



Research & Studies

Avoiding Harm, Respecting Rights: Facilitating Person-centred, Disability-inclusive Informed Consent in Sexual and Reproductive Health Settings (Experience from Uganda & Rwanda)

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Introduction

Aims

The overall aim of this document is to increase awareness of a human rights-based approach to informed consent for sexual and reproductive health (SRH) care and to promote equitable and inclusive practice. That is, to help a wide range of stakeholders facilitate accessible and inclusive informed-consent processes within SRH settings.

The specific aims are to:

- Identify gaps in existing informed-consent guidelines through a separate rapid review;
- Identify practices and knowledge on effective approaches from experts, stakeholders in SRH and disability organisations based on qualitative findings in Rwanda and Uganda;
- Provide recommendations to enhance more disability-inclusive and ethical SRH and gender-based violence (GBV) services in low- and middle-income countries (LMICs), specifically to strengthen safeguarding and informed consent. The recommendations are presented in [part 2](#) as a guide.

Target audience

The target audience of this document:

- SRH/GBV programme managers,
- Technical staff in international non-governmental organisations (INGOs), non-governmental organisations (NGOs) and ministries of health working in the SRH and disability field,
- SRH facility managers and healthcare workers (HCW),
- Organisations of persons with disabilities (OPDs).

Development of the guide: methodology

This guide is based on two sources of information. Firstly, a review of existing online resources was conducted to determine the scope of available toolkits, guidance documents and training modules on informed consent for people with disabilities in SRH services. Secondly, key informant interviews (KIs) and focus group discussions (FGDs) were conducted in Uganda and Rwanda between November 2021 and January 2022. The interviews were part of a **participatory qualitative study** with four different stakeholder groups (12 global experts, 15 healthcare service providers, 17 women with disabilities, 3 caregivers) in both countries to identify key challenges and recommendations for facilitating informed consent for women with disabilities, including women with intellectual disabilities.

- See Appendices [Data Collection Tools](#): Guides for Key informant interview & Family and caregiver focus group.

Limitations

Approaches to enhance safeguarding and informed consent need to be contextualised and should consider resource constraints and a broad spectrum of disability-related functioning. The guide is for consideration, and recommendations need to be piloted in different SRH care settings in LMICs. The guide and its checklist tool ([Quality Assessment Checklist for Inclusive Informed Consent](#)) can be provided alongside training for service providers, OPD members and caregivers to strengthen ethical and disability-inclusive informed consent.

I. Background and lived experience

1. Context and definitions... from a review of the literature

1.1 Key facts

Women and girls living with disabilities have the same sexual and reproductive health rights (SRHR) as women and girls without disabilities. This includes the right to equitable sexual and reproductive health (SRH) services, including contraception and fertility services, comprehensive abortion care (CAC), screening for sexually transmitted infections (STIs), prevention and management of reproductive cancers, and maternal newborn and child health (MNCH) services. Furthermore, women and girls with disabilities also have the right to access comprehensive care and support services for gender-based violence (GBV).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006) enshrines the right of persons with disabilities to make their own decisions about their health, and to get the necessary support when making these decisions (Article 6). Article 12 acknowledges the right of persons with disabilities to enjoy legal capacity on an equal basis with others in all aspects of life, and Article 23 states the right to non-discrimination in all matters relating to “marriage, family, parenthood, and relationships” Article 22 recognises the right to privacy while Article 25 obligates healthcare workers to provide care of the same quality to persons with disabilities, ensuring free and informed consent by “raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private healthcare.”¹ A human-rights approach to disability is central to realising rights and freedoms.

While men and boys with disabilities face various SRH problems (lower fertility, sexual dysfunction, erectile dysfunction, hypogonadism, and premature ejaculation) (Merrick, Morad and Carmeli, 2014) and barriers to SRH services (Frawley et al, 2022), disability prevalence is higher in women and girls, and men and boys with disabilities do not experience the same amount of sexuality stigma and GBV when gender, age and disability intersect (World Bank, 2011). Because of their gender and disability, women and girls with disabilities have historically been denied access to information about sexual health and their rights, and experience multiple barriers to SRH care. The consequences of these barriers are significantly detrimental to their sexual and reproductive health (Nguyen, et al., 2022; Akasreku, et al, 2018; Mitra, et al., 2016; Tanube, et al., 2015, Mitra, et al, 2011).

Women and girls with disabilities face different barriers when making independent, informed decisions about their bodies, health and lives. They are more likely to be denied or forced into pregnancy and abortion, or be subjected to coerced procedures such as contraception or sterilisation. Women and girls with disabilities in particular are at increased risk of intimate partner violence (IPV) (Chirwa, et al., 2020) and sexual violence, which is

¹ [UN Convention of the Rights of Persons with Disabilities](#). (2006).

linked to reproductive coercion, unintended pregnancies, risk of STIs, adverse pregnancy outcomes, and poor mental health.

1.2 What is informed consent

Informed consent is both a legal requirement and an ethical obligation that healthcare workers must obtain from the client prior to any examination, treatment, referral, and/or care. It is fundamental to the provision of quality care. Informed consent is an important **communication process** between the healthcare worker and the client. It means the client can give, withdraw, or refuse to give permission for a treatment or procedure based on full knowledge of the procedure, including its potential risks and benefits as well as information about all available options (International Federation of Gynecology and Obstetrics, [FIGO](#)). It is about the right to receive evidence-based unbiased information, choice and control.

To provide informed consent, the client must have the capacity to know about and understand the services being offered and be legally able, in terms of age, to give their consent. The age at which someone is “legally” able to provide consent depends on the jurisdiction of the country in which the services are provided. While parents usually have the legal authority to consent to healthcare for their minor children, it is crucial to involve children and young people as much as possible in decisions about their care and seek informed assent. Informed assent occurs when an individual is unable to provide legal consent but expresses a willingness to agree to the proposed treatment or care. The UNCRPD asserts that everyone, including those with intellectual disabilities, has legal capacity and the right to receive adequate support to exercise legal capacity on an equal basis with others.

The three components of informed consent are:

1. **Disclosure:** presenting adequate information in a reasonable, accessible manner, in a form and language fully understood by the client.
2. **Capacity:** determining the client’s ability to understand information and the risks associated with the options presented to them.
3. **Voluntary:** ensuring that the client’s decisions are voluntary and not made under duress, or are coerced by others such as family members, caregivers or service providers.

Informed consent is a crucial component of **respectful care**: healthcare workers have a duty to respect their clients’ choices about their bodies and to deliver quality care that upholds the rights, autonomy and dignity of all people, regardless of disability. Respectful care includes:

- Maintaining privacy and confidentiality.
- Preserving women’s dignity.
- Prospective provision of information and seeking informed consent.
- Ensuring continuous access to family and community support.
- Being free from harm and mistreatment.

The principle of '**do no harm**' is also an integral part of informed consent, enforcing the right to be free from torture and cruel, inhuman and degrading treatment for persons with disabilities. Thus, good informed-consent practices lead to better care, freedom from violence and mistreatment, and improved SRH outcomes.

On the basis of rights and freedoms from harm, it is important to highlight the challenges to informed consent in SRH services. Particularly in LMIC, various vulnerable populations, including those with disabilities, face increased resource constraints and attitudinal and physical barriers. This restricts their access to SRH services and their autonomy to choose which services they want to access.

1.3 Barriers to informed consent for women and girls with disabilities

Barriers to SRH are systemic, and are reinforced by disability stigma, lack of disability awareness and training, lack of resources, and access constraints.

Women and girls with disabilities face negative attitudes around their sexuality, pregnancy, and parenting capacity. Moreover, women and girls with disabilities are often stereotyped as needing special protection because of their vulnerability to GBV (Silvers, et al., 2016). Stigma means that they receive suboptimal information and care at SRH/GBV services and often experience discrimination and harmful practices in the control of their reproductive choices (Gartrell, et al., 2017).

Exclusion from access to SRH information can be based on communication barriers and cultural norms about gender, age and disability, including perceptions that women and girls with disabilities are not sexually active, or "lack capacity" to make their own decisions.

Disproportionate to women and girls without disabilities, women and girls with physical, sensory and intellectual disabilities have lower SRH literacy (Vetter, et al., 2021) and may experience multiple barriers to SRH information and care (Holness, 2021; Martin, et al., 2021; Ganle, et al., 2020; Baart, 2017; Burke, 2017; Bradley-Jones, 2015, 2017; Tanube, et al., 2015; Thomson, 2014). Alienation from SRH information and service provision is particularly heightened for women and girls with intellectual and developmental disabilities (IDDs) because of an assumed lack of understanding, and the ethical implications of providing healthcare to a person who may be incapable of giving valid consent to treatment (Goldsmith, 2008; Sowney and Barr, 2007; Keywood, Fovargue and Flynn, 1999).

In addition to communication barriers and concerns around comprehension and capacity, many obstetric providers are untrained and uneducated about critical aspects of providing care to persons with IDDs (Ari, et al., 2022). Given the barriers to SRHR education and information for women and girls with disabilities, knowledge about their SRHR, including about the rights relating to freedom of choice and freedom from violation, may be limited and/or lacking. Women and girls with disabilities, like other marginal population groups, may also mistrust healthcare workers because of internalised stigma (Ho, 2021).

