

CENTER FOR HEALTH, HUMAN RIGHTS & DEVELOPMENT

LAWS, POLICIES & BEST PRACTICES FOR INFORMED CONSENT FOR ADOLESCENTS IN UGANDA

A Hand Book For Health Practitioners

Promoting Adolescent Sexual and Reproductive Health and Rights



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ACKNOWLEDGEMENT

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Special thanks to Safe Abortion Action Fund (SAAF) for the financial support towards the development and publication of this Handbook. SAAF works to de-stigmatize abortion and to legitimize the abortion debate – creating and supporting a 'network of champions' who are more empowered to work at local and national levels.

Disclaimer:

This document should not be construed as medical or legal advice but the recommendations made are drawn from international best practices.

DEFINITION OF KEY TERMS

Adolescent: A person in a stage of growth in which they are transitioning from childhood to adulthood. It is a phase in which an individual is no longer a child and not yet an adult.¹ During this stage (between 10-19 years), a person undergoes rapid physical and psychological development from puberty to adulthood.

Puberty is the period of life when a child transforms into sexual maturity and becomes capable of reproducing. Girls begin puberty between 10-11 years, while boys begin between 11-12 years. The main sign of onset of puberty in girls is the first menstruation, while in boys it is the first ejaculation.

Sexual health is a state of physical, mental and social well-being in relation to sexuality. It requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.

Reproductive health is a state of complete physical, mental and social wellbeing in all matters relating to the reproductive system. It means that people are able to have a responsible, satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so.

Reproductive age: The average woman's reproductive years is considered to be between 15-49 years.

Adolescent friendly services are services that give adolescents respect and confidentiality.² Service providers should be non-judgmental, competent and appealing; health facilities should be equipped to deliver the services adolescents need; adolescents should be aware of where they can obtain the health services they need.

¹ WHO, 1993. The health of young people: A challenge and a promise

² World Health Organization, 2002. Global Consultation on adolescent-friendly health services. A consensus statement

Child: Biologically, a child is a human being between the stages of birth and puberty, or between the developmental period of infancy (1-2 years) and puberty (12-13 years). However, in Ugandan law, a child is a person below 18 years of age.

Minor: A minor is a person under the legally established age of adulthood. Most countries, including Uganda, as well as the UN have set the age of adulthood at 18 years.

Informed consent: Informed consent is the permission that a patient gives a doctor to perform a test or procedure after the doctor has fully explained the purpose, benefits and risks.³ For consent to be valid, it must be voluntary and informed, and the person consenting must have the capacity to make the decision – a person who can clearly appreciate and understand the facts, implications and future consequences of their decision.

Assent: The agreement to treatment of someone without capacity to give legal consent (such as a child). Working with children or adults not capable of giving consent requires the consent of the parent or legal guardian and the assent of the subject.

Counseling: The act of giving someone information about their potentialities, interests and abilities to help them overcome personal problems or difficulties and thereby achieve an optimal level of personal happiness and social usefulness. In the consent process, a subject is counselled to facilitate them to make an informed decision about a medical treatment or procedure.

Emancipated minor is a child who is no longer under the control parents or guardians, by circumstances dictated by reality, e.g. if the child is married, pregnant or already a parent, institutionalized (military service, rehabilitation), or is self-sustaining.

Mature minor: Refers to the older child (16-17 years), who under the doctrine

³ Richard A. Wagner. Informed consent. emedicinehealth. https://www.emedicinehealth.com/ informed_consent/article_em.htm#what_is_informed_consent

of evolving capacities, is presumed to have the capacity to understand certain information and make some competent decisions, unlike younger children. This doctrine justifies the progressive rollback of parental control to nil by the time a child attains the age of 18.

Health worker: A health professional, administrative, scientific and support staff employed in the health service, and designated by the Health Service Commission in consultation with the Public Service Commission.⁴

Medical treatment: Medical treatment means the management and care of a patient to combat disease or disorder. Medical treatment does not include medical observation, counseling, diagnostic procedures, and first aid.⁵

⁴ Health Service Commission Act 2001

⁵ University of Wisconsin. Definition of medical treatment. https://www.wisconsin.edu/ workers-compensation/coordinators/osha-record/medical-treatment/ (accessed e.g 15 May 2019)

UNDERSTANDING THE SEXUAL AND REPRODUCTIVE HEALTH NEEDS OF ADOLESCENTS

1.1 Definition of adolescence

1

Adolescence is defined as the period when a child transitions into an adult, which normally happens between 10-19 years of age. This period usually starts with puberty, which refers to the physical changes that bring about sexual maturity and the ability to reproduce. Puberty is typically accompanied by psychological and social development that facilitate the transition to adulthood.

