and abuse.
- Article 22: The right to privacy.
- Article 23: The right to non-discrimination in all matters relating to “*marriage, family, parenthood, and relationships, including in the areas of family planning, fertility, and family life.*”

SRHR are universal and as such they apply equally to everyone. People with intellectual and sensory disabilities have the same SRHR as everyone, including the right to: bodily integrity, privacy, and personal autonomy; freely define their own sexuality, including sexual orientation and gender identity and expression; decide whether, when, and by what means to have a child or children, and how many children to have; and have access over their lifetimes to the information, resources, services, and support necessary to achieve all the above, free from discrimination, coercion, exploitation, and violence. [Starrs et al \(2018\)](#).

## Principles:

To realise the SRHR of clients with intellectual and sensory disabilities within SRH services, clients must be supported to make decisions for themselves and give (or withhold) informed consent. Additionally, SRH interventions must: Be tailored to the client's circumstances; Apply for the shortest time possible where the will and preference of the client is uncertain; Be less intrusive; Be reviewed and followed up.

## Key terms and their relevance to informed consent:

- **Disability** is a “long-term physical, mental, intellectual or sensory impairment(s) which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. (CRPD, Article 1, 2006)<sup>1</sup>
- **Intellectual disability** is a condition that makes it more challenging to process and understand information, as well as learn new skills (Inclusion Europe, no date)<sup>2</sup>
- **Sensory disability** is a term used to describe one or more impairments of the senses, which include visual impairment, hearing impairment, deaf-blindness (Devon County Council, 2021)<sup>3</sup>
- **Psychosocial disability** is a term used to “describe the experience of people who have intellectual impairments which, in interaction with various societal barriers, may hinder the full realisation of their rights” (Mental Health Europe, 2020)<sup>4</sup>
- **Informed consent** is a process of communication between a service provider and a client that results in the client giving, withdrawing, or refusing to give permission for a procedure or service, based on full knowledge and information.
- **Legal capacity** includes the right to do things and make choices that are respected by law.
- **Supported decision-making** helps to legitimise and dignify the ways that many individuals with disabilities use to seek assistance with decisions.
- **Ascertaining will and preference:** When a client is not able to express a decision even with support, it may be necessary to try to identify any issues the client would take into account and act according to their will and preference. This includes acting in accordance with any religious or moral beliefs they hold – based on views they expressed previously, as well as any insight close relatives or friends can offer.
- **Less restrictive alternatives:** When acting in accordance with a client's will and preference, it is important to choose the ‘less restrictive alternative’ - i.e. the option that will achieve the desired purpose in a way that is less restrictive of the person's rights and freedom of action.
- **Other relevant key terms include:** trauma-informed care, safeguarding, Organisation of Persons with Disabilities (OPD) and SRH(R).

## Terms that are not compliant with CRPD:

- **Substituted decision-making** assumes that a client is not capable of making a decision, and that a guardian should make all decisions on the person's behalf with or without consultation.
- Decisions made in someone's **best interests** may be seen as a form of substituted decision-making.
- Under the CRPD, everyone has ‘legal capacity’, so it is best to avoid talking about people **lacking capacity** to decide.

## Informed consent:

Informed consent is more than the process of acquiring a signature for a procedure. While the process of obtaining informed consent may be time-consuming, it is the service provider's obligation to ensure that the rights of people with disabilities are respected by a **communication process that leads to the provision or withholding of informed consent**. Further:

- **Family members and caregivers play a significant role** in the lives of many persons with disabilities, and are a valuable resource in facilitating understanding and communication. However, decisions should be made by the person with disabilities.
- People with intellectual and sensory disabilities have a right to **supported decision-making** to exercise their legal capacity, and in order to provide informed consent.
- Consent can be **withdrawn at any time**.

## The informed consent process:

The process of informed consent by clients with intellectual and sensory disabilities in SRH services involves the following:

- **Prepare:** If health care workers know they are going to be seeing a client with intellectual or sensory disabilities, they will want to think about challenges that may arise in the consultation, how to prepare for them, and communications needs or accommodations that may be required to facilitate informed consent.
- **Communicate and provide information:** health care workers should aim to provide all possible information, including benefits, risks, duration of an intervention, and alternatives, to a client with a disability in their preferred format and in a way they can understand. Health care workers should use respectful language when talking to clients with disabilities.
- **Ensure privacy and confidentiality:** It may be appropriate to include family members in conversations with clients about sex, or an adult client may prefer to discuss sex without family members or support workers present. Providers are encouraged to respect patient autonomy and consider how to ensure there is as much privacy as possible.
- **Check understanding and determine decision-making support needs:** Assess whether the client can understand the information provided about their care and treatment, and the implications of their decisions. Determine what support the client needs to make a decision.



- **Facilitate supported decision-making:** It can be helpful to do what you can to ensure enough time for discussion and making decisions when and where possible, and provide communication support (devices, interpreters, information in different formats). Facilitation also involves ensuring the client has **support from trusted people** to help them make their decision, if needed. If a health care worker feels that the client is **experiencing coercion** (either from their caregiver or within another relationship), they should talk to a service manager as soon as possible about how to proceed. It is also important for healthcare providers to know where to **refer** clients with disabilities, including to OPDs.
- **Act in accordance with the client's will and preference:** When clients are unable to provide informed consent even with decision-making support, health care workers can: Talk to a supervisor as soon as possible to determine the best way to proceed; Find out if the client has expressed relevant views in the past; Ask close relatives or friends for their insights into what the client would want; Try to identify things the client would take into account if they were making the decision themselves, including their will and preference, and any religious or moral beliefs they hold; Favour 'less restrictive' options.
- **Document the process:** Once the information has been conveyed in an accessible way, and the client has made a decision with the appropriate support, the client can give their voluntary informed consent. This can be given in writing, or verbally and recorded.

## Safeguarding:

The resource provides guidance to health care workers to ascertain whether a safeguarding issue is taking place outside the relationship with the service provider and what to do about it. Providers need to understand:

- **Different kinds of abuse people with disabilities may experience, at home, in the community and in health care settings:** including sexual, emotional, physical, reproductive coercion and disability-specific abuse.
- **How to identify concerns:** there are some things to look out for, which may be signs of abuse and neglect of clients with disabilities such as unexplained changes in physical health (e.g., malnutrition), unexplained changes in mental health (e.g., anxiety, depression) and missed appointments.
- **What to do if there is a concern:** If a health care worker has a safeguarding concern, there are two things to do: report it and refer the client for support.
- **Trauma-informed care:** Trauma- and violence-informed care is an approach to healthcare in which care providers understand the impacts that trauma and violence can have on clients' physical, mental and emotional health and well-being. It also acknowledges the importance of supporting and caring for health care workers.





## Recommendations for organisations that run SRH services:

- Commit to promoting the development, roll-out and uptake of **training for service providers** in SRH provision for people with intellectual and sensory disabilities.
- **Develop training materials** including on: the facilitation of discussions about privacy; identifying and acting on safeguarding concerns; education and awareness of clients with intellectual and sensory disabilities and their families regarding SRHR; and specific guidance on people under the age of consent.
- Every SRH service should have a **safeguarding policy, protocols and guidance**, supported by named staff, to ensure healthcare workers know who to report this kind of concern to, and what referral pathways are available for their client.
- **Trial the tools and guides** presented in this report and accompanying e-learning. These are all adaptations of relevant resources developed by different organisations.
- Support health care workers with **self- and collective care, and trauma-informed supervision**.
- SRH services should carry out **targeted activities with OPDs** that focus on intellectual/sensory disabilities, to identify potential clients and offer awareness-raising activities for them (and their caregivers) on the different SRH services that are available. This would enable them to build relationships with potential clients.
- Develop a **set of standards** for disability-inclusive SRH services aligned with the CRPD.
- Use these recommendations as the **basis for an agreed plan and timeline**, so they can monitor and hold themselves accountable for progress.

# 1. Introduction

There is very little available guidance and evidence of what works regarding the informed consent and safeguarding of people with intellectual and sensory disabilities, particularly in low and middle income country settings, leaving SRH service providers without guidance and unsupported when working with clients with disabilities. This is an area that requires investment and focus if people with intellectual and sensory disabilities are to realise their SRHR.

## Why the focus on people with intellectual and sensory disabilities?

People with intellectual and sensory disabilities face specific problems within SRH services when it comes to informed consent and safeguarding. They may face much bigger barriers when it comes to informed consent and exercising their legal capacity, compared to (for example) people with visual or hearing impairments, who experience communication barriers, but don't see their capacity to make decisions for themselves questioned as often as people with intellectual disabilities do. This resource is also relevant for people with mental health conditions and psychosocial disabilities who, due to stigma related to their impairments and conditions they are often deemed incapable of making decisions for themselves.

For definitions of intellectual and sensory disabilities, see the Key Terms section below.

This guidance builds on both a workshop in 2021 with sexual and reproductive health (SRH) service providers within the **Women's Integrated Sexual Health (WISH)** partnership to understand the challenges they face supporting clients with intellectual and sensory disabilities, and a detailed analysis of existing guidance, practices and processes in different settings.<sup>5</sup> It aims to provide initial guidance to address the gap by drawing on and adapting some of the resources identified in the first stages of this consultancy for SRH providers working with clients with intellectual and sensory disabilities. It also serves as a companion piece for an e-learning module for SRH providers on informed consent and safeguarding in service settings.

This guidance should also be seen as a living document. It will be critical for organisations working on the issue of SRH for people with intellectual and sensory disabilities to hold consultations with people with intellectual and sensory disabilities and their representative organisations. This could also include people with psychosocial disabilities. Their feedback and views should be integrated into and inform learning on the practical implications of ensuring informed consent and safeguarding within SRH services.

While this report focuses on informed consent and safeguarding **within the interaction between the healthcare worker and the client**, this is only a small part of the story. Much of the work required to ensure informed consent and safeguarding for all in SRH settings is about creating an enabling environment for people with intellectual and sensory disabilities to be able to realise their SRHR, starting from societal recognition of their right to sexual and reproductive lives. Such an enabling environment would include meaningful involvement of people with disabilities in

policy-making around SRHR and SRH services, adequate resourcing for organisations of people with disabilities (OPDs), comprehensive sexuality education that is accessible and inclusive, with information on SRHR widely available in braille, sign language, easy-read and other accessible formats, supported by legal recognition, budgetary resources, supportive communities, accessible facilities, peer support, trained staff across all sectors, and more. We recognise that this is a huge challenge everywhere.

Yet SRH clinics can and should be safe for clients, even in discriminatory environments. Individual health care workers can play an important role, though they need the support of the wider SRH health system. We recognise, for example, that guidance to have longer appointment times for clients with intellectual and sensory disabilities is not something an individual health care worker can implement, though this is extremely important. Health service design, management and accountability all need to be adapted to support the SRHR of people living with disabilities and any action by health care workers in their relationship with service users will be most successful when it is embedded in service wide changes that are based on the input, perspectives and experiences of people with disabilities and OPDs.

**Important note on young people:** This guide focuses on adults, however, the WISH partners recognise that the SRHR of young people with intellectual and sensory disabilities are not adequately upheld. Much of the information on informed consent and SRHR included in this guidance apply to young people, however the informed consent and safeguarding requirements can be different for people classified as children. With this in mind the authors recommend the development of a guide specific to people under the age of consent.



## 2. Rights

### 2.1 Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities and its Optional Protocol (CRPD)<sup>6</sup> was adopted by the General Assembly of the UN on 13 December 2006. The CRPD follows decades of work to change attitudes and approaches to persons with disabilities, and views persons with disabilities as subjects with 'legal capacity' and rights who, with the right support, are capable of claiming those rights and making decisions for their lives based on their free and informed consent, as well as being active members of society. It clarifies and qualifies how all categories of rights apply to persons with disabilities, identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced. One key implication of the CRPD is that making a substitute decision for someone - even when we believe it is in their 'best interests' - is problematic, could go against their wishes, and is not in accordance with their legal capacity. Instead, they should have the support they need to exercise their legal capacity. Any actions taken should be in accordance with the 'will and preference' of the client.

For countries that have signed the CRPD, it is legally binding, and should underpin any national laws and policies relating to the rights of people with intellectual and sensory disabilities. (A list of countries that have ratified CRPD can be found on the UN Treaty Body Database<sup>7</sup>.)



## 2.2 Sexual and reproductive health and rights

The CRPD contains a number of articles that are particularly important for the SRHR of persons with disabilities. See box below.

### Some important articles of CRPD that relate to sexuality and SRHR:

- **Article 6:** Recognises that women and girls with disabilities are treated unfairly in lots of different ways and requires countries to make sure that women and girls with disabilities have full, free and equal lives. General Comment 3 (2016) specifically recognises the intersectional and multiple barriers faced by women and girls with disabilities with respect to equal access to education, access to economic opportunities, access to social interaction, access to justice and equal recognition before the law, the ability to participate politically, and the ability to exercise control over their own lives across a range of contexts (for example: with regard to healthcare, including sexual and reproductive health, and decisions about where and with whom they wish to live).
- **Article 9:** Calls for accessibility to be ensured, including access to medical facilities and information.
- **Article 12:** Addresses the right to equality before the law and the issue of legal capacity, which is the law's recognition of the decisions a person makes. It lies at the heart of a human rights based approach to disability and underpins the exercise of many other rights.
- **Article 16:** Requires states parties to take measures to protect persons with disabilities from violence and abuse, including gender-based violence and abuse.
- **Article 22:** Asserts the equal rights of persons with disabilities to privacy, including privacy of personal health information.
- **Article 23:** Requires countries to eliminate discrimination against persons with disabilities in all matters relating to "marriage, family, parenthood, and relationships, including in the areas of family planning, fertility, and family life". Importantly, it recognises the rights of persons with disabilities to decide freely on the number and spacing of children, have access to age-appropriate reproductive and family planning information and the means necessary to enforce this. Therefore, it safeguards against forced abortion and contraceptives. It also protects the right to retain fertility, and is an important check against forced sterilisation.
- **Article 25:** Requires that countries ensure equal access to health services for persons with disabilities, with specific mention of SRH and population-based public health programmes. Health care must be provided on the basis of free informed consent. It also mandates that the same range, quality and standard of free or affordable health care and programmes must be provided to persons with disabilities as provided to other persons, including in the area of sexual and reproductive health.
- **Article 32:** Requires that international cooperation is inclusive of and accessible to persons with disabilities.

(Adapted from [The Convention on the Rights of Persons with Disabilities and its Optional Protocol \(CRPD\)](#) and [ARROW \(2021\) Reclaiming SRHR of Women and Girls with Disabilities](#)<sup>8</sup>)

The SRHR outlined in the CRPD are in addition to the **universal rights that apply to everyone, including sexual and reproductive health and rights**. [WEI and UNFPA \(2018\) Guidelines for providing Rights-Based and Gender-Responsive Services to Address Gender-Based Violence and Sexual and Reproductive Health and Rights for Women and Young Persons with Disabilities](#)<sup>9</sup>, provides a list of all human rights frameworks relevant to SRHR (page: 95). For example, the right to life and health, including sexual and reproductive health, is protected in the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social, and Cultural Rights (ICESCR), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), and the Convention on the Rights of the Child (CRC).

The **Guttmacher-Lancet Commission's definition of comprehensive SRHR** ([Starrs et al, 2018](#)<sup>10</sup>) recognises that the achievement of sexual and reproductive health relies on the realisation of sexual and reproductive rights, which are based on the human rights of all individuals that are enshrined in various frameworks that countries have signed up to. Under this definition, every person has the right to:

- have their bodily integrity, privacy, and personal autonomy respected;
- freely define their own sexuality, including sexual orientation and gender identity and expression;
- decide whether and when to be sexually active;
- choose their sexual partners;
- have safe and pleasurable sexual experiences;
- decide whether, when, and whom to marry;
- decide whether, when, and by what means to have a child or children, and how many children to have;
- have access over their lifetimes to the information, resources, services, and support necessary to achieve all the above, free from discrimination, coercion, exploitation, and violence.