The informed-consent interaction can be a challenge for both clients and healthcare workers. Cultural, age and gender differences can all influence the attitudes of health

workers, and the way access and communication occur (Hare and Hendy, 2003). A study conducted in South Ethiopia with health workers found that only half of them (50.1%) practised proper informed consent during major surgical procedures. Health workers with solid knowledge, over 10 years' work experience and training, an older age, more time spent on consent processes, and non-discriminatory attitudes were significantly associated with effective informed-consent practices (Negash, et al, 2021). In the Democratic Republic of the Congo, a study with healthcare workers found that knowledge and practice of informed consent was very low (Nzaumvila, et al, 2021). In this regard, we must consider that for SRH care workers in LMICs, informed consent is already a challenge. Facilitating informed consent for people with disabilities may exaggerate existing challenges because of a range of barriers, including a lack of training in disability inclusion (Ganle, et al, 2016). Subsequently, those who care for and support women with disabilities may often fail to meet ethical professional standards of care, including: a lack of informed consent and confidentiality, improper conduct of physical examinations and SRH treatment and procedures, and the neglect and abandonment of women with disabilities. Thus, healthcare workers may be enablers of harmful reproductive practices which amount to violations of SRHR.

1.4 Types of SRHR violations

Inappropriate physical examinations: Many women with disabilities have difficulty obtaining comprehensive, accessible, and dignified physical examinations. Clinical procedures such as pelvic examinations, mammograms or Pap smears performed without obtaining informed consent can amount to abuse, and even to rape if involving an act of penetration by the service provider, such as an IUD or speculum insertion that occurs without prior consent (Welner, Foley and Holmes, 1999).

Forced contraception: Women and girls with disabilities are often forced to use contraception to control menstruation, sexual expression and/or fertility, and this can occur, for example, in the form of the insertion of an IUD without informed consent. The common misconceptions around the reproductive capacity of women and girls with disabilities, and a lack of information on disability and rights, often means that they are denied access to safe and effective contraceptives of their choosing (Frohmader and Ortoleva, 2013).

Forced and/or coerced sterilisation: Forced and/or coerced sterilisation of women and girls with disabilities is common practice globally. Women and girls with disabilities are subject to forced hysterectomies to control their menstrual cycles, to prevent pregnancy as a result of sexual abuse, or because of misconceptions and discriminatory attitudes about their parenting abilities (Bradley-Jones, 2015). Forced sterilisation occurs when financial or other incentives, misinformation, or intimidation tactics are used to pressure an individual into undergoing the procedure. Women with disabilities are particularly vulnerable to forced sterilisations performed under the auspices of "protection" or legitimate medical care, often

with the consent of others in their name.² Women with intellectual disabilities, as well as those in institutional care, are at highest risk of forced sterilisation (Tilley, et al, 2012). Although the practice has significant human rights implications, the offenders are rarely held responsible for their actions (Frohmader and Ortoleva, 2013).

Sexual and gender-based violence (including physical, sexual, emotional, psychosocial and financial violence): sexual exploitation and emotional harassment during physical examinations, and clinical treatments and procedures often go unreported by women and girls with disabilities (Welner, et al., 1999).

Obstetric violence is one of the most hidden forms of GBV and is experienced by women and adolescent girls in many parts of the world, regardless of disability status. However, women with disabilities experience various forms of obstetric violence more often than women without disabilities (Wudneh, et al, 2022). It includes physical abuse (including the deliberate withholding of pain relief), verbal abuse, neglect, and coercive use (or withholding) of interventions during labour and/or birth. Procedures adopted without consent may include: physical immobilisation or restraint during pelvic examinations, trichotomy (scraping of pubic hair), excessive and unnecessary touching during examinations, the Kristeller manoeuvre (a procedure whereby the health professional “pushes” a pregnant woman’s belly in order to accelerate the expulsion of the foetus), routine episiotomy (surgical cutting in the perineum region to enlarge the birth canal) and caesarean section without anaesthesia (Terra, et al, 2019). Medically non-indicated caesarean sections, or caesareans performed without prior consent, are commonplace for women and girls with physical disabilities (Nguyen, et al., 2022).

2. Some findings... from interviews and discussions

2.1 Benefits of disability-inclusive informed consent

Everyone should recognise the benefits of inclusive informed consent: Clients and SRH workers alike benefit when a client’s consent to treatment is fully informed as the result of a clear, comprehensive and engaging communication process. A high-quality process of informed consent has many advantages. It helps clients make informed decisions, strengthens the client-provider relationship, and can improve the care-outcome process, follow-up and aftercare. Moreover, informed consent empowers the client (encouraging them to participate actively in their care process) and cultivates a sense of ownership and responsibility for their own health. When clients and their families understand the benefits, harms and risks of treatment, they can work together to ensure client safety. Furthermore, if clients are informed of the risks, they can cope better with any poor outcomes that may happen as a result of treatment.

² Human Rights Watch. [Sterilization of Women and Girls with Disabilities: A Briefing Paper](#), November 10, 2011

2.2 Challenges and actions to enhance inclusive informed consent

KIIs and focus groups with stakeholders helped identify the challenges to disability-inclusive informed consent (from their lived experiences and contexts). The findings provide the context for why inclusive and human rights-based approaches to informed consent are so important, and include challenges and actions for future practices based on multiple stakeholder experiences.

2.2.1 Key challenges for inclusive informed consent

Overall, key challenges to inclusive informed consent include:

Context:

- Women and adolescent girls with disabilities are disproportionately subjected to human rights violations such as forced sterilisation, contraception and abortion
- Decisions about SRH for women and adolescent girls with disabilities are often made by healthcare workers, family members or caregivers, disregarding a woman's right to choose
- Women and adolescent girls with disabilities also face discrimination based on the intersectionality of disability, gender and age.

Facilities:

- Lack of disability-inclusive protocols, supervision and monitoring
- Access challenges in SRH care environments
- Lack of training on disability rights and inclusion
- Lack of coordination with OPDs.

Healthcare workers:

- Negative attitudes, misconceptions and low confidence
- Lack of training in disability rights and care
- Time constraints, high workload (over-burdened staff)
- Poor communication techniques and training (inability to assess or detect a lack of client comprehension)
- Lack of accessible IEC materials (lack of materials in Braille, large print, simple language, and pictures; lack of sign-language interpreters).

Clients:

- Lack of knowledge about SRHR, including a lack of knowledge about rights relating to freedom of choice and freedom from violation
- Anxiety about choices and the outcomes of procedures, and a lack of trust in service providers
- Internalised stigma and low self esteem
- Comprehension, communication and cognitive difficulties.

Family members and caregivers:

- Lack of knowledge about SRHR, including a lack of knowledge about rights relating to freedom of choice and freedom from violation
- Controlling behaviours/rights violations.

Governments:

- Lack of accountability: authorities do not protect vulnerable groups
- Lack of funding
- Laws do not reflect freedom from violence and bodily autonomy
- Lack of disability-inclusive health policies.

2.2.2 Key actions and players

The global UNCRPD quality standards call for actionable change in healthcare systems to facilitate the inclusion of all persons with disabilities (United Nations, 2006). **Informed consent is a complex issue that needs a multi-level/mutual response from a variety of players.** Below is a summary table of key actions to overcome attitudinal, institutional, and environmental barriers to inclusive informed consent, and the players responsible for the actions presented.

Attitudinal	Institutional/facilities	Environmental
<p>Adopt a person-centred care approach that takes into account the intersectionality of the client and the different and changing needs of a person with a disability over their life course (HCWs)</p> <p>Normalise treating and engaging with women with a wide range of disabilities (OPDs, NGOs, schools, church)</p> <p>Provide sensitisation workshops with meaningful participation of women with disabilities for healthcare workers to raise awareness of attitudinal barriers, stereotyping, and controlling behaviours of caregivers and how these may impact their</p>	<p>Review policies and laws to ensure disability rights (local govt)</p> <p>Nurture an organisational culture that supports a high-quality policy of inclusion (facility coordinators)</p> <p>Ensure adequate staffing in the health facility (facility coordinators)</p> <p>Develop clear safeguarding protocols to eliminate harmful forced practices regarding women and girls with disabilities' reproductive rights and health across education, healthcare and legal sectors – monitoring (government, local leaders, healthcare workers, including facility coordinators, OPDs and NGOs)</p>	<p>Conduct accessibility audits (OPDs/facility coordinators)</p> <p>Provide reasonable accommodation (facility coordinators/HCWs)</p> <p>Provide communications in multiple accessible formats (OPDs/NGOs)</p> <p>Bring services to the clients who cannot access services – outreach – decentralise services (disability client advocates/OPD/NGOs)</p>

<p>clients (OPDs/NGOs, facility/programme coordinators/govt)</p> <p>Feature persons with disabilities in SRH materials (local govt and facility coordinators)</p> <p>Learn from the experiences of healthcare workers and hold them accountable for violations of consent (HR/human rights institutions/legal)</p>	<p>Build inclusion into organisational ethics and codes of conduct (facility coordinators, NGOs, OPDs)</p> <p>Training to empower HCW to recognise and promote the agency of women with disabilities to make informed and healthy choices (OPDs)</p> <p>Ensure a client with a guardian can make independent choices without coercion or interference (HCWs)</p> <p>Include disability inclusion and disability rights in HCW and facility-manager training (facilities, university curriculum, local govt)</p> <p>Employ persons with disabilities as interpreters/managers/HCWs (local govt, facility coordinators)</p> <p>Promote linkages and partnerships with OPDs to develop protocols, accessible summary guidelines and technical tools/training (SRH programmers, facility coordinators, OPDs)</p> <p>Identify a (preferably female) inclusion champion in the healthcare setting (OPD, facility coordinator)</p>	
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3. Conclusion

Challenge: Evidence from a rapid review of guidelines and tools for disability-inclusive informed consent reveals a startling gap between clinical guidelines on disability and informed consent and the real-world care that occurs in low–middle income countries and poor settings.