Very young adolescents (10-14 years), who may be physically, cognitively, emotionally and behaviorally closer to children than adults. At this stage, they are just beginning to just physical maturation: pubic and axillary hair appear; girls develop breast buds and may begin to menstruate; in boys, the penis and testicles grow, facial hair develops and the voice deepens.

Middle adolescence (15-16 years), adolescents begin to develop ideals and select role models. Peers are very important to adolescents in this age group and they are strongly influenced by them.

Older adolescents (17-19 years) may look and act like adults, and may make decisions independently and they may even marry and start families. However, they have still not reached cognitive, behavioral and emotional maturity and still need support from adult role models, family and social structures.

1.2 Health challenges of adolescents

Adolescence is characterized by dramatic physical, psychological and social changes that adolescents lack skills to cope with. While adolescents feel capable of performing almost anything independently, they are prone to peer influence, experimentation and risk-taking, all of which are normal and part of the process of developing decision-making skills. They may begin to experiment with sex, alcohol, tobacco or drugs. What makes adolescents particularly vulnerable is their dependency, inexperience and lack of positive guidance.

On the other hand, adults (including health providers) rarely understand or appreciate the situation and challenges of adolescents. Many still look at them children who are incapable of handling any major responsibilities or making sensible decisions. They assume adolescents enjoy robust health, having outgrown childhood diseases and are not yet susceptible to the ailments of old age.

Although the overall burden of disease may be lower in adolescents, they are vulnerable to sexual and reproductive health (SRH) challenges, such as early/unwanted pregnancy, unsafe abortion, sexually transmitted infections (including HIV), substance abuse, sexual violence, delivery complications.

1.3 Barriers to facility-based health services

Individual barriers:

Include feelings of shame, fear or anxiety about issues related to sexuality and reproduction, lack of awareness about the services available, poor health or adviceseeking behaviors, and the perception that services will not be confidential:

Socio-cultural barriers:

Include social norms which dictate the behavior and sexuality of both young men and women, stigma surrounding sexually active adolescents. cultural barriers which limit the ability of women and girls from accessing health services, educational limitations, language differences, the attitudes of health care providers towards adolescents or their unwillingness to attend to their reproductive health needs:

Structural barriers:

Include long distances to health facilities, lack of facilities for clients with disabilities, inconvenient hours of operation, long waiting times, charging fees for services and lack of privacy.

1.4 Making interventions accessible, acceptable and appropriate to adolescents

- Respectful: Interventions and services should demonstrate respect for adolescents and their right to self-determination. Participation of adolescents should be encouraged and their opinions respected.
- Cost-benefit analysis: The benefits of the interventions should outweigh the risks.
- **Provide information:** Adolescents need full information about their health, the available services and where to find them.
- Equality: The services should be provided in manner that reflects equality and protects against discrimination, abuse and exploitation.
- Respect human rights: Health staff, parents and all other actors should be aware of the rights of adolescents and work together to ensure that these rights are protected.
- Participation: Adolescents should be involved as much as possible in the design, implementation and monitoring of program activities, so that programs are more likely to respond to their needs and priorities, and so that interventions are acceptable to them.

2 INFORMED CONSENT TO MEDICAL TREATMENT

2.1 Meaning of informed consent:

"Informed consent is the process by which the health care provider discloses appropriate information to a competent patient (a patient with capacity to consent) so that the patient may make a voluntary choice to accept or refuse treatment."

2.2. Provisions of the law relating to the issue of consent of minors

The capacity of minors to consent is an area of contention with conflicting laws, policies and practices.