## SRHR for all

SRHR rights are universal - they apply equally to everyone. This includes: **women and girls, lesbian, gay, bisexual, transgender and intersex persons (LGBTI) persons with disabilities, poor women, migrants, indigenous or other ethnic minorities, adolescents, LGBTI persons, and people living with HIV, trafficked and sexually exploited women, girls and boys, and women and girls living in conflict situations** who are disproportionately exposed to the high risk of violations of their rights, including through systematic rape, sexual slavery, forced pregnancy and forced sterilisation, among others. Measures to guarantee non-discrimination and substantive equality should be cognisant of and seek to overcome the often exacerbated impact that intersectional discrimination has on the realisation of the right to sexual and reproductive health.

Source: [Committee on Economic, Social and Cultural Rights \(2016\) General Comment No. 22 \(2016\) on the Right to sexual and reproductive health \(article 12 of the International Covenant on Economic, Social and Cultural Rights\)](#)<sup>11</sup> (highlights ours).

## 2.3 The essential package of sexual and reproductive health interventions

The Guttmacher-Lancet Commission has defined an ‘Essential package of sexual and reproductive health interventions’ ([Starrs et al, 2018](#))<sup>12</sup>:

- Comprehensive sexuality education
- Counseling and services for a range of modern contraceptives, with a defined minimum number and types of methods
- Antenatal, childbirth and postnatal care, including emergency obstetric and newborn care
- Safe abortion services and treatment of complications of unsafe abortion
- Prevention and treatment of HIV and other sexually transmitted infections
- Prevention, detection, immediate services and referrals for cases of sexual and gender-based violence
- Prevention, detection and management of reproductive cancers, especially cervical cancer
- Information, counseling and services for subfertility and infertility
- Information, counseling and services for sexual health and well-being

In addition to the essential interventions listed above, this guidance considers four further interventions:

- Menstrual management
- Menopause support
- Voluntary sterilisation
- Breast cancer screening

This essential package of sexual and reproductive health interventions enables health services to facilitate access to sexual and reproductive health and rights.

Involuntary sterilisation is an issue of particular concern for people with intellectual and sensory disabilities. In 2014, [the World Health Organisation \(WHO\), along with OHCHR, UNAIDS, UNDP, UNFPA, UNICEF and UN Women, issued a statement on ‘Eliminating forced, coercive and otherwise involuntary sterilisation’](#).<sup>13</sup> It reaffirms that sterilisation as a method of contraception and family planning should be available, accessible to all, of good quality and free from discrimination, coercion and violence. The statement specifically addresses the forced, coercive and otherwise involuntary sterilisation of people with disabilities.

## 3. Key terms

Key terms in this guidance include:

**Disability:** CRPD defines disability as “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. (CRPD, Article 1, 2006)<sup>14</sup>

**Intellectual disability:** Intellectual disability is a condition that makes it more challenging to process and understand information, as well as learn new skills (Inclusion Europe, no date)<sup>15</sup>

**Sensory disability:** this is a term used to describe one or more impairments of the senses, which include visual impairment, hearing impairment, deaf-blindness (Devon County Council, 2021)<sup>16</sup>

**Psychosocial disability:** This is a term used to “describe the experience of people who have intellectual impairments which, in interaction with various societal barriers, may hinder the full realisation of their rights” (Mental Health Europe, 2020)<sup>17</sup>

**Organisation of Persons with Disabilities (OPD):** An organisation of persons with disabilities, or OPD (also referred to as a disabled persons’ organisation, or DPO), is a representative organisation or group of persons with disabilities, where persons with disabilities constitute a majority of the overall staff, board, and volunteers in all levels of the organisation. It includes organisations of relatives of persons with disabilities, where a primary aim of these organisations is empowerment and the growth of self-advocacy of persons with disabilities (Disability Rights Fund, undated).

There are many terms associated with the implementation of CRPD that are challenging to understand and even more challenging to put into practice. Academics and scholars of disability rights are still grappling with these concepts, and for healthcare workers they can be the source of confusion and practical challenges. This difficulty should be acknowledged. However it is important to understand the provisions of CRPD, and to reinforce efforts to realise the SRHR of people with disabilities by working out what they mean in each interaction between SRH providers and clients with intellectual and sensory disabilities. In later sections, this paper explores the challenges and provides practical examples of guidance.

**Informed consent:** Informed consent is “a consent obtained freely, without threats or improper inducements, after appropriate disclosure to the patient of adequate and understandable information in a form and language understood by the patient on:

- (a) (the diagnostic assessment;
- (b) the purpose, method, likely duration and expected benefit of the proposed treatment or service intervention;
- (c) alternative modes of treatment or service intervention, including those less intrusive, and
- (d) possible pain or discomfort, risks and side effects of the proposed treatment or service intervention.”



Informed consent involves a process of communication between a service provider and a service recipient that results in the client giving, withdrawing, or refusing to give permission for a procedure, treatment or service based on full knowledge of the procedure, treatment or service ([FIGO, 2021](#)).

**Legal capacity:** The new concept of legal capacity was created by CRPD. Legal capacity includes the right to do things and make choices that are respected by law. Everyone has legal capacity, and people require different levels of support to exercise this. CRPD Article 12(3) recognises state obligations to ensure “access by persons with disabilities to the support they may require in exercising their legal capacity” ([CRPD, 2006](#)). Health services need to ensure access by people with disabilities to the support they may require in exercising their legal capacity.

Some systems differentiate between legal capacity and mental capacity. However, the Committee on the Rights of Persons with Disabilities affirmed that the concept of mental capacity is very controversial, being “contingent on social and political contexts, as are the disciplines, professions and practices which play a dominant role in assessing mental capacity” ([Committee on the Rights of Persons with Disabilities 2014](#)). Furthermore, “Research indicates that the decision-making capacity of adults with intellectual and developmental disabilities depends on factors beyond their intellectual and adaptive functioning—factors such as the extent of their previous experience with health care decisions, the degree and quality of interaction between health care professionals and the patient, and the methods of communication used” ([Sullivan and Heng, 2018](#)) In this guidance, the focus will remain firmly on the idea that all adults have legal capacity.

**Supported decision making:** Supported decision-making is an approach to decision making that involves providing a person with impaired capacity the support they need to make their own decision. It helps to legitimise and dignify the ways that many people with disabilities use to seek assistance with decisions. It can help to improve the understanding of family members and others to embrace the roles of supporters and enablers of decision-making, rather than to act as gatekeepers. This represents an important change to traditional mechanisms of restricting legal capacity (for example through substitute decision-making and determining the ‘best interests’ of the person with disabilities, see below), and is meant to enable individuals with disabilities to secure the assistance they may want in making their decisions ([Smith and Ashley Stein, 2021](#)).

**Ascertaining will and preference:** When a client is not able to express a decision even with support, it may be necessary to try to identify any issues the client would take into account and act accordingly. This includes acting in accordance with any religious or moral beliefs they hold – based on views the person expressed previously, as well as any insight close relatives or friends can offer. This is referred to as acting in accordance with the client’s will and preference. Under the CRPD, this is a better option than acting in someone’s best interests, as it upholds their legal capacity.

**Less restrictive alternative:** If acting in accordance with a client's will and preference, it is important to choose the 'less restrictive alternative' - ie the option that will achieve the desired purpose in a way that is less restrictive of the person's rights and freedom of action. For example, if the decision is around avoiding pregnancy, a contraceptive implant would be a less restrictive option than sterilisation, but still achieve the purpose of the decision.

### **Terms that are not compliant with CRPD and that should be avoided:**<sup>18</sup>

- **Substituted decision-making** assumes that a client is not capable of making a decision, and a guardian should make all decisions on the person's behalf with or without consultation. This is not compliant with the CRPD.
- Decisions made in someone's **best interests** may be seen as a form of substituted decision-making - as explained above, it is better to ascertain the person's 'will and preference' and act in accordance with it.
- Under the CRPD, everyone has 'legal capacity', so it is best to avoid talking about people **lacking capacity** to decide.

**Safeguarding:** There are three key aspects to safeguarding in SRH services:

- **Ensuring services do no harm to clients:** Organisations and institutions have a duty to make sure their staff, operations, and programmes do no harm to children and adults nor expose them to harm, abuse or exploitation. This includes inadvertently doing harm by providing inappropriate services and advice. The informed consent process ensures that clients with intellectual and sensory disabilities are not exposed to harm in their use of SRH services.
- **Safeguarding clients who are facing harm in relations with others** (such as community members, family members, caregivers and others). In this case, SRH providers need to ascertain whether a safeguarding issue is taking place outside the relationship with the service provider (e.g. coercion, abuse or violence<sup>18</sup> by a caregiver, sexual or intimate partner, community member, etc), and know what to do if so. A safeguarding issue can undermine the ability of a person to give informed consent to the service being sought. This aspect is the focus of section 7 on safeguarding.
- **Protecting staff from harm:** It is important to safeguard everyone in our organisations and institutions at all times, including protecting staff from harm and inappropriate behaviour such as bullying and harassment ([Bond website](#)<sup>19</sup>).

**Trauma-informed care**<sup>20</sup>: There is growing awareness that people with intellectual and developmental disabilities are disproportionately impacted by trauma ([Rich et al, 2020](#)<sup>21</sup>). A trauma-informed approach to service provision is based on the four "Rs": **realise** the widespread impact of trauma and understand paths for recovery; **recognise** the signs and symptoms of trauma in patients, families, and staff; **respond** by integrating knowledge about trauma into policies, procedures, and practice; actively **resist** retraumatisation. Six key principles of a trauma-informed approach are: safety; trustworthiness and transparency; peer support; collaboration and mutuality; empowerment, voice, and choice; cultural, historical, and gender issues ([Trauma Informed Care Implementation Resource Centre website](#)<sup>22</sup>).

## 4. Principles

Key principles underpinning the right to health, and accordingly, the right to sexual and reproductive health, include confidentiality, privacy, safety, and the obligation that health-related information, goods, and services be Available; Accessible; Acceptable; and of good Quality, collectively known as the AAAQ framework. The AAAQ framework describes the requirements for services that states must fulfill to respect, protect, and fulfill SRHR (UNFPA and Women Enabled International (WEI), 2018).<sup>23</sup>

To realise the SRHR of clients with intellectual and sensory disabilities within SRH services and support their informed consent, the following principles are key:

- Clients must be able to make decisions for themselves about their sexuality and reproduction (with any supports necessary to make those decisions).
- Information, goods, and services must be accessible and available, sensitive to needs, provided on the basis of non-discrimination, and with reasonable accommodations.
- SRH services must ensure safeguarding of clients.
- Health care workers must be trained and supported to provide services that are based on dignity and that respect the autonomy of clients.
- SRH interventions must:
  - Be tailored to the client's circumstances;
  - Apply for the shortest time possible, where the will and preference of the client is uncertain - this means not intervening with permanent measures where temporary ones are possible and effective;
  - Be less intrusive, and;
  - Be reviewed and followed up.

(Women Enabled International, 2021<sup>24</sup>; CRPD Article 12(4)<sup>25</sup>)

**Provision of accessible SRHR services in Colombia by Profamilia** - Profamilia has a (brief) comprehensive care model so that people with disabilities can access sexual and reproductive health services in an informed and free manner.

- The care model establishes as guiding principles accessibility, dignity, privacy, confidentiality and respect for the desires and sexual and reproductive rights of people with disabilities.
- Profamilia provides the supports and reasonable adjustments required by people with disabilities to make informed decisions about their sexual and reproductive health.
- Profamilia has a detection and care route for victims of sexual violence, which provides medical and psychosocial support in these situations.
- Profamilia provides support and information to families of people with disabilities on issues of sexuality, sexual rights and reproductive rights.

[Profamilia website](#) (in Spanish)

# 5. Informed consent

## 5.1 Key considerations for informed consent

CRPD recognises the right of people with disabilities to informed consent to health care.

- **Article 12:** Addresses the right to equality before the law and the issue of legal capacity, which is the law's recognition of the decisions a person makes. It lies at the heart of a human rights based approach to disability and underpins the exercise of many other rights.
- **Article 25:** Requires that countries ensure equal access to health services for persons with disabilities, with specific mention of SRH and population-based public health programmes. Health care must be provided on the basis of free informed consent. It also mandates that the same range, quality and standard of free or affordable health care and programmes must be provided to persons with disabilities as provided to other persons, including in the area of sexual and reproductive health.

Informed consent is more than the process of acquiring a signature for a procedure. While the process of obtaining informed consent may be time-consuming, particularly when there are communication difficulties, this does not absolve a service provider of their obligation to obtain informed consent. **It is the service provider's obligation to ensure that the rights of people with disabilities are respected by a communication process that leads to the provision or withholding of informed consent.** It is also important to remember that consent can also be withdrawn at any time. ([UNFPA and WEI, 2018](#))

**A fundamental part of informed consent is decision-making.** Under CRPD, all adults have legal capacity to make their own decisions unless demonstrated otherwise. This applies to people with all types of disability, including those with intellectual disabilities. Some people might require supported decision-making to exercise their legal capacity, and in order to provide informed consent. Adequate support mechanisms should be put in place before the client reaches the service delivery point.

It is important to note that decisions should be made by the person with disabilities. While family members and caregivers play a significant role in the lives of many persons with disabilities and are a valuable resource in facilitating understanding and communication, they can be the first ones not to believe in or respect legal capacity - particularly in the many countries which don't have a strong legal framework supporting legal capacity for people with disabilities and supported decision making. As such they can end up being gatekeepers and abusers themselves. To ensure people with disabilities are able to exercise their legal capacity, it is important to sensitise families and caregivers on legal capacity and the role they should play. Health care providers can provide relevant information and awareness-raising to families of people with disabilities on issues of sexuality, sexual rights and reproductive rights of people with disabilities in order to help caregivers in supporting the decision-making of the client.

When it comes to people who are unable to make decisions (and how such assessments can be made), there are some tensions around how to provide support. The language used around this is important: it must not be implied that people do not have legal capacity. This makes using terms such as 'decision-making capacity' or 'capacity to consent' sensitive.

## 5.2 The informed consent process

Many aspects of SRH care are not about providing treatment for disease, or alleviating pain or sickness. Providing contraception, fertility advice, sterilisation, screening for cervical cancer etc are somewhat different processes in terms of informed consent.

This section outlines the process of informed consent by clients with intellectual and sensory disabilities in SRH services, which for the health care provider involves the following elements:

- **Prepare**
- **Communicate and provide information**
- **Ensure privacy and confidentiality**
- **Check understanding and determine decision-making support needs**
- **Facilitate supported decision-making by the client**
- **Act in accordance with the client's will and preference**
- **Confirm and document the decision and informed consent.**

(Adapted from [UNFPA and WIE, 2018<sup>26</sup>](#); Tool 9 of the [Women's Refugee Commission and International Rescue Committee 2020<sup>27</sup>](#); [NHS England, 2019<sup>28</sup>](#)).

Considerations for the health care provider are given below for each element of the process.

### 5.2.1 Prepare

For SRH providers to be able to best support the voluntary informed consent of people with disabilities, preparation is important. Service providers should complete available training modules before the appointment, review available support materials, and potentially consult and take advice from relevant organisations such as local OPDs. The first time a client attends a service, the provider should make a note of any reasonable accommodation requirements for subsequent visits. Preparation may be needed that is related to the way the facility is set up (for example, accessibility, equipment, longer appointment times), which is outside the scope of this report. There is preparation that the provider can do to make the appointment run smoothly, provide relevant information, and communicate in the best way possible to support the service user's SRHR.

“Some adults with intellectual and developmental disabilities have had little experience in making their own decisions. They might live in a structured, protective environment in which others make decisions for them without their involvement. Learned helplessness, acquiescence, and suggestibility can predispose a patient with intellectual and developmental disabilities to be compliant with requests from caregivers and health care professionals regarding decisions that do not necessarily promote the patient's goals or values.” ([Sullivan and Heng, 2018<sup>29</sup>](#))

It is important to strive to get to know the client and caregivers, and build good relationships based on effective communication and trust. The client's ability to participate in health care decision making can increase as they gain confidence and skills, and receive appropriate accommodations and support to do so. Some clients with intellectual and sensory disabilities might have limited support for decision-making or might experience neglectful, abusive, or overprotective relationships. In these situations, the health provider should become an advocate and engage other more suitable supports for the client (Sullivan and Heng, 2018<sup>30</sup>).