The purpose of the next part – the guide – is to:

- Help SRH workers comply with legal obligations of respectful care and informed consent
- Help SRH workers meet the principles of the UNCRPD
- Provide a resource for technical staff to respond to the access requirements of women with disabilities in SRH settings
- Provide a background for developing disability-inclusive training for respectful care and informed consent
- Provide a reference checklist for management in SRH care settings.

The guide itself is divided into two parts. Part I includes the challenges and actions that can be taken at community level and within services so as to raise rights awareness and to promote enabling environments. Part 2 focuses on addressing the roles and responsibilities of SRH care workers, caregivers and family members, organisations of people with disabilities (OPDs) and local governments to enhance disability inclusion in informed consent.

II. Guidance for inclusive informed consent in SRH services

1. Enabling environments for inclusive consent

1.1 Address attitudes and rights awareness

Challenge: Women with disabilities reminded us how stigma and negative attitudes towards disability persist in their communities. Healthcare workers were also cognisant of how stigma towards disability can limit clients' rights and their informed consent, and result in harm towards clients with disabilities.



Testimonies

"The process of informed consent starts before the person accesses the services. Informed consent relies upon women with disabilities and service providers, caregivers and community members knowing about disability rights and being free of negative attitudes and persuasions that may affect women with disabilities' SRH choices" (Expert interview).

"To be able to ensure each person can make his or her own decision requires a mindset and attitude change from parents, guardians and community members" (OPD member, Mozambique).

"There is a type of 'trauma of pregnancy' when the community feels this is not suitable for women with disabilities – the situation makes clients silent and affects their self-esteem, and this can impact on decision-making agency and informed consent" (Expert interview).

"The mindset of women with disabilities can be challenging. From a young age they feel rejected by society. They always feel that they should be pitied or ignored and this affects their decision making" (Community HCW, Uganda).

Actions (Everyone):

- 1. Address stigma, stereotypes and misconceptions** about the sexuality and sexual and reproductive rights of persons with disabilities at the individual, family, community and structural levels with the meaningful participation of OPDs, particularly women-led OPDs. Attitudinal barriers from families, communities and health service providers have been identified as the primary obstacles preventing persons with disabilities from accessing SRH services and exercising their right to informed consent.
- 2. Facilitate meaningful participation:** Engage local leaders, HCWs, guardians and women with disabilities and their representative organisations in community mobilisation to raise awareness of rights to SRH and freedom from violence,

particularly focusing on the right to choose and the agency of all girls and women with disabilities to make their own decisions about their bodies.³

3. **Informed consent starts early:** Advocate for inclusive and accessible comprehensive sexuality education (CSE) and access to SRH information and services for children and adolescents with disabilities in school and at home. Information and knowledge empower individuals to exercise their SRH rights, make informed decisions and enjoy a healthy, fulfilling and pleasurable sexual life. Furthermore, iCSE can prevent negative or extremely harmful SRH outcomes.

1.2 Increase the organisational capacity of SRH service providers

Challenge: The absence of standard protocols and routine training about informed consent in SRH services, especially facilities in remote areas, is a general challenge. Services which do have standard informed-consent protocols in place frequently do not include persons with disabilities. SRH service providers often do not have adequate knowledge and skills about informed consent and disability inclusion, and quality assurance checks that cover informed consent for women with disabilities are lacking. Stakeholders recognised that the lack of disability-inclusive protocols within SRH services, combined with inadequate training of healthcare workers, supervision and monitoring, may result in the rights of women and adolescent girls with disabilities being unfulfilled.



Testimonies

“We know that women with disabilities have the right to choose to have sex, the right to access maternal health and FP, the right to love and be in a relationship, but we have no clear policies or mandates that help provide clarity or guidance for informed consent when presented with a woman with communication difficulties” (Client advocate, Uganda).

“The key is to create an environment that gives the clear message that women with disabilities have the right to know about their body, services and most appropriate treatments” (Expert interview).

“There needs to be formal feedback mechanisms or complaints that go for review when obstetric violence is suspected, or in cases of verbal abuse and neglect” (Expert interview).

“The onus should not only fall on the individual service provider. The coverage of human resources should also ensure that there are staff to follow up on challenges with comprehension and decision making” (Expert interview).

³ Humanity & Inclusion. [Sexual and Reproductive Health and Rights for All: Disability Inclusion from Theory to Practice](#). Women’s Integrated Sexual Health 2 Action Project (WISH2ACTION), 2022

“Creating a safe space for the person with disabilities and describing your role in their treatment. From here, they are able to share their story and measures are taken from that basis. We face a challenge of limited time due to many patients, but we try to address it by identifying the patients then allocating time respectively according to the severity of their cases” (HCW, Rwanda).

Actions (facility and SRH programme managers): The premise should always be that clients with disabilities, including clients with mental and psychosocial disabilities, have the right and capacity to consent to SRH services, and that the services should benefit them. Clear standard inclusive informed-consent protocols need to be in place. Facility managers can nurture an organisational culture that supports a high-quality policy of inclusion, especially in informed consent, such as:

- 1. Implement and adhere to minimum standards for equal and discrimination-free SRH care**, including inclusive informed-consent guidelines and clear protocols to eliminate harmful forced practices regarding the reproductive rights and health of women and girls with disabilities.
- 2. Develop inclusive service provision protocols**, along with safeguards, to support decision making in independent ways so that women and adolescent girls with disabilities can provide informed consent for any contraceptive method, childbirth procedure or GBV forensic examination.
- 3. Build staff capacity and organisational knowledge on disability inclusion with the meaningful participation of women with disabilities**. All healthcare staff should undergo continuous learning on the guiding principles of informed consent (See Chapter 2.1: '[Role of healthcare workers](#)') and disability inclusion and display a positive attitude towards clients with disabilities.

Appropriate training is key to ensuring that staff:

- are aware of clients' needs in the area of accessibility and specific accessibility concerns for persons with disabilities.
 - develop the competence and confidence to address these effectively.
 - are trained in communicating with clients with different types of disabilities in general, as well as trained about their specific role and setting. This can be done by arranging awareness training which includes general material on accessible services and communication, as well as tailored training relating to the specific role and setting.
 - can recognise barriers to rights and informed consent, and learn practical ways in which they can be addressed.
- 4. Ensure SRH information and services are accessible**: consider the individual's needs and remove barriers to SRH care services. Conduct a barriers assessment

(accessibility audit) of services⁴ and ensure venues and furniture are suitable/accessible. Provide various ways and opportunities to ensure information about their health and well-being is accessible to persons with disabilities – for example, include posters and pamphlets that represent the spectrum of disability (see also chapter 1.3 '[Information in accessible formats](#)')).

5. **Routinely assess attitudes** towards disability among staff (quarterly) using a validated questionnaire.
6. **Integrate systematic disability screening**, for example by using the Washington Group Functioning questions⁵ to identify functioning limitations and determine necessary support, such as an interpreter, easy-to-read/pictorial materials, etc.
7. **Guarantee sufficient staffing and manageable workloads** to allow health professionals the necessary time to ensure informed consent.
8. **Employ persons with disabilities and particularly women with disabilities** as interpreters, managers, staff, client advocates.
9. **Appoint a disability inclusion officer** (who could be an existing staff member) or identify staff and community members to form a committee (with SRH staff and women-led OPD members) with responsibility for reviewing, updating and implementing the disability-access and inclusion policy.
10. **Launch an informed-consent quality improvement initiative at the SRH facility:** the committee can pilot/test informed-consent processes with persons with disabilities and get their feedback on satisfaction with the informed-consent process and the procedure in client exit interviews.
11. **Implement inclusive feedback mechanisms** and establish robust frameworks for monitoring, evaluation and accountability for breaches of informed-consent procedures or violations of autonomy. Provide opportunities to report harmful practices or rights violations within services, ensuring that persons with disabilities can provide their feedback easily. Ensure that reporting mechanisms to the supervisor and systematic complaints follow-up by the HR departments are in place.
12. **Inclusive budgeting:** dedicated funding is needed to guarantee accessibility and provide reasonable accommodation and accessible communications, i.e., the organisation allocates funds to mitigate communication and comprehension barriers, and allocates funding for staff training, salaried disability advocates and IEC materials.

All these initiatives for organisational capacity strengthening should be carried out with the meaningful participation of persons with disabilities, especially women with disabilities.