- The United Nations Convention on the Rights of the Child (1989) (Art.12) requires Uganda to assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
- The Constitution of the Republic of Uganda, (1995) sets the age of the right to marry at 18 years (Art.31(1)), and that of employment at 16 years (Art.34). It also provides that no child shall be deprived by any person of medical treatment by reason of religious or other beliefs (Art 34(3)).
- The Customary Marriage (Registration) Act, Cap 248 (Sec.11) provides that a female can consent to marry customarily if they are 16 years and above.
- The Marriage Act, Cap 251 (Sec. 17, 19) provides for age of consent to marriage at 21 years.
- The Evidence Act, Cap 6 (2000) (Section 117) provides that evidence from a person above tender years (14 years and older) is directly

admissible in court hence recognizing minors' evolving capacities at different ages.

- The Children's (Amendment) Act, 2016 (Sec.2) defines a child as a person below the age of 18 years, but sets (Sec.8) the minimum age of employment of a child at 16 years. Then it provides (Sec.47) that a child of at least 14 years shall give their consent to adoption. In addition, the Act (Sec.88) provides that the minimum age of criminal responsibility shall be 12 years.
- The Employment Act 2006 allows the employment of children from the age of 12 and above (sec.32(1-2)).
- The HIV Prevention and Control Act (2014) (Sec.9 & 10) restricts consent to HIV testing to persons of 18 years and above.
- The Penal Code Act, Cap 120 differentiates defilement into simple defilement for children aged 16-17 years, from aggravated defilement for sex with children below 16 years.

These different provisions illustrate that the legal framework is inconsistent and contradictory on the issue of capacity to consent, and appears to peg maturity to age. It is also notable that individual laws have inconsistencies within themselves and with other laws, policies as well as with reality and practice.

These inconsistencies and differences between the statutory age of majority and the prescribed ages for employment, participation in justice processes and criminal liability highlight the confusion in the legal framework but shows an awareness that minors have evolving capacities based on their environment and situation which might warrant them making decisions for themselves.

However, the bottom line is that the Constitution provides that no child shall be deprived of medical treatment by reason of religious or other beliefs, meaning that a child should not at any one time be denied health services such services are in their best interests.

2.3 Provisions of the national policy relating to consent of minors

In comparison to the legal framework, the policy framework is relatively more progressive and flexible but also more explicit on the contentious issue of capacity to consent to SRHR services by minors:

- The National guidelines for research involving humans as research participants (2014) gives the best guidance on capacity of minors to consent and provide that all children 8 years and above shall assent to participate in research, and their decision will take precedence over parental/guardian consent. They further provide for consent of mature and emancipated minors. The guidelines define mature minors as individuals aged 14-17 years who have drug or alcohol dependency or an STI; while emancipated minors are those who are pregnant, married, have a child or cater for their own livelihood.
- The National Adolescent Health Policy (2004) which is specific to minors on SRHR prioritizes safe sex and contraceptive use among sexually-active adolescents; abstinence before marriage, delaying sexual debut in females to 18 years, integration of emergency contraception into adolescent family planning programs, etc. The policy is however silent on whether service providers will obtain assent/consent from adolescent client and/or third parties for these interventions but health workers in practice use this policy to provide SRH services to minors.
- The Adolescent Health Policy Guidelines and Service Standards (2012) encourage adolescents to involve their parents *"if they choose to"* in the process of accessing SRH services, including clinical care for sexual violence; antenatal and maternity care; HPV immunization; HIV testing; cervical and breast cancer examination; information on HIV prevention; and information on their rights and responsibilities, etc. This policy is also silent on when and how to obtain assent/ consent from a minor..

- The National Policy Guidelines and Service Standards for Sexual and Reproductive Health and Rights (2006) have the most progressive, detailed and bold guidelines on obtaining consent from adolescents to different categories of services. The guidelines state that "No verbal or written consent is required from parent, guardian or spouse before a client can be given family planning service except in cases of incapacitation (intellectual disability)", and recommends written consent only in cases of long-term and permanent family planning methods. They further prescribe consent from the patient or legal guardian for post-abortion care (PAC) services, including evacuation for incomplete abortion; examination under general anesthesia; and any surgical interventions.
- The National Adolescent Health Strategy (2011-2015) commits to ensuring that services provided are conducive to young people by making them *private and confidential*, etc. The strategy does not set the requirement of informed consent/assent for adolescents to access SRHR services, but its use of the requirements of "private" and "confidential" can be interpreted to mean that adolescents do not need the consent of their parents or guardians to access the services.
- The National Sexuality Education Framework (2018) does not provide for consent of the learners to sexuality education in school settings, but acknowledges the Eastern and Southern African (ESA) Ministerial Commitment on Sexuality Education of 2013, in which ministers of education and health from 20 countries in the region committed to "Urgently review – and where necessary amend – existing laws and policies on age of consent, child protection and teacher codes of conduct to improve independent access to SRH services for adolescents and young people and protect children".
- The Consolidated guidelines for prevention and treatment of HIV in Uganda (2016) provide that all persons 12 years and above can consent to HIV testing services (HTS) on their own. This includes minors (12-17 years).