## Preparing to see a client with disabilities

If you know you are going to be seeing a client with intellectual or sensory disabilities, you will want to think about challenges that may arise in the consultation, and do what you can to prepare for them.

These points can help you prepare in advance and also provide a guide during a consultation:

### Providing relevant information

- Does the person have all the relevant information they need to make a particular decision?
- If different options are available, have they been given information on all the alternatives?

### Communicating in an appropriate way

- Could information be explained or presented in a way that is easier for the person to understand (for example, by using simple language or visual aids)?
- Have different methods of communication been explored if required, including non-verbal communication?
- Could anyone else help with communication (for example, a family member, support worker, sign language interpreter, speech and language therapist or advocate)?

### Making the person feel at ease

- Are there particular times of day when the person's understanding is better?
- Are there particular locations where they may feel more at ease?
- Could the decision be put off to see whether the person can make the decision at a later time when circumstances are right for them?
- Can anyone else help or support the person to make choices or express a view?

Source: UK Government Department for Constitutional Affairs Mental Capacity Act 2005: Code of Practice<sup>31</sup>

During or after the consultation, document any communications needs or reasonable accommodations required in their notes, to facilitate future visits.

Note: You may not have all the resources you need, and your service may not be set up in the best way for clients with disabilities. This report goes some of the way towards supporting your interaction with your client - but it may be that your service needs to change or new protocols developed to support you in your work.

## 5.2.2 Communicate and provide information

As a starting point, service providers should always talk directly to the individual client, and not their caregivers or family members. Provide all possible information, including benefits, risks, duration of an intervention, and alternatives, to a client with a disability in their preferred format and in a way they can understand. Consent depends on understanding, and understanding can vary according to how we communicate information. In some circumstances, it can be more helpful to seek consent for smaller steps in a longer process, so that clients are in control of every part of a process and can stop it at any time.

MSI and WISH partners have a 20 minute e-learning module on [accessible communications](#) focusing largely on information materials. The resource, *Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings A Toolkit for GBV Practitioners (2020) from the Women's Refugee Commission and International Rescue Committee - [Tool 6: Guidance on Communicating with Persons with Disabilities](#)*<sup>32</sup> has more detail that can support health care workers in their communications with people with different disabilities. While it does not focus specifically on informed consent, it is relevant to supporting accommodations and the informed consent process. An adapted section of this tool is featured in the box below. Annex 5 includes a set of case studies on accessible and inclusive communications on SRHR for people living with disabilities, including accessible communication materials such as:

- booklets in easy read with step by step guidance on key medical procedures
- explanation videos in sign language
- information materials in Braille
- posters and other visual materials positively representing people with disabilities accessing services

Healthcare workers should use respectful language when talking to clients with disabilities, and avoid using terminology that people experience as stigmatising and discriminatory. Always respect the terms people use for themselves. Some people prefer people-first terminology (e.g. 'people with disabilities'), others prefer identity first language (e.g. 'disabled people'). The table below gives guidance on this.



What to avoid	What to use
Using terms for people that they do not use themselves.	<p>Use the terms people use when speaking about themselves, as long as these are respectful. Ask your client what term they would prefer you to use.</p> <p>Be aware that some terms may be accepted when used amongst people with disabilities, but not acceptable when used by someone without a disability.</p> <p>Also be aware that different languages may have different conventions.</p> <p>Some people prefer Identity first language that puts the disability first in the description, e.g., “disabled person” or “autistic person.” Many Deaf people prefer identify-first language.</p> <p>If you do not know how someone refers to themselves, it may be better to use person-first language that emphasises the person before the disability, for example “person who is blind” or “person with disabilities”.</p> <p>Person first or identify first language is equally appropriate depending on the personal preference of the person with disabilities. When in doubt, ask the person which they prefer.</p>
Negative language about disability. For example: “suffers” from polio, “in danger of” becoming blind, “confined to” a wheelchair, “crippled”	Instead use neutral language For example: “has polio” “may become blind” “uses a wheelchair” “has a disability”
Referring to persons without disabilities as “normal” or “healthy”	Try using “people without disabilities”, “non-disabled people”.
Negative language that makes the client feel not seen, embarrassed, shamed and/or traumatised	Respectful language that makes the client feel welcomed, included, respected, listened to, in control and/or like reasonable adjustments have been made

Adapted from: [Tool 6: Guidance on Communicating with Persons with Disabilities](#)<sup>33</sup> from the Women’s Refugee Commission and International Rescue Committee (2020) *Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings A Toolkit for GBV Practitioners*.<sup>34</sup>

See annex 4 of this report for more tips from Tool 6 about supporting decision-making through inclusive communications with people with disabilities.

See annex 2 for examples of accessible information resources for people with disabilities and annex 3 for a collection of resources on SRHR for health care providers.



### 5.2.3 Ensure privacy and confidentiality

Article 22 of the CRPD asserts the equal rights of people with disabilities to privacy, including privacy of personal health information. Guiding principles of SRH service provision should include dignity, privacy, confidentiality and respect for the desires and sexual and reproductive rights of people with disabilities. Yet in relation to privacy and confidentiality for people with disabilities in SRH services, there are significant challenges and very little evidence on what works, indicating a clear evidence gap.

Privacy for people with intellectual and sensory disabilities must be balanced against the importance of the presence of sign language interpreters, caregivers and family members to provide support and facilitate communications. Where possible, using interpreters that are recommended by OPDs and/or who have signed confidentiality agreements is important here.

Furthermore, caregivers and family members may have strong opinions regarding sexuality and their loved one. It may be appropriate to include family members in conversations with clients about sexuality, and conversely, an adult client may prefer to discuss sexuality without family members or support workers present. In this case, providers are encouraged to respect patient autonomy. Service providers should check with the client at the start of an appointment who their trusted support person is. If they are accompanied, it may be appropriate to ask family members to step out of the room in order to ask the client whom they prefer to have present, and bear in mind that clients have the right to make medical decisions for themselves, including decisions about sexuality and sexual health care ([Greenwood and Wilkinson, 2013<sup>35</sup>](#)). In all cases, consider how to ensure there is as much privacy as possible.

#### **Privacy and confidentiality for girls and young women with hearing impairments: an example**

A study in Ibadan, Nigeria with 167 girls aged 11-24 years with hearing impairments found that over a third (37%) of girls were embarrassed to ask questions in the presence of an interpreter. Where there were no interpreters, 75% of participants were seen in the presence of family members. 53% of participants were concerned about the confidentiality of the interactions, and felt excluded from their own healthcare decisions ([Arulogun et al, 2013<sup>36</sup>](#)).

Confidentiality is also a right, including for clients with intellectual and sensory disabilities. The client's confidentiality must be upheld except where passing on their information is absolutely necessary to keep them safe (see safeguarding section 7 below). Some tips on confidentiality are provided below:

- Information about clients should be treated confidentially and respectfully.
- Members of a care team should share confidential information only when it is needed for the safe and effective care of an individual. SRH organisations and facilities should be up to date on the laws and rules surrounding confidentiality and sharing of information for safeguarding.
- If you have to share information ask for consent to do so.
- Keep records whenever confidential information is shared.
- Information that is shared for the good of the community should be anonymised.
- An individual's right to object to the sharing of confidential information about them should be respected.
- Organisations should put policies, procedures, and systems in place to ensure the confidentiality rules are followed.

(Adapted from Rushton 2020<sup>37</sup>).

For clients under the age of consent, there may be additional specific considerations regarding the sharing of information that are not covered in this guidance.

#### **5.2.4 Check understanding and determine decision-making support needs**

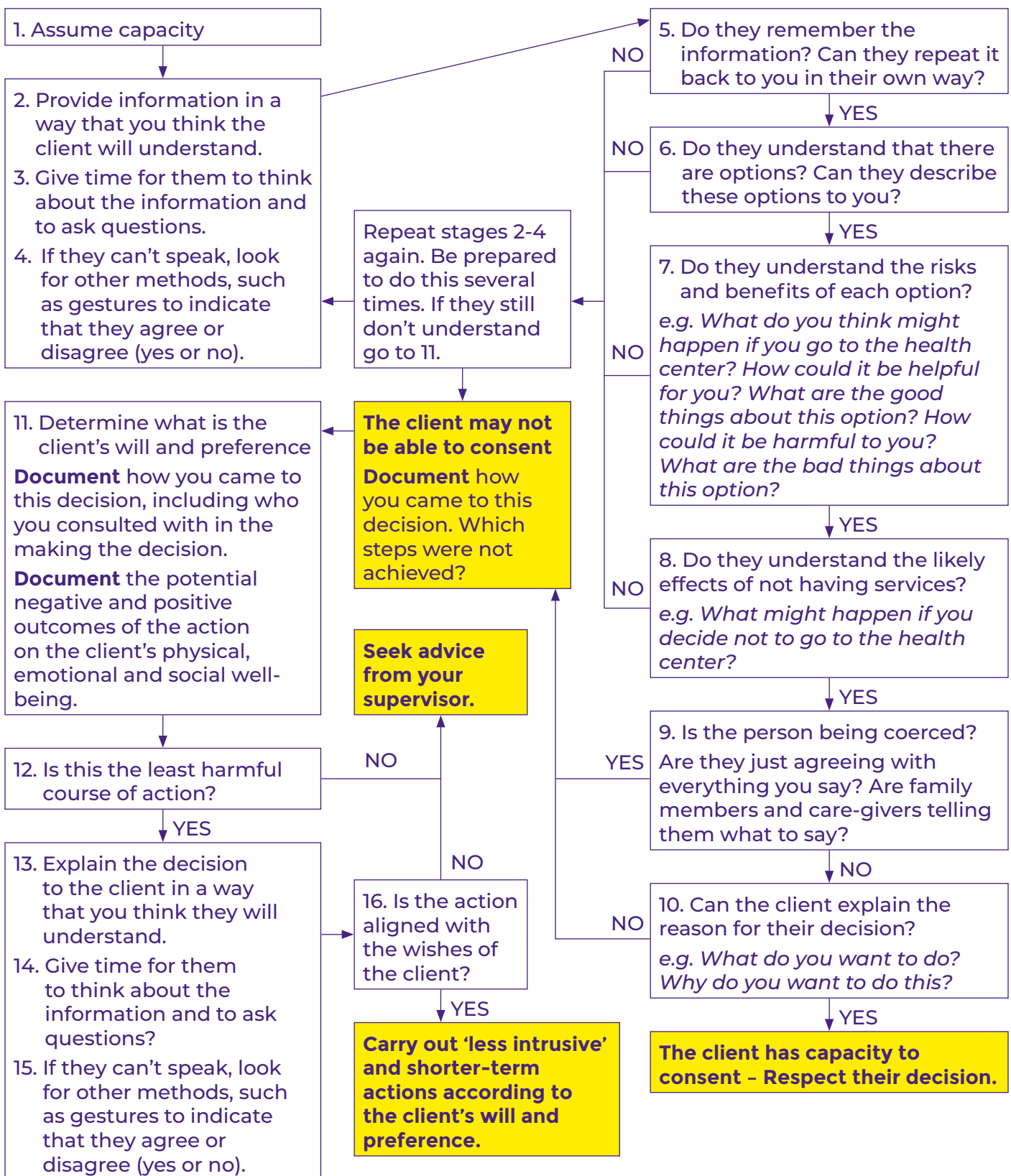
It is important for the client to understand the information provided about their care and treatment, and the implications of their decisions. Under CRPD, assessing the client's understanding **should not be focused on whether the client lacks legal capacity but on what accommodations and support the client needs to contribute to decision making.**

The Women's Refugee Commission and International Rescue Committee have developed a useful tool (Tool 9) providing Guidance for GBV service providers: Informed consent process with adult survivors with disabilities (2020)<sup>38</sup>. It is intended to help service providers navigate informed consent processes with adult survivors with disabilities and includes helpful advice on what to do when a client requires supported decision-making. It is highly relevant to SRH services.

The flowchart (below) featured in the WRC/IRC guidance can help health care providers navigate the informed consent process with a client with a disability, and understand when it may be important to provide decision-making support to enable informed consent, or to ascertain the will and preference of the client and act accordingly. Tips are also provided in the resource that elaborate upon the guidance in the flow chart. (Note that the original flow chart has been adapted here so that it reflects CRPD guidance on legal capacity, and the importance of determining the client's will and preference in cases where they are not able to make a decision themselves. The original flow chart was developed with survivors of GBV in mind - the adaptations also reflect its relevance to clients of SRH services who have intellectual and sensory disabilities.) See the section below on ascertaining will and preference for guidance on how to navigate this.

## Checking understanding and determining decision-making needs

Adapted from Women's Refugee Commission and International Rescue Committee (2020)



Adapted from: Consent and persons with intellectual disabilities: The basics. <http://www.intellectualdisability.info/how-to../consent-and-people-with-intellectual-disabilities-the-basics>

Note about consulting with supervisors: Supervisors will not have all the answers to these ethical issues, but can help to think through any challenges in the light of legal, health policy, and service-level guidance. They can also seek guidance from OPDs and/or national or sub-national government offices providing support for people with intellectual disabilities, or escalate the discussions when higher-level support or action is needed.

There is a useful tool from Surrey Place, [Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities \(2020\)](#)<sup>39</sup>. Designed by a Canadian institution, it provides a step-by-step guide for health providers to information provision, decision-making and informed consent with a client. While this tool is written for cases where informed consent is required for treatment provision (especially in cases of illness), it also provides a useful template for providers in contraceptive services, maternity services, etc, with some amendments to the questions and terminology used. See box below.

## **TOOL TO DETERMINE DECISION-MAKING SUPPORT NEEDS AND TO SEEK CONSENT**

**Adapted from Surrey Place (2020) Decision Making in Health Care of Adults with Intellectual Disabilities: Promoting Capabilities**<sup>40</sup>

*This tool can be adapted for the service you are providing - some suggestions are given, but other adaptations may be necessary, eg for clients seeking contraceptive services etc.*

**INFORM THE CLIENT THAT YOU WANT TO CHECK THEY UNDERSTAND:** E.g., “To help you feel better (or get well again or keep you from getting sick), I would like to give you some treatment. I want to make sure first that you are able to understand the treatment. You can ask to stop at any time. I am going to tell you some things and then ask you some questions. You can ask someone to help you answer if you like.” This question could also be tailored to inform the client that you can help them to avoid getting pregnant, or to explain how childbirth could be managed, etc. Accessible information on SRH issues for health care providers and people with disabilities is provided in annex 2 and 3. The next subsection also outlines key considerations for facilitating supported decision-making.

**TIPS FOR ASSESSING UNDERSTANDING:** Examples of questions are given below for each statement (1-6) in the assessment. Ask the patient to repeat or show you what he or she understands regarding information that you give.

- **IF YOUR ANSWER IS YES TO A STATEMENT** Proceed to the next statement.
- **IF YOUR ANSWER IS NO OR UNSURE TO ANY OF THE STATEMENTS** Ask your client whether he or she wants someone else’s help to hear the information again, or other help, in order to answer your questions. Then with this help, reassess.
- **IF YOU HAVE PROVIDED ALL AVAILABLE ACCOMMODATIONS BUT YOUR ANSWER REMAINS UNSURE** Seek advice or reassessment of the client from your supervisor.

**Discuss the client's health issue:** ASK: Can you tell me or show me what is bothering you? Will you let me try to help you feel better? Or: Can you tell me why it is important for you to keep from getting sick? This question could also be reframed to ask the client about their views on sex, contraception, pregnancy, parenting, whether this is something the client would like or wish to avoid, etc. It could also be reframed to ask a pregnant client about their views on childbirth, and how they would like this to go.