⁴ [Access to Sexual and Reproductive Health and Rights Information and Services: Perspectives of women and girls with disabilities in Uganda and Bangladesh](#), HI, 2021

⁵ Madans, J.H., Loeb, M.E. & Altman, B.M. [Measuring Disability and Monitoring the UN Convention on the Rights of Persons with Disabilities: The Work of the Washington Group on Disability Statistics](#). BMC Public Health 11 (Suppl. 4), S4 (2011)



Memo – Is your health facility free from discrimination?⁶



DISCRIMINATION-FREE HEALTH-CARE SETTINGS

IS YOUR HEALTH FACILITY FREE FROM DISCRIMINATION? MINIMUM STANDARDS HEALTH-CARE SETTINGS COULD USE TO ENSURE A DISCRIMINATION-FREE ENVIRONMENT FOR PATIENTS AND HEALTH-CARE PROVIDERS INCLUDE THE FOLLOWING:

01.

THE HEALTH-CARE CENTRE SHOULD PROVIDE TIMELY AND QUALITY HEALTH CARE TO ALL PEOPLE IN NEED, REGARDLESS OF GENDER, NATIONALITY, AGE, DISABILITY, ETHNIC ORIGIN, SEXUAL ORIENTATION, RELIGION, LANGUAGE, SOCIOECONOMIC STATUS, HIV OR OTHER HEALTH STATUS, OR ANY OTHER GROUNDS.

02.

INFORMED CONSENT IS REQUESTED FROM THE PATIENT BEFORE ANY TESTS ARE CARRIED OUT OR ANY TREATMENT IS PRESCRIBED. FURTHERMORE, PATIENTS ARE NOT FORCED TO TAKE UP OR REQUEST ANY SERVICES.

03.

HEALTH-CARE PROVIDERS RESPECT THE PATIENT'S PRIVACY AND CONFIDENTIALITY AT ALL TIMES.

04.

HEALTH-CARE PROVIDERS ARE REGULARLY TRAINED AND HAVE SUFFICIENT CAPACITIES AND COMPETENCIES TO PROVIDE SERVICES FREE FROM STIGMA AND DISCRIMINATION.

05.

THE HEALTH-CARE CENTRE HAS MECHANISMS IN PLACE TO REDRESS EPISODES OF DISCRIMINATION AND VIOLATION OF THE RIGHTS OF ITS CLIENTS AND ENSURE ACCOUNTABILITY.

06.

THE HEALTH-CARE CENTRE ENSURES THE PARTICIPATION OF AFFECTED COMMUNITIES IN THE DEVELOPMENT OF POLICIES AND PROGRAMMES PROMOTING EQUALITY AND NON-DISCRIMINATION IN HEALTH CARE.

⁶ Source: UNAIDS (2017). [Agenda for Zero Discrimination in Health Care Settings](#). Geneva: United Nations.

1.3 Information in accessible formats



Testimonies

"If communication challenges don't exist, it is much easier to facilitate informed consent" (HI expert interview).

"It's also challenging to communicate with persons with a speech disability.

Sometimes it's hard to tell what they want and the type of help they need.

Depending on the degree of disability (blind or deaf) we try to support them to the best of our ability like using sign languages, and when it's beyond our control we reach out to caregivers with higher expertise" (Doctor, Uganda).

"Each member of staff working in SRH services has a responsibility, relevant to their own role, to ensure that services are accessible to persons with disabilities. They need to have the tools and time to make sure their interactions and communication with clients with disabilities are appropriate, respectful, and are delivered in ways that persons with disabilities can receive and understand" (Expert interview).

Challenge: Service providers mentioned not having access to or knowledge of easy-to-read tools or other adapted materials for inclusive or supported decision making, nor how to use them effectively.

Actions: In order to facilitate inclusive informed consent, clients need to be presented with essential and accurate information in accessible formats, with unbiased, non-directive and non-discriminatory information on contraception, abortion, post-abortion care, prevention and treatment of reproductive cancer, safe pregnancy, labour and delivery, postnatal care, parenting (including the right to parent, and information about available services and supports for parents with disabilities), CMR and context related mandatory reporting.

1. **Information, education, and communication (IEC)** materials can help present information in accessible formats and support communication. The broad spectrum of disability requires a wide variety of formats, including the simplification of informed consent and assessment of client comprehension using easy-to-read texts and printed multi-media or visual/audio presentations, i.e. drawings and illustrations that focus on health choices and the risks and benefits of procedures and treatments. The compilation of IEC materials should be done with the meaningful participation of persons with disabilities.
2. **Get feedback** on how IEC tools facilitate or hinder the consent process and adapt them accordingly. An advisory group of women and adolescent girls with a range of disabilities can ensure that tools are created in line with their experiences and are used to promote their rights and health.
3. **Work with communication assistants** (interpreters/caregivers) or client advocates to ensure information is related in an appropriate manner.

4. Collate inclusive IEC materials and tools into a **local or national resource bank/pictorial bank** for SRH practitioners to support informed decision-making around sexual, reproductive and maternal health.
5. Ensure **access to an accredited (preferably female) sign-language interpreter** when needed. Service-provider staff should not be expected to be trained in sign language. The sign-language interpreter needs to be trained on SRHR/GBV and confidentiality.
6. **Train staff** to use tools and not rely solely on caregivers for communication and comprehension assessment. Adults with disabilities are always assumed competent unless otherwise demonstrated. Furthermore, relying on children and family members to interpret or translate is not recommended on ethical and legal grounds. The document 'On Speaking Terms' gives more information on this.⁷
7. **Conduct monthly debriefing with HCWs** – monitor/document/collate clients who present with communication/comprehension difficulties and discuss challenges with informed consent and the outcomes of treatments or procedures.



Memo – Checklist of resources to facilitate inclusive informed-consent procedures

- Sign-language interpreters for persons who are deaf or hard of hearing
 - Plain language handouts of clients' rights and freedom in decision making
 - Easy-to-read materials for persons with intellectual disabilities or persons who cannot read (e.g. pictorial materials)
 - Information in digital formats for persons using screen-reading technology
 - Braille documents for persons who are blind
 - Private spaces which are accessible for persons with mobility disabilities (ramps, toilets, enough space to manoeuvre a wheelchair or mobile device).
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Memo – Proposed IEC materials

- Simplified information appeals to clients and is associated with decreased anxiety and increased satisfaction with the consent process (Kadam, 2017).
- An advisory group of women with a range of disabilities should ensure that tools are created in line with their experiences and are used to promote their rights and health.
- We suggest an innovative approach that uses poor health-literacy communication strategies and visual aids to augment and potentially replace the traditional approach to informed consent.
- A video that provides do's and don'ts on language to refer to persons with disabilities⁸.

⁷ Health Service Executive. [On Speaking Terms: Good Practice Guidelines for HSE Staff in the Provision of Interpreting Services](#). 2009

⁸ See example: [Disability-inclusive communication guidelines](#), UN, 2022

- Materials that focus on the agency and capabilities of clients – see, for example, the video “[Don't underestimate me](#),” that talks about the importance of positive framing, focusing on what persons with disabilities can do.
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- For more information about **accessibility of SRHR services**, see:
- [Learning from a disability-inclusive sexual reproductive health and rights program \(WISH2ACTION\)](#)
 - [Step Towards Disability Inclusive Sexual Reproductive Health: Learnings from WISH2Action Project](#)

2. Partner engagement to ensure informed consent

The following section of the guide focuses on the roles different stakeholders have to play in facilitating inclusive informed consent.

Below is a visual representation of stakeholders' roles.



2.1. Role of healthcare workers



Testimonies

“The staff are often short-tempered and impatient. They come across as arrogant and not easy to approach” (OPD member, Uganda).

“I had a nurse tell me it would be awful for me to be pregnant, and she told me to take birth control because I am kajotie (disabled)” (Client with disabilities, Rwanda).

“An unwanted pregnancy can lead to further disabling conditions, and being forced to be sterilised can make women with disabilities feel less than human” (Client advocate, Uganda).

“I don’t always know if it is the best option for me. I feel stressed when I need to decide, what if I make the wrong decision?” (Client with disabilities, Rwanda).

“Clients with disabilities don’t trust us and they feel that we have bad intentions” (Nurse, Uganda).

“Service providers in mainstream services are often not aware of disability-specific health challenges or stigma and don’t know what clients need – they don’t feel confident providing services” (SP, HI group, Rwanda).

“I noticed that community health workers were more experienced in recognising people with disabilities as they work in the community. They have a lot of information about people living with disabilities and assist them with knowing what services they need” (SP, Rwanda).

“We need to give service providers technical support to help render their clients independent – What can I do? What are the techniques and the methods I can use to help communication or someone who is struggling to voice their opinions about the choices they are provided with?” (Expert interview).

“Health workers must be honest with themselves and reflect on their mistakes and learn what to do next time. The spectrum of disability is so broad, they must not feel they can do it right for everyone each time. It is about asking the client, and asking for help from a supervisor” (Expert interview).

“Service providers should recognise the boundaries of their own professional competence, in terms of their ability to facilitate inclusive informed consent. They need to be trained to deal with controlling family members and know when to ask for help with assessing comprehension and capacity” (Expert interview).

Challenge: Healthcare workers acknowledged their responsibility to facilitate valid informed consent with clients with disabilities but encountered difficulties when engaging with them.