The policy provisions are clear that adolescents do not need the consent of their parents or guardians to access SRH services, except for long-term and permanent family planning methods and surgical procedures. Besides those exceptions, the service provider needs to assess the maturity and circumstances of the adolescent vis-à-vis the SRH service in question. Service providers must also maintain the privacy and confidentiality of the minors that they treat.

3 THE CONCEPT OF EVOLVING CAPACITIES OF THE CHILD

The majority of adolescents are minors (below 18 years), with no legal control over their actions and decisions. However, the current national and international legal framework recognizes the concept of evolving capacities of the child. This concept acknowledges that children mature over time and their capacities evolve with time and other factors (e.g. the environment they live, the exposure, education level, etc). It thus, also acknowledges that some children mature earlier than others, and earlier or later than 18 years.

The UN Convention on the Rights of the Child and the Children Act clearly show that in considering the views of children, age should be considered alongside maturity and circumstances, implying that a higher age does not necessarily mean that an individual has matured. The Convention requires Uganda and other state parties to consider the views of a child who can form and express an opinion on any matter that concerns them.

There is also a recognition that some minors are emancipated and are no longer under the control parents or guardians, by circumstances dictated by reality for example if the child is married, pregnant or already a parent, or is self-sustaining. These cannot be viewed in the same lens as those still under the control of parents and guardians and must be allowed to consent independently.

Hence, service providers should consider the level of maturity and emancipation of minors in making their own decision to access SRH services, particularly short-term family planning methods, information and non-surgical procedures

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THE YOUTH CORNER AND ADOLESCENT-FRIENDLY SERVICES

4.1 Characteristics of adolescent friendly services

Adolescent Health Policy Guidelines and Service Standards of 2012 provide that service providers will be trained and equipped to provide adolescent friendly reproductive health services. It describes adolescent friendly services as services that respect the sexual and reproductive rights of young people; provided by specially trained providers (including peer counsellors) who are available and accessible all the time, are non-judgmental, with positive attitudes and are keen to serve young people; in a convenient location and environment with both visual and auditory privacy; information education and communication materials; and adequate space for recreational activities.

In practice, the standard indicator for adolescent friendly services has so far been the availability of a youth corner at a public health facility. However, the functionality and standard of these youth corners has varied from facility to facility.

The Guidelines provide that all services offered in Hospitals, Health Center IVs and Health Center IIIs should be youth friendly and offered with privacy. Where possible, youth corners should be provided and located in a place where privacy is assured with no interruption.

4.2 Views of young people

Responses from young people show that they consider youth friendly services to be those services that are provided free of charge, in a friendly way and are receptive to young people of all ages and are provided by fellow young people. They feel that young people need sexuality education before the age at which they usually "make mistakes".

Service providers felt that youth friendly services should be in a separate space where they can have their privacy, but also such a place should be more of a "club" than a health facility – with games, entertainment, peers and

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service providers who connect with young people. It was emphasized that youth friendly services are not about space; it is about the service itself. While many public health facilities have established a youth corner, the services are not yet adolescent/youth friendly because of poor service delivery, lack of skills in dealing with young people, shortage of space and stock-outs of commodities. Also games and entertainment are missing in youth corners, which would help keep the youth busy.

As a result, service satisfaction levels have been low among adolescent service users. Condom dispensers and community health workers have improved adolescent access to condoms. However, many young people have limited information about other contraceptives and their safety in young people. The youth corners rely on volunteers since there are no permanent staff. Service providers report receiving feedback on the services they provide to adolescents mostly through suggestion boxes, peers and direct conversations with clients.