1. *The patient is able to and does understand his or her health issue or service requirement Yes/No/Unsure*

**Discuss the proposed treatment or service:** Describe or show what you and your client would have to do in the proposed treatment or service, eg contraceptive options, or maternity service. ASK: Can you tell me or show me what I am asking you to do?

2. *The client is able to understand and does understand what the proposed treatment or service involves Yes/No/Unsure*

**Discuss the treatment or service benefits for the client:** Discuss immediate or short-term discomforts, likely risks of harm, and long-term needs for additional supports as a result of the treatment or service. For example "What I'm asking you to do can help you feel better (get well) or avoid getting sick or more sick, or avoid getting pregnant, or have a safe conception, pregnancy and birth. But you might also feel....or you might need to....or you might not be able to....until you start to feel (or get) better (or to stay well). You can always ask for more help or ask to stop."

ASK: Can you tell me what will happen with this treatment or service?

ASK: Tell me what you like about this option. Tell me what you don't like about this option.

### **EXPLORE OTHER OPTIONS AS NEEDED**

ASK: Let's talk about another option.

3. *The client is able to and does appreciate the consequences of the treatment or service for his or her life Yes/No/Unsure*

### **DETERMINE IF THE PATIENT IS ABLE TO DECIDE BETWEEN TREATMENT OPTIONS**

ASK: Can you tell me what you want to do? (Or, can you tell me which option you like the most?)

4. *The client is able to decide among treatment or service options eg deciding among different contraceptive options, different forms of giving birth, etc Yes/No/Unsure*

### **IF THE CLIENT REFUSES ALL OPTIONS, DETERMINE IF HE OR SHE IS ABLE TO APPRECIATE THE REASONABLY FORESEEABLE CONSEQUENCES**

ASK: Can you tell me what will happen if we don't do anything?

5. *The client is able to appreciate what could likely happen if he or she refuses all treatment options or services Yes/No/Unsure*

**CONFIRM THAT THE CLIENT'S PREFERRED OPTION OR REFUSAL IS CHOSEN FREELY**

Could there be factors affecting the client's ability to make the decision? Consider factors such as learned helplessness, coercion, need for supports to decrease anxiety, fear or other stressors.

6. *I am free of concerns about factors affecting the client's ability to choose or refuse treatment or a service Yes/No/Unsure*

**Conclusion and seeking consent**

Using the information you gathered in the previous sections, determine whether the client has the understanding needed to give or refuse consent to the proposed treatment. The client must be able to:

1. understand the information that is relevant to this specific decision, AND
2. appreciate the reasonably foreseeable consequences of this specific treatment or service decision or lack of a decision.

The client might be independently capable or interdependently capable with the help of a decision-making supporter.

Decisions regarding any treatment must:

- (a) relate to the treatment/service;
- (b) be informed;
- (c) be given voluntarily;
- (d) not be obtained through misrepresentation or fraud.

7. *Does the client give voluntary informed consent to this specific treatment/ service decision? Yes/No*

Consent or refusal of treatment authorised by: Client (with or without a supporter's help) / Decision-making supporter / Other (say who, and provide justification)

Section 5.2.5 will help to ensure that any decisions made and actions taken are based on providing the support needed. If the client is unable to make a decision and give voluntary, informed consent, Section 5.2.6 will help you to determine the client's will and preference so that you can proceed in accordance with this.

## 5.2.5 Facilitate supported decision-making

The need for support in decision-making can change over time, and also according to the nature and complexity of the decision. Applying supported decision-making with adults with intellectual and sensory disabilities is not always straightforward and can entail adaptations of normal practice and skills, for example:

**Make accommodations:** Accommodating needs can include providing sufficient time for discussion and making decisions, adjusting sensory inputs (lights, sounds), ensuring supports to communicate are in place (devices, translators), scheduling appointments at preferred times of day or across multiple visits, adapting procedures to manage pain or anxiety, allowing the person to bring items or people to enhance comfort and security, offering coaching in decision-making skills or engaging one or more decision-making supporters ([Surrey Place \(2020\)](#)). It also includes the provision of resources specifically designed for people with intellectual and sensory disabilities (see annex 2).

### Scenarios - thinking through these scenarios can help SRH providers understand the practical implications of the informed consent process

Maria has an intellectual disability. She may understand and consent to HIV post-exposure prophylaxis, because she understands the concept of taking medicine as a treatment and has taken medicines before to prevent other illnesses. There may be other things she finds more difficult to understand and therefore would not be able to consent. Consent is an ongoing process and not a one-time event. It is important that we never assume that a client's consent to one service means that she consents to everything.

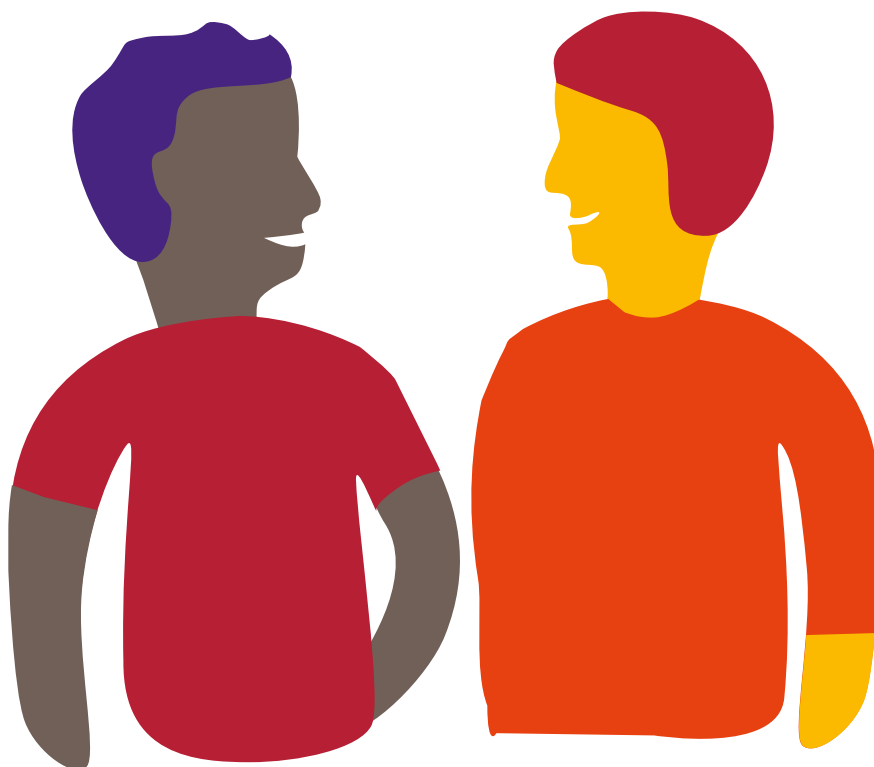
We offer Maria a referral. She may initially decline or accept it. But have we conveyed the information in a way that she can understand it and use it in making her decision? If we discuss her goals, describe what will happen, explore what she likes and doesn't like about this, and support her to visit without having to make any further commitment, then Maria will understand better the possible positive and negative outcomes for her, enabling her to make a more informed decision. Hence, in some circumstances, it can be more helpful to seek consent in small steps, so that clients are in control of every part of a process and can stop it at any time.

Adapted from [Tool 9 of The Women's Refugee Commission and International Rescue Committee, 2020](#)<sup>41</sup>

**Involving caregivers:** Ensure the client has support from trusted people around them to help them make their decision, if needed. Caregivers and family members are very important, and providers should work with them in order to support the person living with disabilities. (See box below which gives more tips on involving caregivers, from [Tool 9 of the Women's Refugee Commission and International Rescue Committee, 2020](#))<sup>42</sup>. However, note that there is little recognition and guidance on their role in existing tools and guidance.

## Involving a carer in the informed consent process

- **It may be necessary in the initial informed consent process to involve another trusted individual who can help facilitate the communication and understanding regarding the services you are offering.** To the extent possible, the decision about whom to involve should be made in partnership with the client. A staff member should never make such a decision on their own. If there is no one accompanying the client, consult your supervisor as to how to proceed. Such a decision must always be reached by analysing the client's will and preferences. Remember that getting the caregiver's consent for services does not mean that you have the client's or the caregiver's consent for any other interventions.
- **Consent for referrals and other services.** If caregivers or others are involved, it is important that you continue to ensure that the client's wishes and needs remain the focus.
- **Consider coercion:** Be sure to observe the client's interactions with the caregiver. If you feel the power dynamic and relationship between the caregiver and the client is affecting the right of the client to participate in decision-making and/or if decisions are not aligned with their wishes and desires, consult your supervisor in order to determine how to proceed. This is not to suggest that supervisors will have all the answers to these ethical issues, but they can help to 1) think through any challenges in the light of legal, health policy, and service-level guidance, 2) seek guidance from OPDs and/or national or sub-national government offices providing support for people with intellectual disabilities, 3) escalate the discussions when higher-level support or action is needed. Remember that the interests of family members and caregivers may not be linked to the will and preference of the client.





**When involving others in the informed consent and decision-making process, remember:**

- **Even people who need significant support can play a role in decision-making and have a right to information.** Share information, listen to their ideas and opinions. Use pictures, hand gestures or symbols to ask if someone is willing to access a service or treatment. Also watch for signs of agitation, anger or distress that may indicate that the client is not happy with something that is being discussed or an activity that is being undertaken.

Source: Tool 9 of the [The Women's Refugee Commission and International Rescue Committee, 2020](#)<sup>43</sup>

**Providing good support for caregivers** is one of the most effective ways to improve the safety and well-being of those they care for. There may be groups locally that provide support for caregivers. Working separately with caregivers (in addition to working with survivors and caregivers together) can serve a psychosocial intervention in and of itself by creating a safe space for caregivers to talk about the issues that affect them, their own emotions – positive and negative – without feeling that they are being demanding or selfish, or that they are not properly heard. It is also important to recognise that feelings about being a caregiver are complex, and it is normal to feel frustration, resentment and anger, along with love and concern. Helping people to develop ways to understand and manage these feelings can be very helpful in strengthening the core relationship between the caregiver and the person being cared for, and developing strategies for ensuring that a caregiver's needs are met.

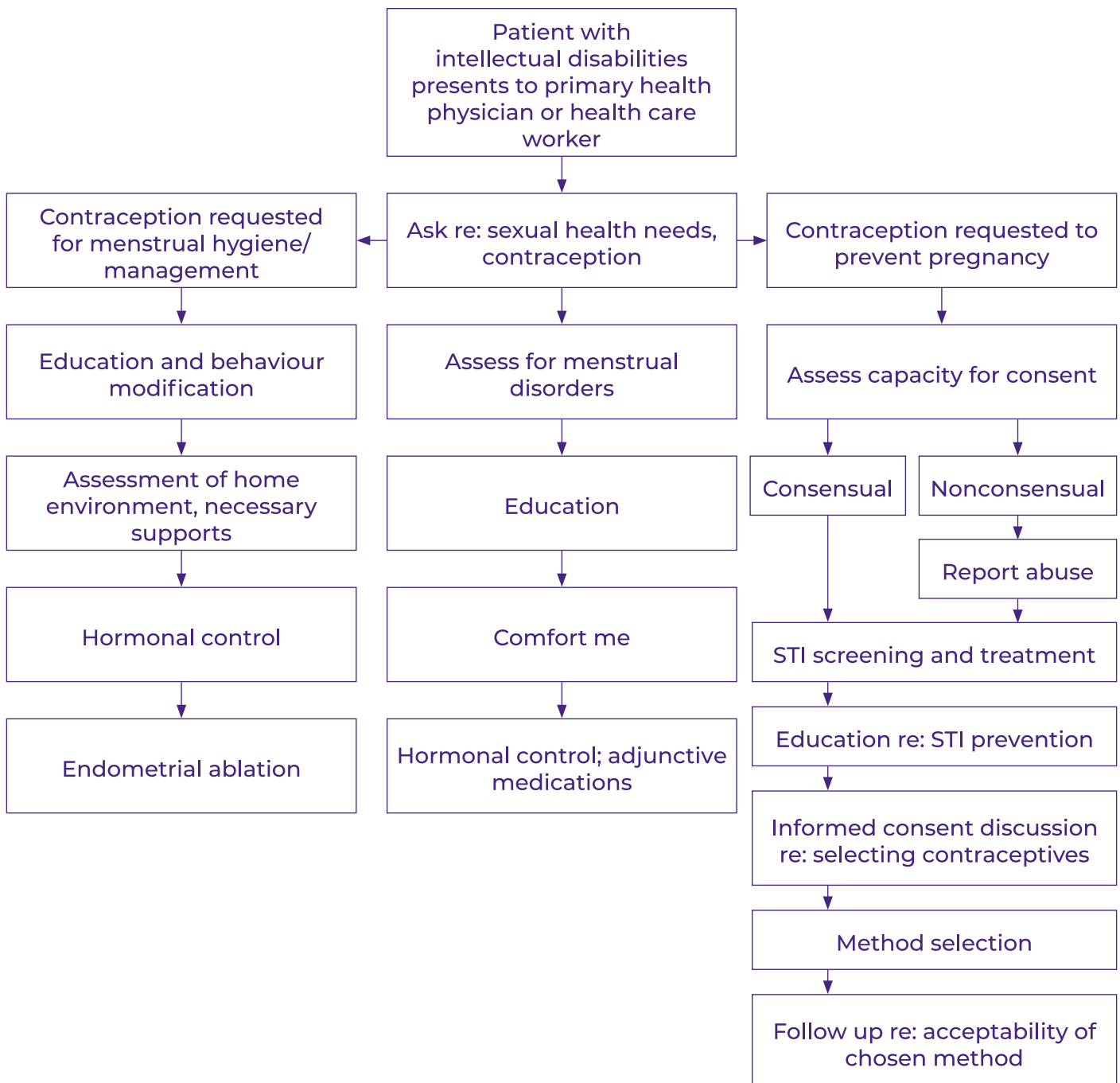
In providing such support to the caregiver, it is important for the health care worker to think about: What is the caregiver looking for from you? What kind of alliance do you want to build with them, and what kinds of boundaries will you need to pay attention to? How realistic/possible are their expectations? What elements of this relationship might be difficult, and what can you build on?

Adapted from: [Tool 10: Working with caregivers of survivors with disabilities](#)<sup>44</sup> – This tool offers guidance on how to approach working with caregivers of survivors with disabilities to ensure all needs are met and positive relationships are strengthened.

**Consider coercion:** The box above discusses coercion around decision-making by a caregiver. If a health care worker feels that the client is experiencing coercion then they need to consult with a service manager about how to proceed.

The client may also be experiencing a coercive relationship that has led to the request for a service or intervention. The section on safeguarding gives more guidance on this.

The tension between protecting adults with intellectual and sensory disabilities from abuse while also respecting their right to consensual sexual expression may at times be difficult for healthcare providers to navigate. A balance needs to be found between protection and empowerment. [Greenwood and Wilkinson \(2013\)](#) developed the following **rights-based framework for providers in addressing contraception needs of clients with disabilities** and making an assessment of whether their contraceptive needs are because of consensual or non-consensual sexual relations:



**Referrals:** Informed consent should be sought for any referrals. It is important for healthcare providers to know where to refer clients with disabilities, including to OPDs, government departments focusing on disability, specialist health services focusing on people with intellectual disabilities, as well as legal services and departments which may provide guidance and support around legal capacity and supported decision making. Connecting clients with OPDs is a key way to ensure they have peer support with understanding and making decisions, which facilitates their informed consent. The WISH partners should have trusted referral pathways in place, although services in those referral pathways may not always be sensitive to the rights of people with disabilities. This makes it crucial to ensure there are links to OPDs. In addition, recognise that OPDs may not have the specialist knowledge and skills regarding the SRHR of people with disabilities and therefore where possible referral pathways to specialist help and services that combine a focus on disability and SRHR should also be developed.