- HCWs felt they lacked the skills and tools to help with independent interpretation, communication, and comprehension testing.
- HCWs mentioned that disability training is not systematic and often one off, and that new staff are not considered. Those in obstetric care mentioned not having received training in caring for pregnant women with intellectual and developmental disabilities.
- Staff mentioned that when they encountered challenges with clients with sensory or intellectual disabilities, they did not know of a relevant person to approach for guidance or assistance.
- HCWs are seemingly over-burdened, with little support or supervision, and time and resource constraints.

Actions:

1. **Develop disability-inclusion competency among staff with the meaningful participation of women with disabilities:** A competency framework to optimise informed consent i.e. healthcare workers in SRH care settings need to be familiar with the content and implications of current UN instruments, including the Convention against Torture and other Cruel, Inhuman, and Degrading Treatment or Punishment, the UNCRPD, the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) and national legislative frameworks relating to the rights of persons with disabilities.⁹
 2. Continuous capacity-strengthening of SRH care workers on the principles of inclusive informed consent.
-



Memo – Guiding principles for inclusive informed consent

1. Adopt a **person-centred approach** placing the client at the centre of care. Listen attentively to the client's needs, preferences and life experiences. Provide comprehensive information and healthcare options tailored to clients' individual needs. Uphold their rights and autonomy, consistently prioritise and respect the client's wishes. Empower them to make decisions about their health and well-being.
2. **Respect the right to non-discrimination and dignity:** Treat clients with empathy, compassion, courtesy and thoughtfulness. Ensure full respect for their dignity regardless of age, disability, education level, social status, race, ethnicity, marital status, gender identity, sexual orientation, or any other characteristics.
3. **Assume capacity to consent:** Unless otherwise demonstrated, all adults, including those with intellectual disabilities, have the capacity to consent. Guarantee the mobilisation of every available resource to ensure the person with disabilities can exercise their capacity to consent. Use caregivers and family members as resources to support communication and to facilitate informed

⁹ <https://www.un.org/esa/socdev/enable/rights/documents/ahc6idcda21infosheet.doc>

consent, bearing in mind they are not always the ultimate decision-making authority. When a person with disabilities does not have the capacity to make their own decisions, involve them as much as possible in the care process, communicate with them directly, and seek permission before any examination. Adopt measures to ensure decisions reflect the individual's rights, will, and preferences, and are tailored to their circumstances.

4. **Respect the right to information:** Offer unbiased and comprehensive information, enabling clients to make informed and autonomous decisions about their fertility and other sexual and reproductive health matters.
5. **Respect the right to choose:** Recognise and uphold the rights of women with disabilities to decide freely on having children, choosing contraceptive methods, or terminating a pregnancy. Provide a wide range of care and treatment options, unless medically contraindicated, and support women in making their choices without judgement or stigma.
6. **Address personal biases:** Regularly self-reflect and remain aware of any implicit or subconscious biases. Ensure that these biases do not influence the SRH care options you offer, and always respect and uphold a client's autonomy.
7. **Respect the right to privacy and comfort:** Ensure the consultation and counselling is done in a private setting and reassure the client that confidentiality is guaranteed. If a client arrives with an accompanying person, always provide the option for the client to be alone during both the consultation and examination. Communicate clearly the roles of all the healthcare workers present and provide the option to limit the number of staff present. Whenever possible, based on staffing, give clients the choice of their healthcare provider's gender. Many women may prefer to be consulted by a female staff member. Respect the woman's right to her bodily autonomy, explain the nature and purpose of any physical examination. Ask for consent and address any questions and concerns prior to the examination. If a client asks for the presence of a supporting person or requires them for communication, always offer the option for the physical examination to be conducted in private. Inform the client that she can withdraw her consent at any time and that the examination will be stopped if the client is uncomfortable. Reassure the client of her having control over the examination. Do not question or challenge the decision of a client to decline an examination.
8. **Respect the right to confidentiality:** Uphold the Hippocratic Oath by ensuring that the personal and medical information of all clients, including women with disabilities, remains private. Adhere to local legal and ethical standards, avoiding discussions about clients within or outside healthcare settings.

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3. Provide **tailored disability awareness and appropriate, evidence-based training** for healthcare workers facilitated by a person with disabilities. Integrate case studies and topics on disability into current SRH-provider training on informed consent.

Include building capacity on how to screen for disability and comprehension, provide reasonable accommodations, and how to engage with clients effectively.

- a. Include how to communicate with clients with disabilities, i.e. using rights-based language and **inclusive communication strategies**.
 - b. **Safeguarding:** Train healthcare workers on the various types of abuse so they can understand how their actions, words, and power imbalances can affect informed decision making for clients with disabilities.
 - c. Encourage staff **to take their time** when treating women with disabilities and raise awareness of who to ask for assistance when met with communication or comprehension challenges that are beyond their training.
 - d. Raise HCW **awareness of supported decision-making models** and how to use them to enhance clients' rights.
4. **Follow up** – With the client's consent, ensure that the details of a woman's accessibility or communication requirements are included in follow-up appointment plans.
 5. **Debrief** – Collate identified clients with communication/comprehension difficulties and discuss outcomes with the supervisor.
 6. **Educate clients about their rights** on giving consent, protection from abuse and violence, and rights to SRH care, including contraceptives, maternal healthcare, positive childbirth etc.
 7. **Create awareness of human rights violations and safeguarding concerns**, including clients' freedom to feel safe during examinations, and freedom from gender-based violence, intimate partner violence and sexual abuse by caregivers, family or health care workers.
 8. **Empower:** Encourage women with disabilities to take an active role in obtaining information relating to SRH issues and treatment choices.
 9. **Decentralise skills and training:**
 - a. While awareness of disability rights and informed consent needs to be strengthened among all healthcare workers, 1-2 staff members should receive intensive training to become disability advocates. They will be consulted to support the inclusive informed consent process and be responsible for linking with OPDs for referrals. Staff members with disabilities or family members with disabilities can be considered to become disability advocates among the staff
 - b. Decentralise service delivery (use community-based approaches) to increase accessibility and acceptability for key populations. Outreach, mobile services, drop-in centres and venue-based approaches are useful for reaching those with limited access to, or who are underserved by, SRH care facilities. These approaches call for critical linkages/partnerships with OPDs and community health workers.
 - c. Reinforce the role of community healthcare workers and village health teams to identify and refer persons with disabilities to SRH services.

- d. Outreach and home visits – mobile client advocates can be a first line for realising rights and explaining choices for treatment. These healthcare workers could flag communication/access issues quickly and get assistance for the health visit. With training, they could be advocates for SHR rights and informed decision making.
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Memo – What should healthcare workers' training look like?

Considering the multiple levels and layered process of engagements and rights in the informed-consent process, and the barriers in low-resource settings, training should be efficient, brief, cost effective, participatory, engage with persons with disabilities, use inclusive rights affirming language, and include family members.

Challenge: In addition to the physical and psychological consequences of GBV, it can also result in low self-esteem and affect SRH decision making.

Action: SRH workers are crucial in identifying and responding to GBV. They need to be trained in the identification of silent signs of GBV, provide trauma-informed care for GBV survivors, and must be well-informed about the heightened risk of GBV among persons with disabilities, particularly women and girls.



Memo

Trauma-informed care is a healthcare approach that considers the influence of past trauma on an individual's well-being, aiming to create a supportive and safe environment while preventing re-traumatisation. It emphasises empowerment, choice and collaboration to promote healing and overall well-being.

2.2 The role of caregivers and support persons

SRH programme managers and healthcare workers need to be well-informed and aware of the roles that caregivers and support persons play in the informed-consent process.



Testimonies

“Guardians are often overprotective, but sometimes they have the best interests of the woman at heart... we must acknowledge that those closest to our clients – their caregivers or support people – know their needs due to proximity, and they may be able to provide us with information we may not otherwise get” (HCW, Uganda).

“We need to make decisions for them in order to protect them from the burden of pregnancy” (Caregiver, Rwanda).

“Involving family and caregivers is important. They are often the ones who are violating rights and blocking consensual services, but they can also be instrumental in realising rights. They may have recommendations to share on how they can help realise rights. They know the dangers and violations, but their voices are not sought” (HI expert interview).

“My child is 20 years old and we try to protect her as much as we can. Even when we have a visitor, we make sure that she isn’t alone so that she doesn’t suffer sexual abuse and get pregnant” (Caregiver, Rwanda).

Challenge: Decisions about family planning for women and adolescent girls with disabilities are often taken by others, and service providers often have a dependency on parents or caregivers when it comes to informed consent. Discussions with stakeholders reveal that parents often worry that their daughters are unsafe and vulnerable to abuse, and want to protect them. Women with disabilities’ differing levels of dependence on caregivers makes independent informed consent difficult. Women with disabilities may also be economically dependent on caregivers and rely on family members for daily care, transport and communication support. Women with disabilities may also experience abuse and negative attitudes from caregivers and family members, all of which affect their utilisation of SRH services and their decision making. In many cases, parents or caregivers will dominate the client/healthcare worker exchange, and this can affect clients’ self-esteem, trust and confidentiality. Furthermore, service providers may assume incapacity or lack ways or time to communicate, thus relying on guardians has become everyday practice. Furthermore, health workers are often caught in an ethical dilemma with guardians. While the literature and some of the consultation narratives reveal that guardians can pressurise or bar access to reproductive health services, it was acknowledged that they can provide critical support to facilitating travel to the services and communication assistance.