4.3 Package of adolescent/youth friendly services:

- The Guidelines state that standard package of services to be provided in a youth corner, depending on the level of the Health Center, should include:
- Monitoring growth and development
- Assessment, detection and management of behavioral problems
- Information provision and counseling on issues such as body changes, personal care and hygiene, nutrition, alcohol and substance abuse, reproductive health, STI, life planning skills, ABC strategy, sexual gender-based violence
- Vaccination according to national guidelines
- De-worming according to national guidelines
- Management and treatment of general conditions, e.g. malaria, injuries, dental care, eye care

- Counseling, management and rehabilitation for mental conditions including alcohol and substance abuse
- For selected adolescents, should screen those for those with high risk to develop hyper-lipidaemia, coronary heart disease, diabetes, sickle cell, following protocols developed by experts in these areas
- Provision of HIV counseling and testing (HCT)
- Assessment and provision of care to HIV positive adolescents and comprehensive care for AIDS
- Management of Sexual Gender-Based Violence
- Linking the SGBV survivors to the protection and legal system
- Reproductive Health (pregnancy testing and counseling, antenatal care, maternity, newborn care to babies born to adolescents, postnatal care, contraceptive counseling and provision of methods (including condoms), post-abortion care and management, STI diagnosis and management, screening for breast cancer and disease, screening and treatment of obstetrical fistula)
- HPV screening and testing
- Counseling and rehabilitation of sexual dysfunctions and deviations
- Referral of problems that cannot be managed

HOW TO OBTAIN INFORMED CONSENT FROM MINORS (BEST PRACTICES)

 Generally speaking minors cannot consent to serious medical procedures, a health worker should however obtain the assent of a minor to ensure their involvement in the decision making process and the consent of their guardian to show that both understood the treatment/procedure to be received. A minor can however consent to receive treatment if they are a mature minors depending on their condition or if they are emancipated minors.

Identifying a Mature Minor

• 14 - 17 years

5

- Have drug or alcohol dependency
- Sexually active
- Capacity to understand information
- Level of education

Identifying an Emancipated Minor

- Pregnant
- Married
- Have a child
- Institutionalized (prison/ military)
- Cater for their own
 livelihood
- The informed consent process is a non-delegable duty that the health worker must perform through discussions with the patient and or their guardian.⁶
- 3. Proof of the informed consent process is usually evident in the signing of a consent form which captures;
 - The patient and or the patient's guardian's name
 - The name of the hospital or healthcare practice
 - The treatment/procedure name

^{6 &}quot;Patient safety and risk solutions: Guideline risk management strategies for informed consent"

- A description of the treatment/procedure
- The names of all practitioners performing the treatment/ procedure and the significant tasks of each
- A statement that the treatment/procedure was explained to the patient and or the patient's guardian
- The name and signature of the person who explained the treatment/procedure to the patient and or guardian
- The patient's signature providing assent and or the patient's guardian's signature providing consent
- The date and time consent is obtained
- A witness signature
- 4. A common misperception among health workers is that a signed consent form demonstrates consent. It does not. By itself, a consent form may not verify that true informed consent was obtained. Rather, it merely documents one phase of the informed consent process. For the patient to be truly "informed," he or she must understand the information that the health worker has disclosed⁷ and the health worker must give adequate and accurate information to the patient, in a language that the patient understands.

Explain the following to the patient and or the patient's guardian prior to signing the consent form:

- The treatment/procedure name
- A description of the procedure
- The names of all health workers performing the treatment/ procedure and the significant tasks of each
- The risks and benefits of the proposed treatment/procedure
- Alternatives to the proposed treatment/procedure, including doing nothing

⁷ Ibid.

5. The different policies indicate the services that minors can receive without parental consent and by only giving oral consent and these include accessing SRH services.

SR	SRH Services a minor "CAN" receive without parental consent				
-	Clinical care for sexual violence				
-	Antenatal and maternity care				
-	HPV immunization				
-	HIV testing				
-	Cervical and breast cancer examination				
-	Breast cancer examination				
-	Information on HIV prevention				
-	Information on their rights and responsibilities				
-	Short term family planning				

6. Recommendations are given that written consent should be obtained only in cases of long-term and permanent family planning methods.