## 5.2.6 Act in accordance with the client's will and preference

Service providers and support staff may encounter clients who are unable to provide informed consent even with the necessary supports. To make this determination, all of the foregoing steps to acquire informed consent should have been exhausted.

The **'will and preferences'** of a client is the guiding principle for all support for or exercise of decision-making under the CRPD, but what this means in practice is poorly understood. Key questions arise in understanding what is 'will' and what are 'preferences', whether they overlap to any degree, and how they express themselves. To ascertain will and preference, is it a case of simply 'reading' a face, or does it need a process of interpretation? And if interpretation is involved, how can it avoid imposing the meaning of the listener rather than the real meaning of the speaker? ([Carney et al, 2019<sup>45</sup>](#))

If the client is not able to make a decision themselves even with support, it is vital to try to identify any issues the client would take into account if they were making the decision themselves, including their will and preference, and any religious or moral beliefs they hold – these would be based on views the person expressed previously, as well as any insight close relatives or friends can offer. Decisions made should favour less restrictive options. In this case, it is important that a healthcare worker consults a supervisor to determine the best way to proceed. A supervisor can help think through the best ways to determine will and preference and any challenges in the light of legal, health policy, and service-level guidance. The guidance above on involving others is also relevant to this section.

### What happens in emergency situations?

Clearly in emergency medical situations (for example, where a person is unconscious), urgent decisions will have to be made and immediate action taken. In these situations, it may not be practical or appropriate to delay the treatment while trying to help the person make their own decisions. However, even in emergency situations, healthcare staff should try to communicate with the person and keep them informed of what is happening ([UK Government Department for Constitutional Affairs Mental Capacity Act 2005: Code of Practice<sup>46</sup>](#)).

Note however that there are instances where service providers sterilise women with disabilities during labour to prevent them from becoming pregnant again. This is absolutely not a medical emergency, and there is no justification for such an intervention without informed consent.

## 5.2.7 Document the process

Once the information has been conveyed in an accessible way (as outlined above), and the client has made a decision with the appropriate support, the client can give their voluntary informed consent. This can be given in writing, or verbally and recorded. Whichever way consent is given, the informed consent process must be documented. Any assistance provided to support decision-making should also be documented. This will also aid the monitoring and review of decisions made.

The adapted version of the Surrey Place tool [Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities](#) (2020) provided in section 5.2.4 is useful for documenting informed consent and the discussions and decisions that underpin it.

Alongside documenting the informed consent process, there are also important considerations around the storage of documentation and information to ensure privacy under data protection and the General Data Protection Regulation (GDPR). It is important to note that informed consent to process sensitive data can be withdrawn at any time. WISH partners have informed consent forms they give to all clients of SRH clinics and in mobile outreach, and partners provide staff training on using these, and have reviews regularly to ensure they meet legal and data requirements.



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## 6. Different SRH issues and the relevance of informed consent

The table below details each element of the SRH essential service package ([Starrs et al, 2018<sup>47</sup>](#)) with the addition of menstruation, menopause, breast cancer and sterilisation. These are vital for meeting public health and human rights standards, and should be provided following the “Availability, Accessibility, Acceptability, and Quality” framework of the right to health.

The table below outlines key issues on informed consent and rights for people with disabilities, and relevant resources providing further information against each element. This table is not designed to provide an exhaustive list of relevant issues on each SRH area for people with disabilities, but to give a flavour of the informed consent and safeguarding issues that might arise. See also annex 2 for accessible SRHR information for people with disabilities and annex 3 for information for healthcare providers on SRHR. These include *practical information* on each SRHR element.

Element of an essential SRH package	Key issues for informed consent	Further resources <sup>48</sup>
<b>Comprehensive sexuality education</b>	While it is not the responsibility of health service providers to provide CSE, providers are encouraged to offer sex education when appropriate or feasible, particularly when it is necessary to enable informed consent about SRH. Confidentiality and privacy may be an issue when caregivers, family members or interpreters are present. It may be appropriate to provide opportunities for private conversation during visits.	<a href="#">ARROW, 2021</a> <a href="#">Greenwood and Wilkinson, 2013</a>
<b>Counselling and services for a range of modern contraceptives, with a defined minimum number and types of methods, including emergency contraception</b>	<p>Bear in mind that consenting or otherwise to using contraception is separate from consenting or otherwise to sexual activity. Contraception should be seen in terms of the needs of the person rather than in terms of relieving the anxieties of caregivers and relatives. Every effort must be made to ensure that the person understands any contraceptive method advised, and the person's wish to inform relatives or not must be respected.</p> <p>All clients, including women with intellectual disabilities, should be asked about their contraceptive and gynecological needs, including any issues with menstrual regularity and pain. See the rights-based framework (section 5.2.5) for use by health care providers in addressing contraception needs of clients with disabilities.</p>	<a href="#">NHS Lothian, 2016;</a> <a href="#">ARROW, 2021; UNFPA/WEI, 2018</a> <a href="#">Greenwood and Wilkinson 2013</a>
<b>Sterilisation</b>	In 2014, the UN issued a statement on ' <a href="#">Eliminating forced, coercive and otherwise involuntary sterilisation</a> '. It reaffirms that sterilisation as a method of contraception and family planning should be available, accessible to all, of good quality and free from discrimination, coercion and violence. The statement specifically addresses the forced, coercive and otherwise involuntary sterilisation of people with disabilities.	<a href="#">NHS Lothian, 2016;</a> <a href="#">The World Health Organization (WHO), along with OHCHR, UNAIDS, UNDP, UNFPA, UNICEF and UN Women, 2014</a>

Element of an essential SRH package	Key issues for informed consent	Further resources <sup>48</sup>
<p><b>Antenatal, childbirth and postnatal care, including emergency obstetric and newborn care</b></p>	<p>Fundamental SRHR services for women and young people with and without disabilities include antenatal care, skilled attendance at delivery, emergency obstetric care, postpartum care, and newborn care. UNFPA and WEI recommend that healthcare workers work with people with disabilities to create and implement a birth plan that accounts for any necessary accommodations for the client. Health care policy embedded in discriminatory practice can lead to non-consented procedures, for example women with disabilities are often told they must give birth by cesarean section, despite the fact that this is not always necessary. Further, women who also have physical disabilities should be offered support with, and information about, alternative birthing positions and support.</p> <p>While clinicians who suspect pregnancy is a result of sexual assault have a moral (and often legal) duty to report, clinicians should carefully assess the desires and preferences of a pregnant woman with intellectual disabilities. Does she herself express a desire to parent? Was her pregnancy planned? Women with intellectual disabilities may choose to terminate a pregnancy, but, to the extent possible, this should be a fully informed and shared decision between the woman, her family, and her physician, with the woman's wishes respected. (Greenwood, N. and Wilkinson, J. (2013)</p>	<p><u><a href="#">UNFPA/WEI, 2018; NHS Lothian, 2016; ARROW, 2021;</a></u></p> <p><u><a href="#">Greenwood and Wilkinson 2013</a></u></p>

Element of an essential SRH package	Key issues for informed consent	Further resources <sup>48</sup>
<p><b>Safe abortion services and treatment of complications of unsafe abortion</b></p>	<p>People with intellectual and sensory disabilities have the right to information, counselling and support to make a reasoned decision about whether to continue the pregnancy or to terminate it (where legally permissible), regardless of the reason for the choice. The wellbeing of the person must always come first and they have the right to choose. If a termination is chosen, it is essential that help is provided to understand all implications and give consent freely. Family or carer demands for a termination must not override the rights and wellbeing of the person concerned. Judgements on the ability of the person to be a parent are not grounds for termination of pregnancy, just as this would not be considered sufficient grounds for anyone else.</p> <p>Post-abortion care (PAC) is always legal, even in countries where abortion is severely restricted or illegal. It is vitally important for many women. In PAC the same procedure is given to women who have miscarried and those who are experiencing the outcomes of an incomplete abortion. (In most cases, a health care provider cannot distinguish between the two.) Life-saving care is given to stop bleeding and prevent infection.</p>	<p><a href="#">NHS Lothian, 2016</a>; <a href="#">ARROW, 2021</a>; <a href="#">UNFPA/WEI, 2018</a>, <a href="#">Frontline AIDS, 2018</a></p> <p><a href="#">MSI, 2020</a></p>

Element of an essential SRH package	Key issues for informed consent	Further resources <sup>48</sup>
<p><b>Prevention and treatment of HIV and other sexually transmitted infections</b></p>	<p>The medical background and matters relating to the sexual health of a person with intellectual and sensory disabilities are strictly confidential. Information about a client’s sexual health should be restricted to essential (need to know) persons only.</p> <p>In terms of HIV, people with disabilities face many of the same challenges that other people living with HIV face, based on social and gender inequality, assumptions and HIV-related stigma, discrimination and violence, including within services. HIV service providers should use effective communication skills to deliver good-quality care to clients with disabilities, treat clients with disabilities with respect and dignity in a culturally appropriate manner, and make every effort to respect and promote the will and preference of people with disabilities and support and engage them and their carers in the most inclusive way. Informed consent processes must be followed at every stage through HIV prevention, testing, treatment and care, and the client’s privacy and confidentiality must be respected.</p>	<p><u>NHS Lothian, 2016;</u>  <u>ARROW, 2021; UNFPA/WEI, 2018;</u>  <u>WHO (2017)</u></p>



Element of an essential SRH package	Key issues for informed consent	Further resources <sup>48</sup>
<p><b>Prevention, detection, immediate services and referrals for cases of sexual and gender-based violence</b></p>	<p>CRPD Article 16 concerns protecting persons with disabilities from violence and abuse, including gender-based violence and abuse.</p> <p>It is important to screen clients with intellectual and sensory disabilities for abuse without assuming that all sexual activity is always abusive.</p> <p>Sexual violence: Adults with intellectual disabilities should be asked if they are sexually active, with a definition of this term provided in accessible language, if necessary. Providers should then attempt to ascertain if sexual activity was/is consensual. (See section 7 below on safeguarding).</p> <p>Screen for sexual exploitation and unintentional risky or harmful sexual practices. When these are present, facilitate deliberation with the client and their caregiver (and service manager) of a range of methods to reduce risks of STIs and HIV, to regulate fertility and refer to other support services.</p> <p>Other types of violence: People with disabilities should also be screened for other types of violence, and safeguarding protocols and referral pathways should be followed. (See section 7 below on safeguarding).</p>	<p><a href="#">ARROW, 2021; UNFPA/WEI, 2018</a></p> <p><a href="#">Greenwood and Wilkinson 2013</a></p> <p><a href="#">Surrey Place, 2022</a></p>

Element of an essential SRH package	Key issues for informed consent	Further resources <sup>48</sup>
<p><b>Prevention, detection and management of reproductive cancers, especially cervical cancer</b></p> <p><b>Breast cancer screening</b></p>	<p>Women and people with a cervix who have intellectual and sensory disabilities have the same right to pap smears as anyone else, and the same right to decide whether to have one or not. Health care workers should convey the need for a smear in order for the client to make an informed decision.</p> <p>For both pap smears and pelvic examinations, consideration should be given to alternative positions. A useful resource on this is the Women’s Wellness Project (2016). Additionally, there is some evidence to suggest that obtaining a pap specimen using a “blind” technique and liquid cytology may be less traumatic for clients than a conventional speculum exam.</p> <p>Breast cancer screening, through both self-examination and mammogram, is as important for women with intellectual and sensory disabilities as other women. Easy-read and picture guides are available and can help health workers explain the process to clients.</p>	<p>Cervical cancer screening and pelvic examinations: <a href="#">ARROW, 2021</a>; <a href="#">UNFPA/WEI, 2018</a>; <a href="#">Women’s Wellness Project, 2016</a></p> <p><a href="#">Greenwood and Wilkinson 2013</a></p> <p>Breast cancer: <a href="#">Hesperian, 2007</a>; <a href="#">Centres for Disease Control and Prevention, current website</a>;</p> <p><a href="#">Public Health England, 2018</a> (note all the images are of white women)</p>
<p><b>Information, counselling and services for subfertility and infertility</b></p>	<p>CRPD Article 23 requires countries to eliminate discrimination against persons with disabilities in all matters relating to “marriage, family, parenthood, and relationships, including in the areas of family planning, fertility, and family life”. The focus of literature is largely on the right to control one’s own fertility rather than the right to have help with subfertility and infertility concerns. However, UNFPA and WEI (2018) state that fundamental SRH services for women and young persons—with and without disabilities— include treatment for sexual and reproductive health issues (e.g. infertility).</p>	<p><a href="#">ARROW, 2021</a>; <a href="#">UNFPA/WEI, 2018</a></p>

Element of an essential SRH package	Key issues for informed consent	Further resources <sup>48</sup>
<p><b>Information, counselling and services for sexual health and well-being</b></p>	<p>Health care providers should familiarise themselves with the barriers to care facing adults with intellectual and sensory disabilities and sensitively broach the topic of sexual health with all clients, including those with intellectual and sensory disabilities.</p> <p>Where appropriate and safe, give clients, their family, or other caregivers the opportunity to talk about the client’s relationships, intimacy and sexuality (eg, sexual behaviour, gender identity, sexual orientation, genetic risks) in order to provide appropriate support and care. Provide or refer for education and counselling services that are adapted to the needs of people with intellectual and sensory disabilities.</p>	<p><a href="#">ARROW, 2021; UNFPA/WEI, 2018</a></p> <p><a href="#">Greenwood and Wilkinson 2013</a></p> <p><a href="#">Surrey Place, 2022</a></p>
<p><b>Menstruation</b></p>	<p>Discuss menstrual hygiene with women and girls with disabilities and their caregivers. If menstrual regulation is requested, the client should be supported to decide on a method, considering safety and effectiveness, the client’s health circumstances, and the client’s and caregiver’s views on the benefits and burdens to the client.</p> <p>Menstrual suppression for teens and adults with disabilities who need significant help with menstrual hygiene is sometimes recommended by health care providers. Menstrual suppression can have psychosocial and hygienic benefits, but also physical risks including potentially life-threatening complications. Distinguish caregiver convenience from client benefit, respecting the desires of client and ensuring informed consent.</p> <p>ARROW (2021) includes case studies on ‘menstrual myth busting’.</p>	<p><a href="#">ARROW, 2021; UNFPA/WEI, 2018</a></p> <p><a href="#">Surrey Place, 2022</a></p> <p><a href="#">Acharya &amp; Lantos, 2016</a></p>

Element of an essential SRH package	Key issues for informed consent	Further resources <sup>48</sup>
<b>Menopause</b>	<p>The menopause can be a time in women’s lives when they experience a range of uncomfortable and sometimes debilitating symptoms and they may need help and treatment with these. Ask perimenopausal women with disabilities about menopausal symptoms, and provide support as needed. This needs to be subject to the same informed consent process as other SRH concerns.</p>	<p><a href="#">ARROW, 2021</a>  <a href="#">Surrey Place, 2022</a></p>

## Key studies on clients with intellectual disabilities, contraception, and the informed consent processes.

- **Contraceptive choices for women with learning disabilities (Walmsley et al, 2016) UK<sup>49</sup>** – The majority of women interviewed for this paper knew too little about contraception to make an informed choice. Information was hard to come by, and parents, staff and GPs appeared as major influences. Despite known side effects of long term contraceptive use, basic health checks were rarely reported. In some cases women reported having been forced to use contraception and this had had a lasting impact on them. However, some women were able to make independent choices about sex and contraception. The researchers made a number of recommendations for policy and practice, including:
  - recognising by service providers that some women would prefer to speak to a female doctor or nurse and efforts should be made to facilitate this choice
  - closer monitoring and reviewing of contraception would help women to manage their contraceptive use more effectively
  - making specialist advice and support available to women with high support needs who might also be more vulnerable to coercion.
- **Prescribing contraception to women with intellectual disabilities: general practitioners' attitudes and practices (McCarthy, 2011) UK<sup>50</sup>** – It can be hard for health care professionals to resist pressure from parents and carers: a number of doctors in this study described parents as 'pushy', 'over-protective', or arriving at surgery having 'made their minds up already'. Busy doctors, in short consultations which do not facilitate full and frank discussions, are faced with the choice of trying to resist undue pressures from parents and other carers or going along with what they request. The study also explores issues related to the women's capacity to consent to sex. It is reasonable for doctors to share their concerns about a client's vulnerability<sup>51</sup>, not only to sexual intercourse, but also regarding her long term health. Evidence suggests that once they start contraception, women with intellectual disabilities tend to remain on it, with all the possible health consequences associated with that.