Action:

- Service providers need to be aware of the role of caregivers and trained in facilitating informed consent and supported decision making for women and adolescent girls with disabilities.
 - **Supported decision making:** SRH care workers must be trained to facilitate independent decision making, with supported decision making a viable and rights-enhancing option. SRH care workers can facilitate independence when the client with disabilities first arrives at the service by talking directly to the client – even if an interpreter is used – and letting the client decide who should assist them with access, communication, and decision making. The supporter has no other influence on the process other than giving advice. The client with disabilities makes the final decision.
 - Make both clients and supporters aware of the **limitations of guardian authority**, especially the in-country legalities or lack of, i.e.
 - termination of parental rights – a guardian never has authority to consent to the termination of the individual's rights as a parent;
 - abortion – a guardian cannot force an individual to terminate a pregnancy against her will (these limitations may differ country to country/state by state).



Memo

Where capacity or comprehension is in doubt, supported decision making (SDM) has emerged as a possible alternative to legal guardianship.

SDM requires making available various support options that can enhance an individual's capacity in the decision-making process, enabling them to retain their independence.

Supported decision-making models prioritise the individual's will and preferences and protect fundamental human rights, including rights relating to personal autonomy, legal capacity and equal recognition before the law.¹⁰

Challenge: Caregivers and parents said they themselves often lack the necessary knowledge and information to help ensure that the reproductive health needs of women and girls with disabilities are met. This makes it more difficult for caregivers to facilitate/support informed decision making and reproductive health choices.

¹⁰ Jeste, D. V., et al., (2018). [Supported Decision Making in Serious Mental Illness](#). Psychiatry, 81(1), 28–40. <https://doi.org/10.1080/00332747.2017.1324697>

Action: While it is important to respect the person's privacy, it is also important that family members, caregivers, support persons, or those assisting them, understand key information for their safety; for example, what medication should be taken and when, and under what conditions the person needs to return to the service. Through their proximity, family and friends know the needs of women with disabilities. Build on what they know and facilitate their input to be rights enhancing.

Challenge: A common challenge that was encountered by caregivers was that the community considered disability as a curse to the family or as a consequence of being possessed by an evil spirit or bewitched. These misconceptions make caregivers feel marginalised by the community.



Testimony

“Due to her mental disability, she’s not able to make her own decisions but as her caregiver I try to emphasise her value and make people know her situation is not because of witchcraft, as many say. As a caregiver, I don’t want people to call me a witch. I need the right to be respected and not stigmatised” (Caregiver, Rwanda).

Action: Training should also involve community members so as to debunk myths and beliefs about witchcraft and evil. Training also needs to happen early – “parents often lack guidance and support on how to talk about sex and relationships with disabled young women and girls, including with regard to sex, menstruation and puberty. Early intervention is also fundamental for facilitating informed consent” (SP, HI). Make sure that caregivers are included in awareness campaigns, along with activists who fight for rights and are aware of issues in their local communities.



Realise that many of these actions may be beyond healthcare workers' duties or exacerbate already-overburdened staff. Work within these constraints.

→ See Tool – [Quality assessment checklist for inclusive informed consent](#)

2.3 Role of OPDs

OPDs are important structures within societies and play a role in facilitating self-representation and amplifying the voices of persons with disabilities. The participation of persons with disabilities and their representative organizations is critical to the success of any multi-stakeholder effort to advance implementation of the UNCRPD. Persons with disabilities and OPDs provide greater understanding of the day-to-day experience of disability and thus a basis for informed decisions and policies.

However, it is important to acknowledge the gender dynamics within these organizations. In many cases, OPDs are predominantly led by men, and their priorities may not necessarily focus on advocating for the sexual and reproductive rights of women with disabilities. Therefore, it is crucial to engage and collaborate with OPDs led by women.

Moreover, participation and inclusion are empowering and facilitate active involvement in decision-making.

Including persons with disabilities and OPDs, particularly women-led OPDs and other civil society organizations into informed consent partnerships is a fundamental requirement for achieving truly inclusive and informed consent processes. Whether the focus is on developing and facilitating trainings or monitoring the UNCRPD implementation, their inclusion is not just a choice but a necessity to ensure that the rights and needs of persons with disabilities, especially of women with disabilities, are fully recognised and respected.



Testimonies

"Through women-led OPDs, women can be empowered to talk and express and decide for themselves on what the best options for their SRH are" (OPD member, Rwanda).

"OPDs can work with civil society to help identify people with disabilities in the community and facilitate their access to services such as independent transportation or an accredited sign-language interpreter. OPDs can establish trust and a rapport with clients and provide a 'third eye' for monitoring a rights-based informed-consent process" (Expert interview).

"We don't see clients with disabilities, they are invisible" (Doctor, Uganda).

"Remember OPDs can also be conservative, hierachal, and not gender friendly, and their resources, capacity and time are often stretched." (Expert interview).

Challenge: SRH service providers, SRH programmes and health ministries do not always consult women with disabilities on how to provide appropriate disability-friendly SRH services.

Action: Keeping organisations and health facilities accountable to disability rights commitments and safeguarding women with disabilities requires the participation of OPDs,¹¹ particularly women-led OPDs.

¹¹ United Nations. [Toolkit on Disability for Africa: Building Multistakeholder Partnerships for Disability Inclusion](#). 2017, p. 4



Memo – Types of support OPDs can give...

- By driving advocacy activities and engaging in political processes that support greater representation of persons with disabilities, OPDs can campaign and raise awareness of the right to informed consent and help build trust in SRH services.
- OPDs can support an inclusive informed-consent agenda by giving inputs on disability rights and help align the informed-consent process with UNCRPD.
- Give input to and facilitate ongoing capacity-building and sensitisation training for healthcare workers.
- OPDs may help develop accessibility standards and codes of conduct for interacting with clients with disabilities, and can work with healthcare workers to assist with accommodations, modifications of informed-consent tools and communication barriers. OPDs may be able to facilitate sign-language interpretation, facilitate information on procedures, and help determine client comprehension and client capacity.
- OPDs can harness their representation in local communities for targeted outreach, e.g. OPD engagement officers can identify clients with disabilities and their specific SRH and support needs.
- OPDs may follow-up with clients with difficulties and facilitate client satisfaction feedback or rights-violations reporting to the appropriate justice institutions.

Challenge: The absence of standardised informed-consent procedures, particularly of inclusive informed-consent procedures, is a common challenge in health facilities in LMICs. In certain contexts, this can contribute to persons with disabilities lacking awareness and not exercising their right to informed consent when seeking SRH services.

Action: Strengthen the awareness and capacity of OPDs, particularly women-led OPDs, about sexual and reproductive rights and the right to informed consent. Facilitate linkages between OPDs and women's rights organisations, empowering them to become effective advocates for sexual and reproductive rights.

2.4 Role of governments



Testimonies

“Authorities don’t protect vulnerable women and girls, so there is a lack of accountability” (OPD member, Uganda).

“We know there is a lack of funding for accessibility and inclusion. This makes progress for disability-sensitive healthcare extremely difficult. The lack of funding for training or service providers particularly is a big challenge” (OPD member, Rwanda).

“In many cases, guardians make family planning decisions or encourage sterilisation, and these have emotional damage on the woman with a disability; they do not respect the voice or opinion of women with disabilities” (Client advocate, Rwanda).

“Violations will continue to occur if there is no consequence for providers” (Expert interview).

Challenges: There is a lack of transparency and accountability for disability inclusion in policies.

Actions: Governments have specific obligations under international law to respect, protect, and fulfil the SRH rights of women and girls with disabilities. Governments must:

- Protect women and girls with disabilities from interference by third parties, for instance by ensuring contraceptive or abortion access irrespective of parental or guardian consent. Governments must eliminate requirements for third-party consent for SRHR services;
- Review policies to align with the UNCRPD and the convention on torture, and ensure decriminalisation of abortion;
- Ensure SRH information, education and services are accessible, affordable and inclusive (sensitive to gender, cultural and disability needs) in both law and practice, and are distributed throughout the country;
- Ensure healthcare personnel are adequately trained and held accountable for their service provision;
- Ensure persons with disabilities have equal employment opportunities in SRH organisations and services;
- Ensure information and services conform to ethical standards and respectful, quality care, i.e. obligating informed consent and respecting a person’s privacy and confidentiality;
- Ensure the offenders of forced sterilisation are held responsible for their actions.

As described in this section, partner engagement is important and necessary to ensure informed consent for women with disabilities. However, the role of the client in the informed-consent process should also not be forgotten. A client must feel empowered to make a decision about her/his SRH. Throughout the informed-consent process, partners need to ensure that clients receive clear and complete information about SRH. Having the necessary information and knowledge will empower a client to be able to make decisions about her/his SRH, and to consent.

Conclusion

Gaps and research needs

For inclusive informed consent and better-quality care, future projects need to engage stakeholders in participatory and longitudinal research to:

- Highlight the barriers and facilitators for inclusive informed consent – particularly in low-resource and poorer settings;
- Evaluate the sustainability and long-term effects of informed-consent training interventions on healthcare workers' attitudes, skills and confidence in facilitating inclusive informed consent, client experiences and healthcare outcomes;
- Analyse the cost-effectiveness of disability training for healthcare workers.