SRH Services a minor "CANNOT" receive without parental consent

- Long-term and permanent family planning methods
- Post-Abortion Care (PAC) services
- Examination under general anesthesia;
- Any surgical interventions
- 7. Note that confidentiality and privacy are critical in the provision of SRHR information and services to adolescents. Many young people would not wish their parents to know that they are sexually active as they would be judged to be immoral and health workers have a duty to ensure that they maintain the confidentiality of their patients including minors.
- 8. It is also important to ensure that services are not provided in a judgmental manner if they are to be adolescent friendly.

If a minor comes to a health facility unattended do the following;

- Determine and develop a guide as a health facility if and under what circumstances minors will be seen without a parent or guardian present based on the services that can be offered to minors without parental consent.
- Explain your policies related to informed consent in minors and treatment of unaccompanied minors in your organization's welcome brochure or informational packet and to the unattended minor.
- Determine the types of procedures/treatments that will be made available to unaccompanied minors.
- Communicate in advance the limitations of services and care provided to unaccompanied minors.
- In case of emergencies establish protocols where a senior medical officer can act in the capacity of a guardian for a minor until their legal guardian can be traced.

6 TEMPLATE OF A CONSENT FORM

(This should be accompanied with a checklist to obtain informed consent and should be customized to suit the needs of a facility)

Patient's name:
Patient's guardian's name:
Name of the health facility:
The treatment/procedure name:
A description of the treatment/procedure:

6. The names of all practitioners performing the treatment/procedure and the significant tasks of each

7. PERSON GIVING CONSENT

I understand the provided information including the risks involved and have had the opportunity to ask questions. I understand that the treatment/procedure being given to the patient is voluntary and that I am free to withdraw the patient at any time, without giving a reason. I understand that I will be given a copy of this consent form. I voluntarily agree for the patient to be given this treatment/procedure.

Name of Patient's guardian:
Relationship to patient:
Signature:
Date:
Day/month/year

8. PERSON GIVING ASSENT

I understand the provided information including the risks involved and have had the opportunity to ask questions. I voluntarily agree to be given this treatment/procedure.

Name of Pa	itient:	 	
Signature: _			

Date:

Day/month/year

9. PERSON TAKING THE CONSENT

I confirm that the patient and their guardian was given an opportunity to ask questions about the treatment/procedure, and all the questions asked have been answered correctly and to the best of my ability. I confirm that the patient and their guardian have not been coerced into giving consent, and the consent has been given freely and voluntarily.

	Name of Person taking the consent:		
	Signature:		
	Date: Day/month/year		
10.	0. A WITNESS SIGNATURE		
	Name of witness:		
	Signature:		
	Date:		
	Day/month/year		

 $Overall, the international \, and \, regional \, legal \, frameworks \, do \, not \, directly \, address$

7 CONCLUSION

the question of consent to medical treatment for children, but recognize the rights, responsibilities and duties of parents and guardians to protect their children, and to provide for them, including ensuring access to health care. Most importantly, the frameworks require states parties to respect the views of the child in making decisions that affect them, and recognize the concept of evolving capacities. The frameworks clearly show that in considering the views of children, age should be considered alongside maturity, implying that a higher age does not necessarily imply that an individual has matured. This is a recognition that some children mature earlier than others, and earlier than 18 years, and, as the Convention for the Rights of the Children commends, children who can form and express an opinion on any matter that concern them should be accordingly be considered.

The National Adolescent Health Policy 2004 outlines a range of sexual and reproductive health information and services that adolescent will be provided with. These include: information on sexuality and STIs, family planning counselling and services, contraceptive use rate among sexually active adolescents, HIV prevention and care services; maternal health services for adolescent mothers, post-abortion care, and psychosocial support. To achieve and maintain good sexual and reproductive health, adolescents need access to accurate information related to sexuality and a choice of safe, effective, affordable contraception options are key. A human rights framework emphasizes access to information to empower individual freedom of choice with respect to: deciding whether to be sexually active or not (e.g. sexual debut); the pursuit of a satisfying, safe, and pleasurable sexual life; choosing a partner; consensual sexual relations and consensual marriage; protection from sexually transmitted infections (STIs); and family planning (e.g. whether or not, and when, to have children).⁸

⁸ Family Care International. Briefing Cards: Sexual and Reproductive Health and Rights (SRHR) and the Post-2015 Development Agenda. http://www.unfoundation.org/what-we-do/campaigns-and-initiatives/universal-access-project/briefing-cards-srhr.pdf

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