# 7. Safeguarding

## 7.1 Introduction

Safeguarding policies usually apply to staff or employees of an organisation, to protect those they come into contact with. In this report, safeguarding of SRH clients in their relations with service providers is explored through the lens of ensuring informed consent to services, based on accessible information and communications, and the appropriate level of support for understanding and decision-making by the client. This ensures that clients with intellectual and sensory disabilities are safeguarded and harm is avoided in their use of SRH services.

**If you have concerns that a colleague may be acting inappropriately, coercively, disrespectfully or abusively with a client with intellectual or sensory disabilities:** follow your facility or organisation's safeguarding reporting process, or tell a supervisor about your concerns.

**There are other safeguarding concerns that may arise and that healthcare providers will need to take action on. In this section we look at harm that people may face in their relations with people other than the SRH service provider** (such as community members, family members, caregivers and others). This section provides guidance to health care workers to ascertain whether a safeguarding issue is taking place outside the relationship with the service provider, such as coercion by a caregiver or guardian, sexual or intimate partner violence, etc. There are two aspects to this:

a) as it influences the client's ability to consent to SRH services, for example if contraception is being sought because the client is in a coercive relationship.

b) to provide information for service providers who have concerns that a client is experiencing harm in their home or community.

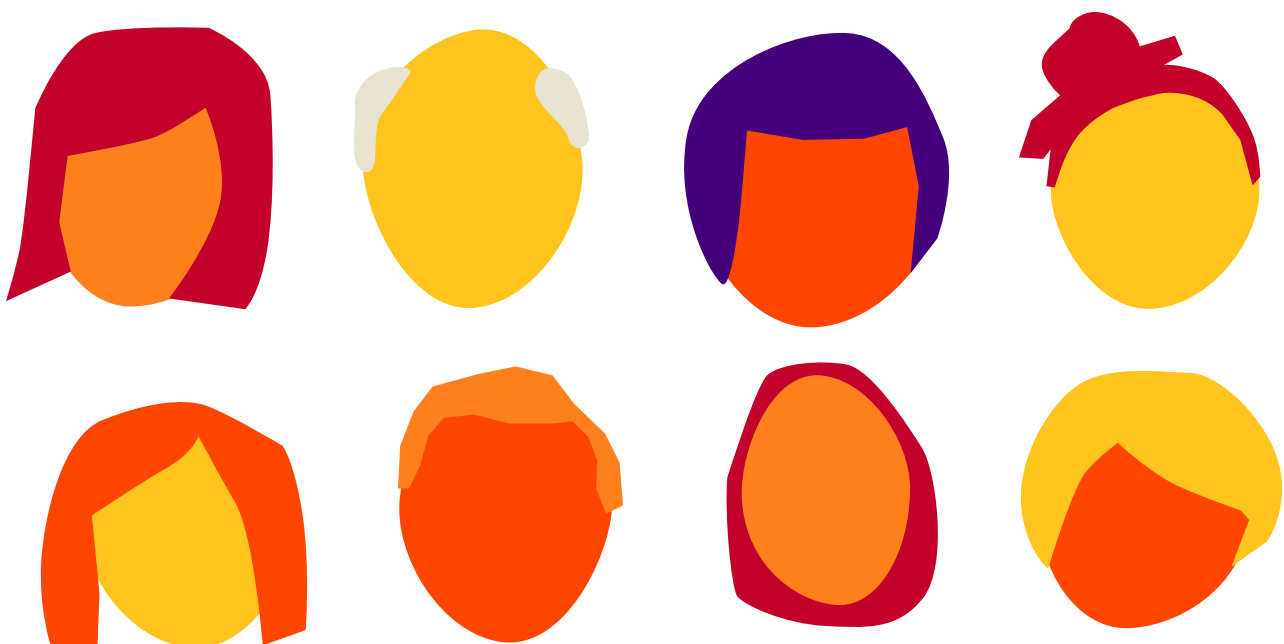
There are other levels of safeguarding management and reporting within SRH services that are not covered in this resource. For example, the development of data protection, safeguarding protocols, and referral pathways for safeguarding incidents will not be addressed here. These will be addressed only as they may be used by the health care provider to support the client.

## Safeguarding in an emergency

Leonard Cheshire has developed a [briefing \(2021\)](#)<sup>52</sup> that aims to outline what they consider to be the most urgent challenges regarding protection and care that people with disabilities will face in light of the COVID-19 pandemic and what can be done to ensure that persons with disabilities are not left further behind as a result of this global crisis, but are properly included in policy and programmatic responses to COVID-19. What needs to be done?

- Appropriate safeguarding responses should be locally-designed and gender-responsive.
- Coordination between different stakeholders is essential to strengthen the response and for effective use of resources.
- Donors should consider offering additional funding to organisations in order to ensure that safeguarding is not only prioritised in programme design, but effectively resourced.
- Mechanisms for reporting safeguarding issues should be strengthened or created where necessary.

There are some key issues in relation to safeguarding and protection of people with disabilities. One obvious difficulty is when a potential abuser is a family member or caregiver and is in the room with the SRH provider. There are also tensions that providers may face between protecting adults with intellectual disabilities from abuse while also respecting their right to consensual sexual expression ([Greenwood and Wilkinson, 2013](#), [Esmail and Concannon, 2022](#))<sup>53</sup>. The safeguarding process must respect a client's right to make what the healthcare provider may consider to be bad decisions, as long as these decisions are consensual, legal and do not raise a safeguarding concern.



## 7.2 Potential safeguarding concerns

The box below provides information about different kinds of abuse for people with intellectual disabilities. It is also useful for healthcare providers, and details the kind of safeguarding concerns that a healthcare worker may become aware of or suspect. The UNFPA / WEI [Guidelines for providing Rights-Based and Gender-Responsive Services to Address Gender-Based Violence and Sexual and Reproductive Health and Rights for Women and Young Persons with Disabilities \(2018\)](#)<sup>54</sup> provide some data about different types of abuse faced by people with disabilities.

### Safeguarding concerns: information for People with Learning Disabilities

Here are some different kinds of abuse that clients may experience, at home, in the community and in health care settings:

**Abuse** - when someone hurts you or treats you badly. Abuse is always wrong. There are different kinds of abuse that overlap:

- **Physical abuse** - when someone physically hurts you, for example hitting, kicking, biting.
- **Sexual abuse** - when someone touches your body or your private parts in ways you do not like or want. This can include kissing you, making you touch them, having sex with you when you do not want to.
- **Reproductive or obstetric coercion or abuse** - when someone forces you to use or not use contraceptives, get pregnant, have an abortion or get sterilised, or when someone abuses you when you are pregnant or giving birth.
- **Emotional abuse** - when people talk to you in unkind ways. For example, teasing, threatening, swearing, shouting, putting you down.
- **Financial abuse** - when people take your money or things which belong to you, without you saying it's OK, e.g. controlling the welfare benefits of people with disabilities.
- **Neglect** - this is when people who are supposed to help you don't look after you properly. For example, not giving you enough food, not keeping you warm and safe, not giving you medication or taking you to the doctors if you are ill.
- **Discrimination** - is when people treat you badly or unfairly because of certain factors such as, the colour of your skin, your religion, your disability or because you are lesbian, gay and/or trans.
- **Disability-specific abuse** - such as removing, hiding or controlling your access to mobility aids, sensory aids (eg spectacles, white cane, hearing aids, etc), medication, etc
- **Controlling behaviours** - including isolating a person from family and friends; monitoring their movements; and restricting access to financial resources, employment, education or medical care.



## 7.3 Identifying concerns

Below are some things to look out for, which may be signs of abuse and neglect of clients with disabilities.

Abuse can present as:

- unexplained changes in physical health (eg, malnutrition)
- unexplained changes in mental health (eg, anxiety, depression)
- changes in behaviour (eg, withdrawal, disruptive behaviour, inappropriate attachments, sexualised behaviour).

Neglect can present as:

- a recurring pattern of inadequate care
- missed appointments
- nonengagement
- nonadherence.

(Surrey Place website, 2022)<sup>55</sup>

To decide if a safeguarding concern needs to be raised, a healthcare worker can think about the following questions:-

- Is there a concern that the client is at risk of or is experiencing abuse or neglect?
- What types of abuse or neglect are they concerned about?
- Have they had a conversation with the client about the concerns? Have they sought the views and wishes of the client?
- Are there any immediate risks to the client or to others including children? Have they discussed and agreed next steps with the client?
- Have they provided advice, information or signposted the client?

(Local Government Association (UK) and Directors of Adult Social Service, 2021)<sup>56</sup>

## Ensuring the physical and emotional safety and security of the client

All actions taken on behalf of the client must safeguard their physical and emotional well-being in the short and long term. The space in which we speak to the client must feel safe to them. In our assessment of their needs and in our reporting and referral planning, we must prioritise discussions and actions that will minimise the client's risk of further harm. Care and treatment must be carried out in a space and in such a manner that the client can trust that they will not be not be physically or emotionally harmed by the provider or the provider's actions.

- i) Communication: Getting to know the individual with disabilities - the things they like and dislike, and the ways they behave and communicate - may help us understand when a client does not feel safe talking to us and why. It may also help us to understand their will and preference so we can act accordingly. **Watch for signs of agitation, anger or distress that may indicate the client is not happy to proceed at this time, and respect this, especially if you are talking with the caregiver.**
- ii) Caregiver involvement: While many caregivers play a supportive role in the client's disclosure of abuse and healing, there may also be cases when the caregiver is the perpetrator of abuse, or we have **concerns that the client will be harmed if the caregiver finds out about the abuse and/or the client's disclosure**. It is important to remember that in many GBV cases, a client seeking help can significantly increase their risk of further harm if the perpetrator or perpetrator's family and friends find out. In such cases, safety is paramount, and we need to support the client in telling us who and where is not safe for them and with whom and where they feel safe. It may be possible, then, **with the client's consent**, to involve this person/people in the client's care and to make sure the client has a safety plan in place.

(adapted from [Tool 8: Guidance for GBV caseworkers: Applying the guiding principles when working with survivors with disabilities](#))<sup>57</sup>

## 7.4 If there is a concern

If you have a safeguarding concern, there are two things to do: **report** it and **refer** the client for support.

WISH partners have safeguarding policies in place. This explains what to do and who to tell if a health care worker has a concern about a client. SRH services and clinics should have trusted referral pathways in place for people with disabilities who have or are experiencing coercion of violence. An extract from an organisational safeguarding policy is provided in annex 1.

### **If you have a concern about the caregiver:**

Caregivers can be overprotective. This can be a challenge for informed consent, but is not in itself a safeguarding issue. In this case:

- Make advice, rights and principles available to caregivers - sometimes they may just not know when their intentions to protect go too far and become potentially humiliating, neglectful or abusive.

However, if you feel a caregiver may be acting in ways that are coercive, abusive or violent towards your client, that is an issue for safeguarding. In this case:

- Follow your safeguarding and reporting protocols.

As a health care worker, you may also need safeguarding from the caregiver.

- If you feel unsafe, trust your instincts. You may want to alert a colleague if you feel unsafe and need support.
- Take follow-up action with your supervisor if your instinct is that the situation is too threatening to address during the consultation.

As already stated the tension between protecting adults with intellectual and sensory disabilities from abuse while also respecting their right to consensual sexual expression may at times be difficult for healthcare providers to navigate. See section 5.2.5 for a rights-based framework for providers in addressing contraception needs of clients with disabilities by [Greenwood and Wilkinson \(2013\)](#) which indicates when health care workers need to inform a supervisor or make a referral in the informed consent process. Your clinic should have an established disability-inclusive pathway for clients with intellectual and sensory disabilities experiencing a safeguarding issue. If the clinic does not have one they should develop one with urgency.

### **For health care workers in SRH facilities who conduct sexual assault examinations**

The [Illinois Imagines' SANE Picture Guide to the exam after sexual assault for medical staff \(undated\)](#)<sup>58</sup> was developed to assist women with disabilities to better understand the sexual assault examination process. There are different guides depending on the needs of the woman and guides for medical staff and advocates to assist a woman with a disability, including a useful picture guide on how to prepare a person for an exam after sexual assault.

## 7.5 Trauma-informed care

### What is trauma- and violence-informed care?

Trauma- and violence-informed care is an approach to healthcare in which care providers are aware of and understand the impacts that trauma and violence can have on clients' physical, mental and emotional health and well-being. Trauma- and violence-informed care acknowledges all forms of violence. It aims to make services a safe space. Trauma- and violence-informed care acknowledges clients as equal experts in their care and respects their priorities and preferences.

Trauma- and violence-informed care means that the care provider knows that experiences of trauma and violence may affect a client's development, mental and emotional health, substance use and physical health. Care providers should be trained to be able to help with these effects by sharing information on coping strategies, triggers and reactions. They should put the client's choices and safety first.

**Please note:** it is not a client's responsibility to tell their healthcare provider or anyone else what has happened to them during their lives to cause trauma, unless they want to. Instead, people working in healthcare should be trained to understand that clients may have experienced trauma - and that this can affect how clients react to them and cope with life in general.

#### Trauma- and violence-informed care is about:

- Empowerment – in which clients use their strengths to improve their well-being. Health care providers can help clients to identify their strengths.
- Safety – SRH service settings should feel safe. This means that it feels safe physically, emotionally, psychologically, and culturally.
- Collaboration – the client is part of the care team, and has the right to decide.
- Informed choice – the client has the right to be told about all care options and make their own choices. They should be able to choose the care option that will work best for them.
- Trustworthiness – SRH service providers should explain what all options will involve, who will provide the care and how it will be provided.



**Caring for, and supporting, health sector workers:** When the rights of those working in the health sector are upheld they are better able to work in a respectful manner ([Dynes et al, 2016<sup>59</sup>](#); [Frontline AIDS, 2020<sup>60</sup>](#)). Many SRH providers, midwives and maternity providers work in situations of adversity, with negative effects on wellbeing, morale and retention ([Liu et al, 2019](#)). While adequately supporting health care workers is a wider structural issue that the sector has to engage with, there are basic steps that can be taken at the clinic level which include providing a space for health care providers to talk to mentors and supervisors about the tensions and challenges they face (while at the same time maintaining the confidentiality of clients).

## 8. Recommendations

The recommendations in this section aim to support the creation of an enabling environment for people with intellectual and sensory disabilities to be able to realise their SRHR, and to ensure that SRH services are safe environments. The relationship between health care workers and clients with intellectual and sensory disabilities will be most successful when it is embedded in supportive services that have strong links to OPDs, and when there is access to good training, helpful tools, accessible communications materials, and policies and protocols that health care workers know, understand and are able to follow.

The following recommendations are for organisations that run SRH services, including those organisations that make up the WISH consortium:

- The WISH consortium should commit to promoting the development, roll-out and uptake of training for service providers in SRH provision for people with intellectual and sensory disabilities.
- There is a gap in accessible and relevant training materials and in situ training for SRH service providers and health workers on how to work with persons with intellectual and sensory disabilities, and provide trauma-informed care. This is critical, and this piece of work aims to begin to address that. Particular gaps that the WISH partnership could address through the development of new training materials include the following:
  - Privacy considerations can be a challenge for SRH providers seeking a client's informed consent. The WISH consortium should develop with OPDs a picture guide to use with clients to facilitate discussions about *privacy, who they would like in the consultation room with them, and when they would prefer not to be accompanied*.
  - There is little guidance on supporting health care workers on how to *identify and act on* safeguarding concerns, and similarly little guidance for those who think their client may be experiencing violence, abuse or coercion. The WISH consortium should develop training and guidance for SRH providers on this.
  - The WISH consortium should work with OPDs to develop SRHR education and awareness materials for people with intellectual and sensory disabilities and their families. This is critical. Women and young women with disabilities, in particular, are reliant on their families/ care-givers due to limited mobility and social norms.
  - Much of the information on informed consent and SRHR included in this guidance applies to adults of all ages including young people. However the informed consent and safeguarding requirements can be different for people classified as children. The WISH consortium should develop a guide specific to people under the age of consent.
- Every SRH service should have a safeguarding policy, protocols and guidance, supported by named staff, to ensure healthcare workers know who to report this kind of concern to, and what referral pathways are available for their client.