Conclusion

Better and inclusive informed consent is a mere spoke in the wheel of ensuring improved sexual and reproductive health outcomes for all women, regardless of disability. Informed consent is at the centre of the wheel. Informed consent must be viewed as a continuous dynamic process rather than an isolated event, involving multiple stakeholder collaborations on multiple levels. It is essential that collaborative efforts and innovative strategies and materials are used to tackle stigma and promote inclusive communication in order to facilitate valid and meaningful consent for positive client outcomes. Improving healthcare workers' disability knowledge and awareness and increasing person-centred consensual care through organisational policies and provider training may help address the inequities women with disabilities face in accessing high-quality SRH care.

Tool – Quality assessment checklist for inclusive informed consent

This checklist can act as a quality assessment tool to be used by facility managers, healthcare workers and client advocates to ascertain rights enhancement.

NB!! The following quality assessment checklist only touches on a small rights-enhancing process – it needs to be piloted and tested in multiple LMIC and poor settings.

Elements for inclusive informed consent	Yes	No	N/A
Are there clear values/guidelines/protocols /mandates in place to enhance ethical and informed treatment practices?			
Have staff received training in disability inclusion and inclusive informed consent?			
Are there decision-making and communication aids available for use? Has the healthcare worker been trained to use these tools?			
Have different communication options been presented and used?			
Did you feel confident, are you happy with what was presented, what would have made it better?			
Has a disability been identified? Screening with Washington Group questions?			
Has comprehension been assessed using a verified technique?			
Has support for decision making been offered – what level of assistance is required?			
Have trusted family members/carers been involved in the process of communication/comprehension?			
Are there staff members to provide support?			
Has someone been made responsible to check in/follow up with the client before the procedure to ensure consent is ongoing? That they may opt out/change their mind?			
Has the healthcare worker consulted with the client more than once and given all the correct information and options?			
Has enough time and due diligence been taken?			
Are you certain that the client knows her rights and is giving consent free from emotional distress or coercion?			

Are there safeguards in place to protect women from harmful practices such as forced sterilisation?			
Can they voluntarily choose sterilisation?			
Are referral systems in place for other needs – disability-specific support? Reporting and support for GBV?			
Is the healthcare worker satisfied that consent was given freely without outside/third-party influence?			
Is the client satisfied with the information and options presented?			
Is the client satisfied that consent was give freely without experiencing emotional duress and without outside/third-party influence?			

Appendices: Data collection tools

Participants with disabilities and their caregivers were identified and recruited by supporting organisations (OPDs) which provide services to persons with disabilities in Rwanda and Uganda. Discussions lasted approximately 60 minutes and took place at locations close to health services. Participants with disabilities were asked about their experiences of accessing sexual and reproductive healthcare and their interactions with healthcare providers. The scope of the discussions included knowledge on what is consent, satisfaction with HCW interactions, access to sexual-health education and information, family planning, contraception, abortion, antenatal care (ANC), childbirth and postnatal care (PNC) services, experience of violence at home and in the community, and obstetric and gender-based violence in healthcare facilities. Do you know your rights/rights of persons with disabilities? Who stands in the way of your/their right to health? What are the barriers and enablers to informed consent?

1. Key informant interview guide

KIIs with health and GBV service providers

Objective To explore the experience of service providers in the SRH sector in ensuring informed consent when WWD access SRH, MNCH, and GBV care.

Design Exploratory, qualitative study.

Setting Rwanda, Uganda and South Africa

Participants Purposive sample of 12 SPs (4 in each country)

Methods Semi-structured interviews or focus groups will be conducted face to face/online with participants. Discussions will be audio-recorded, notes will be summarised, and relevant quotes will be captured and transcribed verbatim. The consultant and researcher will read the notes and quotes and generate key themes for the presentation of the data findings. Consent will be recorded verbally or written.

Background of service providers

Interview date and place	
Consent acquired	Yes/No
Name	
Place or residence/village/country	
Name of facility/organisation	
	Government

Type of sexual and reproductive healthcare setting	Private for profit Private not for profit CHW
Sex of the respondent?	Male Female Other (please specify)
Which of the following best defines your role?	Nurse/midwife Clinician Nursing assistant Community health worker Other (specify)
How long have you been working in healthcare (total in years)?	
How long have you been involved in offering sexual and reproductive health services (total in years)?	
What is your current employment status?	Government employee Private employee Intern Volunteer Other (specify)
Which of the following is your primary role at this health facility or community?	Direct patient care Administration Research Support function Other (specify)

Questions		
Theme	Questions	Notes
Consent and recording	<p>Do you understand the purpose of this discussion?</p> <p>Do you consent to participate in the discussion?</p> <p>Do you consent to the audio recording?</p> <p>Do you have any questions before we start?</p>	
Icebreaker	<p>What words or phrases come to mind when you hear “informed consent”?</p> <p>Please describe your role in SRH or the disability sector.</p>	Ask participants for a few words or phrases – don’t spend too long.
Knowledge of rights frameworks and legal mandates	<p>Can you describe any national regulations (in the Constitution, legislation or in other legal codes) that should be implemented in SRH, MNCH or GBV services?</p>	<p>i.e. the right to equal access for women and men to all forms of healthcare, at the highest available level.</p> <p>Incl. access to sexual and reproductive health services; women’s rights to make autonomous decisions regarding their sexual and reproductive lives; all women have the right to a positive childbirth experience whether disabled or not.</p> <p>Intrapartum respectful maternity care is defined as a fundamental human right that includes respecting women’s beliefs, independence, emotions, dignity, and preferences to reserve their right to have a</p>

		<p>companion or to perform their cultural rituals.</p> <p>Aware of the minimum legal age to provide independent informed consent.</p>
Inter facility/ programme mandates	<p>Please describe what mandates/written guidelines/policies for IC with vulnerable groups, especially women with disabilities, exist in your facility/programmes.</p> <p>Is informed consent considered when designing and implementing SRH programmes?</p> <p>To the best of your knowledge, what sources of information on sexual and reproductive health rights at health facilities are available? Are these readily available? (brochures?)</p>	
	<p>What do you think is the overall preparedness of staff to ensure informed-consent procedures?</p> <p>Experience in developing mechanisms for monitoring compliance and ensuring accountability to set standards?</p> <p>How can we identify any gaps in tools that are evident when ensuring staff adhere to the minimum standards?</p> <p>How should we address challenges in referral pathways between SRH and OPDs and make information on the available services in the area widely accessible to women and girls?</p>	

Identify/screening	<p>How do SPs know or recognise a woman client as living with a disability?</p> <p>What are the ways SPs screen for disability?</p>	<p>Probed for Washington Group questions.</p> <p>Are the questions sufficient to screen and identify clients with disabilities?</p>
Role and responsibilities/ Who is accountable for informed consent?	<p>Who should ensure the safety and dignity of women with disabilities when seeking SRH services?</p> <p>Who should take the lead on ensuring consent is informed and fulfilled for all persons with disabilities?</p> <p>How do you perceive your role in upholding the rights of clients [with disabilities]?</p> <p>What are the limits/challenges to safeguarding clients with disabilities when they access SRH?</p> <p>When you provide services to persons with disabilities, what challenges do you face?</p> <p>Do you feel confident in providing SRH services for women with disabilities in an autonomous and independent way?</p> <p>What are the indications/when do you know if there is a need for proxy consent, i.e. for facilitating the person with an intellectual disability to participate in the consent procedure?</p> <p>Parents, guardians and care assistants often make decisions for women with disabilities – what are the positive/negative outcomes of this?</p> <p>What quality assurance protocols or steps do we need to take when</p>	<p>Maternity patients seeking care in public health facilities</p> <p>A pregnant woman's decision to refuse recommended medical treatment</p> <p>Forced compliance</p> <p>Mistreatment in childbirth</p> <p>Loss of autonomy; being shouted at, scolded, or threatened; being ignored, refused, or receiving no response to requests for help</p> <p>Patient-designed items included indicators of verbal and physical abuse, autonomy, discrimination, failure to meet professional standards of care, poor rapport with providers, and poor conditions in the health system.</p>