- Checklists and tools provided in this report and the accompanying e-learning for each step in the process of ensuring informed consent and safeguarding (all of which have been adapted from existing tools developed in other settings) should be trialled and validated with OPDs and WISH partners.
- The WISH consortium should recognise the pressure on health care workers striving to provide a good SRH service that supports the informed consent of clients with intellectual and sensory disabilities, and the trauma they may experience in aiming to provide this. Support them with self- and collective care, and trauma-informed supervision.
- Service providers don't necessarily have the time to establish good relationships with clients/caregivers when they first come to seek a contraceptive method or other SRH service. SRH services should carry out targeted activities with OPDs that focus on intellectual/sensory disabilities, to identify potential clients with intellectual and sensory disabilities and carry out awareness-raising activities with them (and their caregivers) on the different SRH services that are available. This would enable them to build relationships with potential clients.
- The WISH consortium could develop a set of standards for disability-inclusive SRH services that are aligned with the CRPD. These would include:
  - the way services are set up
  - meaningful connections established with OPDs
  - linking SRHR services to referral and support systems
  - accessible resources and materials available to facilitate informed consent and decision-making by people with intellectual and sensory disabilities
  - good training for health care workers that also addresses attitudes and behaviours of health care workers
  - full consideration given to providing confidentiality and privacy
  - guidelines and templates for good documentation of the informed consent process, and
  - safeguarding reporting and referral pathways that have been approved by OPDs.
- Creating and sustaining an enabling environment is always not an instant or short term process and needs to be well woven into a longer term SRHR approach. The WISH consortium should take these recommendations and use them as the basis for an agreed plan and timeline, so they can monitor and hold themselves accountable for progress.

# Annex one: MSI Adult Safeguarding Policy

## Extracts from the MSI Adult Safeguarding Policy

Survivor Support: It requires courage to speak up about abuse. In many cases survivors may have been wrongly made to feel as if they were to blame, and they are likely fearful of what their abusers would do if they found out they reported. Recognising this, MSI encourages team members to adopt the LIVES approach when listening to reports of abuse, to help survivors feel safe, protected, and supported.

- Listen closely with empathy and no judgement
- Inquire about needs and concerns
- Validate their experience, show you understand.
- Enhance their safety and do no harm
- Support them to connect to additional services

Where available MSI will identify specialist organisations where survivors can be referred for specialist support, such as psychosocial support, comprehensive sexual, gender-based violence (SGBV), forensic examination, legal support, on-going medical assistance, protection, and follow-up care. The organisations/facilities identified must demonstrate adequate standards of care and treatment, and assurances of their commitment to maintain confidentiality and provide quality and sensitive care must be gained, ideally in a written agreement.

MSI's Adult Safeguarding Policy outlines the following **standards of conduct** in order to ensure vulnerable adults, MSI People and MSI Partners are safeguarded from all forms of harm.

At all times (whilst carrying out professional activities or whilst acting in a personal capacity outside work) MSI People and Partners are expected to:

- Be sensitive to the power imbalances that may exist between themselves and clients, community members, colleagues, or partners; and not seek to misuse the power they hold.
- Recognise that everyone has the potential to experience vulnerability, and therefore treat everyone equally with dignity and respect regardless of their age, disability, socio-economic status, religion, race, caste, indigeneity, ethnic group, sex, gender identity, sexual orientation, or any other characteristic.
- Not engage in any behaviour which may be considered sexual exploitation, harassment or abuse, discrimination, victimisation, or violence against any client, community member, colleague, or partner, at any time.
- Maintain professional boundaries with clients and vulnerable adults at all times, including refraining from contacting clients outside of the approved client-follow up channels.

- Refrain from providing services to clients they have a relationship with unless declared as a conflict of interest and approved by the County Programme.
- Provide respectful, client-centred, and non-judgemental services, using non-technical language. Take care to ensure that vulnerable clients feel heard and supported to make autonomous decisions about their healthcare. Adapt communication approaches where necessary.
- Ensure a chaperone (i.e., a second staff member or government health worker) is present or offered to clients of the opposite gender throughout all intimate examinations and procedures.
- Clearly explain to clients what a service involves, using non-technical language. Seek active and continuous consent and do not touch clients without permission. Be prepared to stop if a client is uncomfortable.
- Maintain client privacy and dignity e.g., offer use of a paper drape and private changing areas.
- Follow MSI's Data Privacy Standards in order to ensure sensitive and personal (i.e., client-level data, employee records, or information relating to safeguarding cases) is not misused and/or does not expose individuals to risks of harm.
- Act in accordance with MSI's SGBV guidelines where someone discloses or indicates that they may be a victim of sexual or gender-based violence.
- Report any suspicion, allegation or witness of abuse, exploitation or harassment of a vulnerable adult or other breach of MSI's Safeguarding Policies and Code of Conduct by MSI People or Partners via MSI's Speak Channels outlined in Section 5.2.1.
- Actively promote and seek client and team member feedback in order to identify potential and mitigate safeguarding risks.
- Promote a caring and inclusive culture at MSI which safeguards children and vulnerable adults and speaks up about concerns



# Annex two:

## Resources for people with disabilities

### Examples of accessible information resources for women with disabilities<sup>61</sup>

#### For people with intellectual disabilities:

- **MSI materials on SRHR**
- **Centre for Developmental Disability Health, Monash University (2016)** -This Australian resource is a simplified guide on **Pap smear tests** that service providers can use to help clients with disabilities. The guide explains in plain language what women with disabilities can expect as part of a Pap smear test and uses drawings to explain the procedure.
- **NHS Easy read resources on sexual health** - Abuse, Contraception, Feelings, Growing Up, Menopause, Menstruation, Resources, STIs, Thrush.
- **Mencap resources on sex and relationships.**
- **Brothers of Charity services on love, sex and relationships.**
- The accessible website and blog, **Sexuality and Disability**, produced in India, empowers individuals with disabilities toward positive sexuality, answering questions on a range of issues related to sexual health and sexuality for women and girls with disabilities, including relationships, sex, violence, parenthood, and knowing one's own body.
- **A Health Handbook for Women with Disabilities (2007)** provides extremely comprehensive and useful information for women and girls living with disabilities regarding the nature of different disabilities and how it may impact her ability to understand health and services. It covers: Disability and the community, Organising for disability-friendly health care, Mental health, Understanding your body, Taking care of your body, Health Exams, Sexuality, Sexual health: Preventing sexually transmitted infections including HIV/AIDS, Family planning, Pregnancy, Labor and birth, Caring for your baby, Growing older with a disability, Abuse, violence, and self-defense, and Support for caregivers.
- **The Canadian consensus guidelines on primary care for adults with Intellectual and Developmental Disabilities (2018)** -Tools provided for people with intellectual and developmental disabilities include **Today's Visit** which helps in preparing for a visit to the doctor with adults with intellectual and developmental disabilities.
- **Safe Sex and Contraception in Easy Words and Pictures. CHANGE (2010)** - Parenting Collection, My Pregnancy, My Choice, Sexuality Collection, You and Your Baby, You and Your Little Child, Friendships and Relationships, LGBTQ+, Safe Sex and Contraception, Sex and Masturbation and Understanding Sexual Abuse.

- **Supporting Women with Learning Disabilities through the Menopause (2017)**

This is a set of three leaflets in easy read format –one for women, one for parents and care-givers, and one for staff in learning disability services. There is also a **set of training exercises** for staff on the menopause in women with disabilities, which may be useful for health providers in LMICS helping them to provide accessible information.

**People with sensory disabilities:**

- **iDecimelo A Mí! : Derechos Sexuales En Lengua De Señas Argentina (Tell me about it! Sexual rights in Sign Language, Argentina)** is a Spanish language campaign for deaf youth supported by UNFPA, which included posters with barcodes giving them access to **videos in sign language** addressing sexuality, gender equality, body development, and other CSE topics. (Note that resources produced for this campaign are all in Spanish).
- **Straight Talk Foundation** promotes Sexual Reproductive Health Rights for **young people with disabilities**. **The Straight Talk Foundation in Uganda** set up mobile clinics with trained multidisciplinary teams. Training girls and young women with disabilities as educators or community health workers has improved access to SRHR services in rural or otherwise isolated areas. Young people with disabilities are reached through peer education, IEC materials, school visits and through their teachers and caregivers. Straight Talk also reaches millions of young people through social media, print and radio, working in 17 Ugandan languages, and includes Braille publications in different Ugandan languages.

# Annex three:

## Resources for healthcare workers

The resources listed here are **useful references to help health care providers and others understand specific aspects of SRH, disability and rights. They are not necessarily specific to informed consent or safeguarding.**

(Note that all resources in this box are available only in English except where otherwise stated)

- **Women’s Refugee Commission and International Rescue Committee (2020) Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings A Toolkit for GBV Practitioners.** This resource includes 12 useful tools, many of which are adapted for SRH services in this guidance. The tools are also available in **French**.
- **Sexual and Reproductive Health Care for Women with Intellectual Disabilities: A Primary Care Perspective (2013) USA.** Based in a literature review related to six aspects of sexual health care of women with intellectual disabilities, including barriers to sexual health care, sex education, sexual abuse and consensual sexuality, contraception, screening for sexually transmitted infections and cervical cancer, and pregnancy and parenting. After providing background information about each topic, the authors suggest practice recommendations for primary care clinicians, using a rights-based framework.
- **The UNFPA Guidelines for providing Rights-Based and Gender-Responsive Services to Address Gender-Based Violence and Sexual and Reproductive Health and Rights for Women and Young Persons with Disabilities (2018)**<sup>62</sup> has sections on contraceptive information, goods and services, maternal and newborn health services, An accessible version is available. information, testing and treatment services for STIs and HIV and access to other women’s health and information services for women, young people and adolescents with disabilities.
- **The Health Care for Adults with Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers from Vanderbilt University (2011) features a Preventive Care Checklist Form - ‘Females with Intellectual or Developmental Disabilities (IDD)’** but is very medical, for example it includes a tick box for whether an HIV or STI screening has been conducted.
- **Supporting Women: Information and resources for general practitioners supporting women with intellectual disabilities to manage their menstruation (2016)**
- **A Handbook On Best Practices Regarding HIV And AIDS For People With Disabilities by LVCT** (not dated) This handbook is divided into four chapters, each addressing a particular broad topic in reference to best practices for Disability and HIV, including with people who are Deaf, visually impaired, or who have physical or intellectual disabilities.

# Annex four: Guidance on Communications

## Communication tips:

### Use a strengths-based approach:

- Do not make assumptions about the skills and capacities of persons with disabilities – this can affect the way we communicate and interact with them. Remember that persons with disabilities are people, first and foremost. Just like all people, they have different opinions, skills and capacities.
- Look at what people can do. This can often give insight into how they can communicate and participate in your activities.
- Greet persons with disabilities in the same way you would other people. For example, offer to shake hands (if culturally appropriate), even if they have an arm impairment.
- Speak directly to the individual with disabilities, not to their interpreter or assistant/caregiver.
- When speaking for a length of time, try to place yourself at eye level with the person if they are not already at the same height (e.g., by sitting in a chair or on a mat).
- Treat adults with disabilities like you treat other adults. Discussions and activities should continue to be age appropriate and then adapted for the communication needs of the individual.
- Ask for advice. If you have a question about what to do, how to do it, what language to use or the assistance you should offer – ask people. The person you are trying to work with is always your best resource and may have their own preferences.

Working with people with different impairments In addition to the tips provided above, there are specific communication and engagement strategies to consider, depending on the type of disability the person has.

### When working with people who are deaf or hearing impaired:

- Find out how the person prefers to communicate. People with hearing impairments may use a combination of writing, lip reading and/or sign language. This can be determined by observing their interactions with others or by using simple gestures to suggest communication options.
- Get the person's attention before speaking, by raising your hand or waving politely.
- Face and talk directly to a person who is deaf, not to the interpreter (as they are only facilitating the communication).

- Speak clearly – don't shout or exaggerate words as this will make it more difficult to lip read.
- Try not to sit or stand with your back to the light – this can put your face in the dark and make it difficult to lip read.
- Do not cover your mouth or eat while talking. This will make it difficult to lip read.
- Allow the person who is deaf or hearing impaired to choose the best place to sit at a meeting to be able to see people clearly and communicate more easily.
- In meetings, ensure the interpreter can hear the presenter and the rest of the group. They should also be visible to the individual for whom they are interpreting. A note about sign language: Like spoken languages, sign languages are different in different countries and regions. Some people also use unofficial sign language, and in these cases a family member or friend may need to do the interpretation. Ask them to teach you some simple signs (e.g., good, bad and thank you) and try to include these in your discussion with a person who is deaf or hearing impaired.

### **When working with people with vision impairments:**

- Always introduce yourself and any other people in the group by name.
- Tell the person if you are moving or leaving their space – don't just walk away.
- If the person has arrived at a new place, tell them who is in the room or group, and offer to describe the environment.
- Avoid vague language, such as "that way" or "over there" when directing or describing a location.
- Always ask the person first if she/he would like assistance to get from one place to another. Ask how they would like to be assisted and where they would like to go. Some people prefer verbal guidance, whereas others may prefer for you to physically guide them.
- If you are asked to physically guide someone with a vision impairment, they may want to hold your arm just above the elbow. This will allow them to walk slightly behind you, following you as you turn or step up or down onto steps.
- In the event that a person uses a support pet or guide dog to assist them, do not distract or pet the animal while it is working.
- In presentations, meetings and events, describe all pictures and diagrams that are shown.
- Ask persons with vision impairments if they would like documents in alternative formats, such as Braille or large print. In some contexts where people have access to computers, persons with vision impairments may prefer electronic documents that are accessible through screen reader software (e.g., Word documents).

## When working with people with intellectual impairments

People with intellectual impairments may experience difficulty in understanding, learning and remembering, as well as applying information to new situations. It is important to note, however, that persons with intellectual disabilities can learn new things and participate in our activities, with just some small changes to the way we work.

- Communicate in short sentences that convey one point at a time.
- Use real life examples to explain and illustrate points. For example, if discussing an upcoming medical visit, talk the person through the steps they are likely to go through both before and during the appointment.
- Give the person time to respond to your question or instruction before you repeat it. If you need to repeat a question or point, then repeat it once. If this doesn't work, then try again using different words.
- Allow persons with intellectual impairments to ask questions.
- Make sure that only one person is speaking at any given time, and that the person with an intellectual impairment is not being rushed to answer.
- Persons with intellectual impairments may want some more time to think about decisions or to discuss their options with someone they trust.
- Identify quiet environments to have conversations in order to reduce distractions.
- Pictures can also be used to communicate messages to people with intellectual impairments – these are sometimes called “Easy Read” documents.

## When working with people with speech impairments:

- Plan more time for communicating with people with speech impairments.
- It is OK to say “I don't understand.” Ask the individual to repeat their point, and then say it back to them to check that you have understood it correctly.
- Don't attempt to finish a person's sentences – let them speak for themselves.
- Try to ask questions that require short answers or yes/no gestures.
- If you have tried several ways to understand a person without success, ask if it is OK to communicate in a different way, such as through writing or drawing.

Source: **Tool 6: Guidance on Communicating with Persons with Disabilities<sup>63</sup> from the Women's Refugee Commission and International Rescue Committee (2020) Building Capacity for Disability Inclusion in Gender-Based Violence Programming in Humanitarian Settings A Toolkit for GBV Practitioners**

## Annex five: Case studies<sup>64</sup>

- **Bridging the mystery gap of deaf girls sexual and reproductive health using a human rights based approach** by the Federation of Deaf Women Empowerment Network – Kenya (FEDWEN-KENYA) which is a national umbrella network of Deaf women and youth/girls. Some of the issues this project covers include Sex education, Menstrual health management and Family planning. The project promotes accessibility of sexual and reproductive health services by involving key stakeholders, including raising awareness among health care practitioners to address the needs of deaf girls and women in areas concerning sexual and reproductive health and also train them on best practices when working with deaf women and girls. (Source: FEDWEN-KENYA website and [Dutch Coalition on Disability and Development \(2017\) Everybody Matters: Good practices for inclusion of people with disabilities in sexual and reproductive health and rights programmes](#))
- **In Nepal, the Karuna Foundation** helps to strengthen inclusive reproductive health services via its Inspire2Care programme by training Community Based Rehabilitation (CBR) facilitators in disability inclusion and the importance of healthy pregnancies and safe deliveries in order to prevent disability and diseases. Female community health volunteers are trained and then work closely with the Nepalese Government in each community and ward to distribute medicine and raise awareness on reproductive health and vaccines. They go from home to home and play a crucial role in bridging the gap between community members and the often distant local health post.
- **A project by Leonard Cheshire Disability in Zimbabwe**, working with 21 local partner organisations working for people with disabilities through the country, with special schools, health centres, community based rehabilitation partners working together and targeting young men and women equally, ensuring a sound interaction between gender and disability. Disability-specific organisations were linked to SRHR/HIV-specific organisations for collaboration on a variety of SRH activities including: training on SRH and being change agents for 357 adolescents with disabilities, peer education, safe spaces, school activities and providing information in accessible formats, and through meetings, flyers, pamphlets, a video documentary and a radio programme they ran a campaign on raising awareness of SRHR and disability at community and service provision level. (Source: [Dutch Coalition on Disability and Development \(2017\) Everybody Matters: Good practices for inclusion of people with disabilities in sexual and reproductive health and rights programmes](#))
- **'It's my body!' sexuality education, designed by Niketan Foundation and Rutgers Foundation for use at special schools in Bangladesh** – The course on sexual and reproductive health aims to empower adolescent girls and boys with intellectual disabilities aged 13-15. Although not yet evaluated, a recent report highlighted lessons learned about breaking taboos while keeping parents on board; and tailoring communication to people with (severe) intellectual disabilities. Project workers had to balance between breaking taboos and keeping parents on track. For their consent, they had to make sure images were not too explicit. Eventually they agreed on using drawings of naked bodies, because it was the only way the target group would understand. The biggest challenge remains customising the information to fit the targeted youngsters with often complex (intellectual) disabilities who attend the special schools. The risk for confusion or misinterpretation, possibly resulting

in problematic sexual behaviour, remains a subject of constant concern. *'It thus requires positive and clear feedback on desirable behaviour. For example, telling youngsters in a 'negative' way that masturbation is not allowed in public might be problematic for youngsters with (severe) intellectual disabilities, who often do not understand the word 'not'. They might understand 'masturbation is allowed in public. Recommendable would be to tell them that they can masturbate in their bathroom or bedroom.'*

- In Ethiopia, the **Resource Manual for Reproductive Health / Family Planning Service Providers on the Inclusion of Persons with Disabilities in Reproductive Health/Family Planning Services** provides step-by-step guidance for both mainstreaming disability and developing disability-specific targeted approaches (UNFPA, 2018).
- **Straight Talk Foundation** promotes Sexual Reproductive Health Rights for young people with disabilities. **The Straight Talk Foundation in Uganda** set up mobile clinics with trained multidisciplinary teams. Training girls and young women with disabilities as educators or community health workers has improved access to SRHR services in rural or otherwise isolated areas. Young people with disabilities are reached through peer education, IEC materials, school visits and through their teachers and caregivers. Straight Talk also reaches millions of young people through social media, print and radio, working in 17 Ugandan languages, and includes Braille publications in different Ugandan languages.
- **iDecimelo A Mí! : Derechos Sexuales En Lengua De Señas Argentina (Tell me about it! Sexual rights in Sign Language, Argentina)** is a Spanish language campaign for deaf youth supported by UNFPA, which included posters with barcodes giving them access to videos in sign language addressing sexuality, gender equality, body development, and other CSE topics. [many of the links for this project are broken]
- **Ensuring Deaf young people aren't excluded from sexual and reproductive health services** (VSO) In Nyagatere, an isolated region of Rwanda, the Imbere Heza (Bright Futures) project works to improve SRHR for marginalised and at-risk Deaf young people. The project has trained 200 healthcare providers in Deaf culture and Rwandan Sign Language (RSL). Community health workers identified 250 Deaf young people aged 15-24, and have raised awareness of their family planning needs, as well as the potential SRH risks they might experience. By gaining skills in basic RSL and learning about Deaf culture, healthcare providers have reduced any fear of working with Deaf clients. Before the project, five Deaf women at one health centre were reportedly prescribed a contraceptive they did not want; following training, health workers at this centre feel more confident interacting with Deaf clients and have ensured these women receive their preferred choice.
- **Provision of accessible SRHR services in Colombia: Profamilia** - a private non-profit organisation that, for more than five decades, has been promoting and defending the exercise of sexual and reproductive rights of the population in Colombia so that they can make free, safe and informed decisions about their sexuality, without discrimination, coercion or violence. Their activities and resources include:
  - Along with WEI they are part of the Colectiva Polimorfos a support group for women in functional diversity/ disability to make the violence they face visible. In this meeting space, they deal with subjects such as legal capacity, sexual and reproductive rights, responsible motherhood, diverse sexual orientation, and gender violence, among others. As a Collective they defend, protect and promote the human rights of women and girls with disabilities.



- Addressing the needs of women and girls with intellectual (cognitive) disabilities, who experienced forced sterilisation, and simultaneously challenging the system that allowed this to happen by tackling the legal framework. They also created awareness amongst community healthcare workers and care-givers about the rights of persons with disabilities and successfully advocated for change of this practice.
- A comprehensive care model so that people with disabilities can access sexual and reproductive health services in an informed and free manner. Profamilia has a [comprehensive care model](#).
- Produced a tool: Support in Decision Making in Sexual and Reproductive Health, which provides images, attitudes and actions that health care providers can use to support people with intellectual and psychosocial disabilities in making decisions about contraceptive methods, abortion, sterilisation, detection of violence etc. [can't find]. Taking time to talk with parents was crucial in changing their minds to allow their children to take courses that included sexuality and SRH. A video about this tool is available [here](#), though we are unable to find the tool itself.

(Source: [Dutch Coalition on Disability and Development \(2017\) Everybody Matters: Good practices for inclusion of people with disabilities in sexual and reproductive health and rights programmes](#))

# Annex six: Methodology

Leonard Cheshire previously carried out work with WISH consortium partners to explore the potential challenges that service providers may face when seeking informed consent from clients with disabilities. This shed a light on the complexities that come with safeguarding and informed consent, particularly for women with intellectual and sensory disabilities. This highlighted the need to further explore existing resources available in this arena and how they could be utilised by the Women's Integrated Sexual Health Programme (WISH) consortium partners.

The current report and e-learning have been developed through a consultancy commissioned to produce five deliverables:

- **Deliverables one and two** provide a review of practice and available resources, related to safeguarding and consent in SRH (for example when accessing contraception services) when supporting persons with disabilities. These resources include guidelines and training materials, practice frameworks, reporting and data sources produced across the UK and internationally. Other sources related to accessible materials, approaches and information to ensure persons with various disabilities have access to safeguarding procedures, understanding and providing consent and SGBV reporting and support mechanisms are also identified. Particular focus is given to resources relevant to people with intellectual and sensory disabilities. These deliverables feature annotations of relevant resources, guidance frameworks, practices and processes with summary overview.
- **Deliverable three** identifies transferable practices and resources, with recommendations on additional tools, information and resources required to fill gaps identified in low resource settings.
- **Deliverable four** (this report) is a comprehensive report outlining all findings from deliverables 1-3
- **Deliverable five** is the content of an e-learning module, using the analysis of information gathered in deliverables 1-3. This e-learning module will be targeted for service providing staff and will serve to help them identify safeguarding concerns and what can be done to safeguard women with disabilities accessing their services.<sup>65</sup>

For deliverables one and two we followed the same **methodology**:

- Internet search using googlescholar and non-academic search engines for resources including keywords: disabilities, informed consent, safeguarding, decision-making, supported decision-making, capacity assessment, guidelines, guidance, sexual and reproductive health and rights, services, low and middle and high income countries.
- Mining of bibliographies of key resources
- Review of resources recommended by WISH partners
- Review of recommendations from WISH partners.

Resources found were read for relevance to informed consent of people with intellectual and sensory disabilities. Where possible we included resources that also addressed SRH and R.

**For Deliverable One on guidance**, relevance was assessed based on whether a resource contained **guidance** for health care workers on informed consent and safeguarding of people with disabilities within SRH services, or within other service settings but of relevance to SRH. Resources that were highly relevant to informed consent and safeguarding of people with disabilities in other settings were included if they provided guidance that could also be applied to SRH service settings.

Resources that were assessed to be relevant (n=30) were compiled in an annotated bibliography available [here](#), categorising each resource by setting (global, high-income countries, low- and middle-income countries), focus area within the themes of informed consent and safeguarding, relevance to SRH, and type of disability (intellectual and developmental, visual, hearing).

The annotated bibliography was then used to develop an overview of guidance that can inform practice of SRH service providers in LMIC settings with regard to informed consent of people with intellectual and sensory disabilities.

**For Deliverable Two on practices and processes**, relevance was assessed based on whether a resource **evaluated, reflected on, or assessed practices and processes** around informed consent and safeguarding of people with disabilities within SRH services.

Resources that were assessed to be relevant to deliverable two (n=20) were compiled in an annotated bibliography available [here](#), categorising each resource by setting (global, high-income countries, low- and middle-income countries), focus area within the themes of practices and processes around informed consent and safeguarding, and type of disability (intellectual and developmental, visual, hearing).

The annotated bibliography was then used to develop an overview of evaluations and assessments of practices and processes of SRH service providers with regard to informed consent of people with intellectual and sensory disabilities.

In Deliverables Three, Four and Five we focused in on resources identified in One and Two that we could draw on and/or adapt, keeping in mind the different contexts these might be used in, including low-resource settings, where health workers have limited time and budgets, as well as changes brought about by the CRPD.

With the aim of the report and e-learning being available in English and French, we included links to French versions of the resources referenced where available.

Each deliverable was reviewed by the WISH partners.

# Endnotes

1. Available in French at: <https://www.ohchr.org/fr/instruments-mechanisms/instruments/convention-rights-persons-disabilities>
2. Not available in French.
3. Not available in French.
4. Not available in French.
5. This guidance draws on three other resources that were developed as part of the process of creating this guidance and the accompanying e-learning. See annex six for more information about these three other resources, and the methodology for this consultancy.
6. Available in French at: <https://www.un.org/disabilities/documents/convention/convoptprot-f.pdf>
7. Treaty database in French at: [https://tbinternet.ohchr.org/\\_layouts/15/TreatyBodyExternal/Home.aspx?lang=Fr](https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Home.aspx?lang=Fr)
8. Not available in French.
9. Available in French at: <https://www.unfpa.org/sites/default/files/pub-pdf/18-158-YouthDisabilities-FRENCH-FINAL-web.pdf>
10. Summary available in French at: <https://www.guttmacher.org/fr/guttmacher-lancet-commission/accelerer-le-progres-resume>
11. Available for download in French and other languages at: [https://tbinternet.ohchr.org/\\_layouts/15/TreatyBodyExternal/Download.aspx?symbolno=E%2fC.12%2fGC%2f22&Lang=en](https://tbinternet.ohchr.org/_layouts/15/TreatyBodyExternal/Download.aspx?symbolno=E%2fC.12%2fGC%2f22&Lang=en)
12. Summary available in French at: <https://www.guttmacher.org/fr/guttmacher-lancet-commission/accelerer-le-progres-resume>
13. Not available in French.
14. Available in French at: <https://www.ohchr.org/fr/instruments-mechanisms/instruments/convention-rights-persons-disabilities>
15. Not available in French.
16. Not available in French.
17. Not available in French.
18. Note that some of these terms are still common in national laws, policies and practices.
19. Resources in English only.
20. Note that the term ‘trauma-aware’ is sometimes used rather than ‘trauma-informed’. See for example the work of Salamander Trust on this issue.
21. Resource in English only.
22. Resources in English only.
23. Available in French at: <https://www.unfpa.org/sites/default/files/pub-pdf/18-158-YouthDisabilities-FRENCH-FINAL-web.pdf>
24. Not available in French. Translations available in Spanish, Arabic and Chinese at: <https://womenenabled.org/fact-sheets/>

25. Available in French at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
26. French version available at: <https://www.unfpa.org/featured-publication/women-and-young-persons-disabilities>
27. Available in French at: [https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015\\_FR\\_0.pdf](https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015_FR_0.pdf) .
28. In English only.
29. Available in French at: <https://pubmed.ncbi.nlm.nih.gov/29650742/>
30. Available in French at: <https://pubmed.ncbi.nlm.nih.gov/29650742/>
31. In English only.
32. Also available in French: Women's Refugee Commission and International Rescue Committee (2020) [https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015\\_FR\\_0.pdf](https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015_FR_0.pdf)
33. Also available in French at: [https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015\\_FR\\_0.pdf](https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015_FR_0.pdf)
34. Also refer to WISH partner guidance terminology and language, found in the Disability Inclusion VCAT Toolkit (pgs. 73-75): <https://www.ipas.org/resource/disability-inclusion-in-reproductive-health-programs-an-orientation-and-values-clarification-toolkit/> [Also available in French at: <https://www.ipas.org/resource/inclusion-du-handicap-dans-les-programmes-de-sante-reproductive-boite-a-outils-de-consignes-et-de-clarification-des-valeurs/> ]
35. In English only.
36. In English only.
37. In English only.
38. Available in French at: [https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015\\_FR\\_0.pdf](https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015_FR_0.pdf)
39. In English only.
40. This tool has been fully adapted for SRH service settings in e-learning Module 2.1.
41. Available in French at: [https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015\\_FR\\_0.pdf](https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015_FR_0.pdf)
42. Available in French at: [https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015\\_FR\\_0.pdf](https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015_FR_0.pdf)
43. Available in French at: [https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015\\_FR\\_0.pdf](https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015_FR_0.pdf)
44. Available in French at: [https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015\\_FR\\_0.pdf](https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015_FR_0.pdf)
45. In English only.
46. In English only.
47. Summary available in French.
48. For availability in French see footnotes earlier in the report (all resources cited in this section have already been cited).
49. In English only.
50. In English only.

51. Note there are different requirements around sharing information for safeguarding purposes when the client is under the age of consent. This is not covered in this guide.
52. Not found in French.
53. In English only.
54. Available in French.
55. In English only.
56. In English only.
57. Available in French at: [https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015\\_FR\\_0.pdf](https://gbvaor.net/sites/default/files/2019-07/GBV%20disabilities%20toolkit%20IRC%20WRC%202015_FR_0.pdf)
58. In English only.
59. In English only.
60. Available in French at: <https://frontlineaids.org/wp-content/uploads/2020/07/Implementers-guide-FR.pdf>
61. Note that none of these accessible resources are available in French.
62. Available in French.
63. Available in French at: Renforcement des capacités pour l'inclusion du handicap dans les programmes contre les violences basées sur le genre dans le contexte humanitaire Outil 6: Aide à la communication avec les personnes handicapées.
64. Note that all case study links are to resources in English, except where otherwise stated. None are to French resources.
65. Note: digital/e-learning expertise will be contracted separately to convert content into appropriate e-learning formats, the consultant is expected to provide coordination, review and sign off on design in agreement with the Project Officer.

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