	<p>caregivers want to get involved in decision making?</p>	
Current and past experience with informed-consent procedures	<p>Gaining consent can at times be difficult and complex – can you tell me about any circumstances or scenarios under which consent will be difficult to obtain?</p> <p>Tell me about a time when you felt that consent was not understood.</p> <p>Are there procedures for determining participant literacy and mental capacity?</p> <p>Based on your experience, and to the best of your knowledge, what is the situation with regard to the accessibility of the informed-consent procedures and forms in your profession/health setting?</p> <p>So what is realistic in terms of getting consent?</p> <p>Why is it important that women with disabilities are given support to participate in their own decision making? What support should they get and from whom?</p>	<p>Procedures for determining participant comprehension of the required information</p> <p>Procedures to ensure that informed consent is obtained in a setting free from coercion and undue influence</p> <p>Procedures for documenting the informed-consent process</p> <p>Storage locations for blank ICFs</p> <p>Storage locations for completed ICFs</p> <p>Informed-consent information is available in Braille Y/N</p> <p>Information is available in audio, drawings, graphs and illustrations; uses simple language, accessible formats and is in visible format; is available in national and local languages; the materials are widely available in health facilities; at least 1 health staff member can use sign language</p> <p>[Mention usage of low health-literacy communication strategies and visual aids to augment and potentially replace the</p>

		traditional approach to informed consent.]
What are the key barriers to informed consent?	<p>Which health problems may clients present where IC can become a difficult procedure to undertake?</p> <p>Can you tell me of a time when you felt it was difficult to get informed consent from a women with a known disability?</p> <p>In your experience, do caregivers accompany and answer when questions are put to patients?</p> <p>Are current guidance tools or training adequate to assess patients' consent and understanding of treatment?</p> <p>Considering the barriers, what is realistic in terms of getting consent?</p>	<p>Are you aware of identifying dissenting behaviours?</p> <p>Are you able to do comprehension assessments?</p> <p>What signs does one have to look out for when assessing comprehension and consent?</p> <p>How can you tell whether the patient understands what treatment options you are offering?</p> <p>Appropriate communication strategies and the inclusion of familiar caregiver(s).</p>
Harmful practices	<p>What are some of the community beliefs about WWDs and whether they have a right to decide what is to be done with their body?</p> <p>Pregnant women with disabilities are often discriminated against by health providers and scolded by caregivers for becoming pregnant and bearing children, how does this impact on the SRH choices of women with disabilities?</p> <p>Have you ever known of or heard of rights violations in your services against a women with a disability? (i.e. have you heard of a time when a pregnant woman experienced abuse and disrespect at the FP clinic or hospital?)</p>	<p>Probe for:</p> <p>Obstetric violence – verbal, physical, and sexual abuse in maternity care</p> <p>i.e. parental rights after giving birth are violated; HIV testing without consent; contraception without consent</p> <p>Forced coercive treatment, such as sterilisation of a women with a known disability that you felt was not in their best interest and not consensual.</p>

	<p>Why do you think this happens in your community?</p> <p>How do these problems/situations affect the lives of women with disabilities?</p> <p>What are some of the negative consequences if informed consent is not fulfilled in SRH services?</p>	
Referrals and partnering with OPDs	<p>How do you find support to make sure violations in services don't happen?</p> <p>If you find it challenging to care for a woman with a disability, where do you refer them to and how?</p> <p>How important do you think it is to have a referral system that caters to the needs of persons with disabilities? Please describe.</p>	
Training and capacity How can we improve the quality of informed consent?	<p>Please describe any information or training related to SRH and persons with disabilities that you have received.</p> <p>Have you ever received any training related to disability inclusiveness at a health facility?</p> <p>What were the training topics you covered relating to disability inclusiveness at the health facility?</p> <p>Have you ever received any training relating to ethics and informed consent to sexual and reproductive health services? How long ago was this?</p> <p>What current training around privacy, confidentiality and informed consent is there? Do you think this is satisfactory and what are the gaps?</p>	<p>What technical assistance would you need? What resources to help WWD? What support services do service providers need? (i.e. help with comprehension assessments)</p> <p>What resources, materials and knowledge are lacking in obtaining or facilitating IC with women who have a disability?</p>

	<p>Can you tell me of a case where such gaps were evident?</p> <p>Are current guidance tools or training adequate to assess patients' consent and their understanding of treatment? Do you feel trained/able to ensure informed consent, especially with women with disabilities?</p> <p>Who should take the lead on improving informed-consent procedures for persons with disabilities?</p> <p>With the current training, materials and current infrastructure at a health facility, what actions can your institutions take to ensure that improvements/changes are made, and that training is maintained?</p>	
Good practices	<p>What are good ways in which practitioners can support WWD to make informed and healthy decisions about their SRH?</p> <p>What works in ensuring that women with disabilities can provide informed consent?</p> <p>How can we ensure respectful means of determining a person's capacity to consent?</p>	
Recommendations	<p>What in your opinion could be improved in the future to make sure no harm comes to women with disabilities?</p> <p>What actions can your institution put in place to ensure that informed consent is accessible and ensured for all, regardless of disability?</p>	

2. Family and caregiver focus group guide

Interviews with parents, caregivers, guardians, partners

Objective To explore the experience of guardians and caregivers in ensuring informed consent when WWD access SRH, MNCH, and GBV care and autonomous decisions about their ward's health.

Design Exploratory, qualitative study.

Setting Rwanda, Uganda and South Africa

Participants Purposive sample of 10 caregivers (particularly women with intellectual disabilities)

Methods: Semi-structured interviews or focus groups will be conducted face to face/online with participants. Discussions will be audio-recorded, notes will be summarised, and relevant quotes will be captured and transcribed verbatim. The consultant and researcher will read the notes and quotes and generate key themes for the presentation of the data findings.

Theme	Questions	Notes
Consent and recording	<p>Do you understand the purpose of this discussion?</p> <p>Do you consent to participate in the discussion?</p> <p>Do you consent to the audio recording?</p> <p>Do you have any questions before we start?</p>	
Icebreaker	<p>When you think of consent and the rights of persons with disabilities, what words or phrases come to mind?</p>	
Family perceptions	<p>How does the community treat women with disabilities?</p> <p>How are the women with disabilities cared for by their families? What support do caregivers give in relation to sexual health and reproduction needs?</p> <p>What responsibilities do caregivers have to help with making sure women with disabilities have good sexual and reproductive experiences and health?</p>	

	<p>What are the challenges when women have mental and intellectual disabilities and need counselling for sexual health, contraception, pregnancy?</p> <p>Who has the right to make decisions for women with intellectual disabilities?</p>	
Caregiver awareness of reproductive health issues for women with disabilities	<p>What have been your main concerns about the contraception needs of women with disabilities? Sexual relationships? Childbearing?</p> <p>What happens when they need to get care for pregnancy or contraception?</p> <p>When they are violated sexually, what needs to happen and what rights do women with disabilities have?</p>	
Knowledge of informed-consent procedures	<p>Do you have knowledge about what informed consent means?</p> <p>Has anyone ever educated you on the rights of women with disabilities?</p> <p>How can we ensure that women with disabilities have privacy and can make their own decisions about their sexual health?</p> <p>For women with disabilities who have problems understanding information about their sexual health, how can they make the right decisions?</p> <p>For contraception- or pregnancy-related care, is it the caregiver's decision or their own decision to get contraception or undergo/receive other sexual health treatment?</p> <p>Are you asked to provide information to health workers on behalf of women with disabilities?</p>	
Proxy decision making	Tell me about a time when you had to make a decision regarding the sexual	

	<p>health or pregnancy of a woman with disabilities.</p> <p>Have you ever known of a forced coercive treatment i.e. sterilisation that you felt was not in the best interest of, or consensual for, a woman with a disability?</p>	
Satisfaction of service providers	<p>What are your experiences with health workers and their treatment of women with disabilities in maternity care or sexual healthcare?</p> <p>What are their approaches and how do they treat women with disabilities?</p> <p>Do you feel that when you help a woman with a disability make a choice or decision about a treatment or SRH care option, it is followed and respected by service providers?</p>	
Experiences on violence in healthcare	<p>Can you tell me about a time when you felt a women with a disability was discriminated against/received medical treatment that was forced non-consensual and not in their best interest?</p> <p>How can local leaders and health departments ensure women with disabilities are safe from harm?</p>	
Good practices	<p>What are good ways in which practitioners can support you, as a caregiver, in facilitating informed and healthy SRH decisions for WWD?</p> <p>What works in ensuring WWD can provide informed and independent consent?</p>	

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Acronyms

ANC	Antenatal Care
CAC	Comprehensive Abortion Care
CHW	Community Health Workers
CSE	Comprehensive Sexuality Education
FGD	Focus Group Discussion
FP	Family Planning
HCW	Healthcare Worker
IC	Informed Consent
ICF	Informed Consent Forms
iCSE	inclusive Comprehensive Sexuality Education
IDD	Intellectual and Developmental Disability
IEC	Information, Education and Communication
IPV	Intimate Partner Violence
IUD	Intrauterine Device
KIIs	Key Informant Interviews
LMICs	Low-middle Income Countries
MNCH	Maternal, Newborn, and Child Health
OPD	Organisation of People with Disabilities
PNC	Postnatal Care
SDGs	Sustainable Development Goals
SDM	Supported Decision Making
SGBV	Sexual and Gender-Based Violence
SP	Service Provider
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health Rights
STIs	Sexually Transmitted Infections
UNCRPD	United Nations Convention of the Rights of Persons with Disabilities
WHO	World Health Organization
WWWD	Women With Disabilities



Avoiding Harm, Respecting Rights: Facilitating Person-centred Disability-inclusive Informed Consent in Sexual and Reproductive Health Settings (Experience from Uganda & Rwanda)

The overall aim of this document is to increase awareness of a human rights-based approach to informed consent for sexual and reproductive health (SRH) care and to promote equitable and inclusive practice. That is, to help a wide range of stakeholders facilitate accessible and inclusive informed-consent processes within SRH settings.

The specific aims are to:

- Identify gaps in existing informed-consent guidelines (separate rapid review)
 - Identify practices and knowledge on what works from experts and stakeholders in SRH and disability organisations (qualitative findings in Rwanda and Uganda)
 - Provide recommendations to inform more disability-inclusive and ethical SRH and SGBV services in low-middle income countries (LMICs). The recommendations are presented in part 2 as a guide.
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