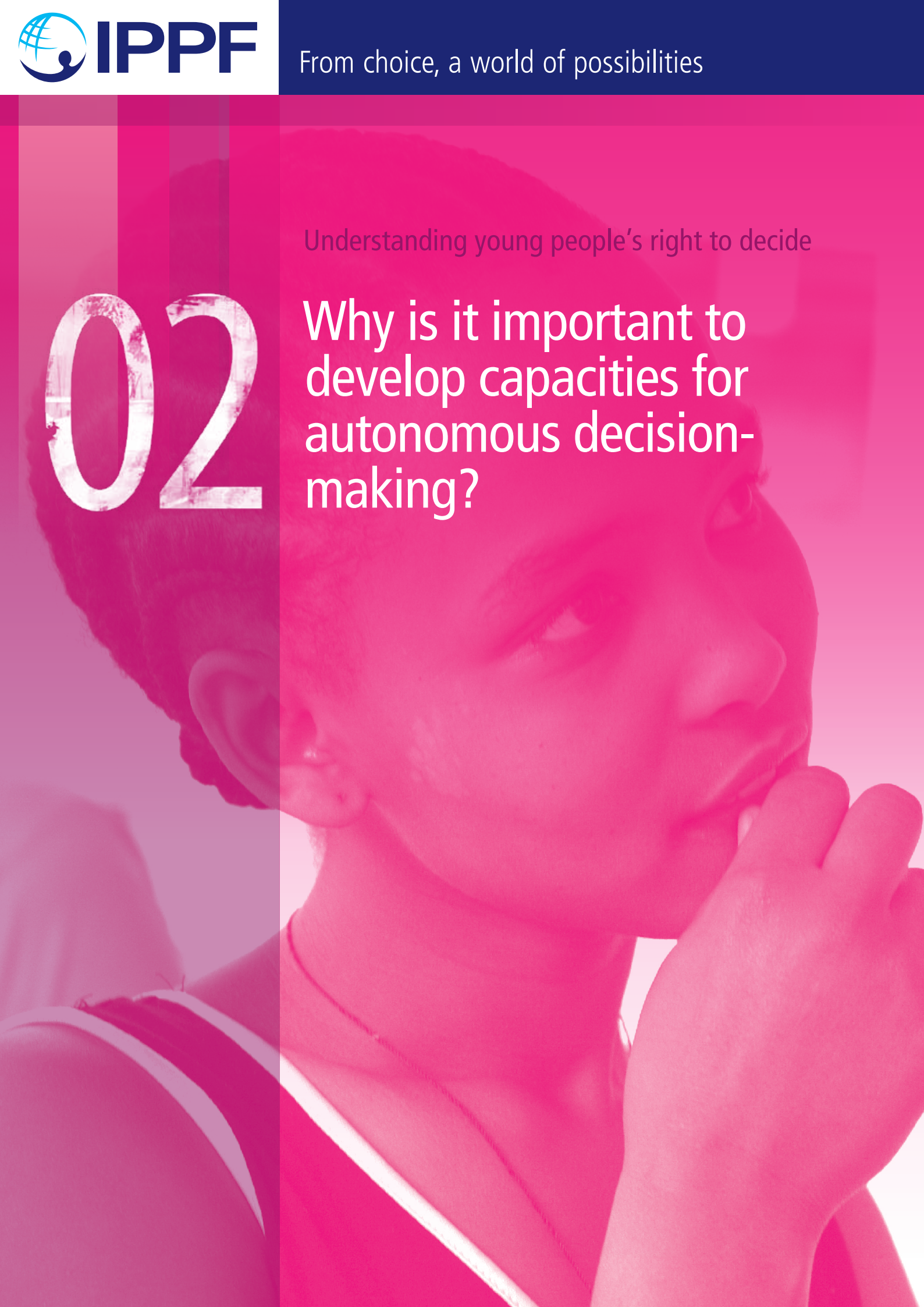
IPPF

From choice, a world of possibilities

Understanding young people's right to decide

02 Why is it important to develop capacities for autonomous decision-making?



About the Right to Decide series

The International Planned Parenthood Federation (IPPF) works towards a world where women, men and young people everywhere have control over their own bodies, and therefore their destinies. We defend the right of all young people to enjoy their sexuality free from ill-health, unwanted pregnancy, violence and discrimination.

IPPF believes that all young people have the right to make autonomous decisions about their sexual and reproductive health in line with their evolving capacities. We also recognize that the estimated 1.7 billion young people in the world are sexual beings with diverse needs, desires, hopes, dreams, problems, concerns, preferences and priorities. Amongst the 1.7 billion, there are young people living with HIV; young women facing unwanted pregnancy and seeking abortion services; young people with an unmet need for contraception; people with sexually transmitted infections and lesbian, gay, transgender and bisexual young people. IPPF advocates for the eradication of barriers that inhibit access to comprehensive sexuality education, information and sexual and reproductive health services that respond to all young people's needs and realities.

One such barrier that impedes young people's access to education and services is the widely-held and historically-rooted belief that young people are incapable of making positive decisions about their own sexual and reproductive health. IPPF's experience providing education, information and services around the world for the past 60 years tells us that this is untrue. Thus, in 2010 IPPF initiated a year-long project to learn more about young people, autonomy and sexual rights from experts working on these topics in various fields. We wanted to understand the theory behind the laws, policies and practices that both facilitate and restrict young people's autonomy as well as the key factors contributing to the development of young people as autonomous decision-makers.

IPPF commissioned five experts to answer the following questions that form the basis of the papers you find in the Right to Decide series:

1. What is childhood? What do we mean when we say 'young person'?
2. Why is it important to develop young people's capacities for autonomous decision making?
3. Are protection and autonomy opposing concepts?
4. How can parents support young people's autonomous decision making?
5. How do we assess young people's capacity to make autonomous decisions?

With an enhanced understanding of young people, autonomy and sexual rights, we hope to be better placed to promote and fulfill our vision of a world where young people are recognized as rights-holders, decision-makers and sexual beings whose contributions, opinions and thoughts are valued equally, particularly in relation to their own sexual and reproductive health and well-being.

About the author

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01 Introduction

Access to health services and information is crucial to human development. Comprehensive sexual and reproductive health (SRH) services and education are especially critical. Sexually transmitted infections (STIs), unwanted pregnancy and childbearing, stigma against people who do not conform, and denial of young people's sexuality carry profound individual and societal implications.

Quality health services and comprehensive sexuality education are necessary means to reduce maternal morality and morbidity, stigma and discrimination on the basis of gender and sexuality, and unwanted pregnancy and infection. Ideally, these services should be delivered in a sex-positive manner that acknowledges pleasure and desire as integral to human sexuality, including among young people.[i]

Despite this urgency, minors continue to experience significant practical and legal obstacles in accessing sexual and reproductive services and education. The nature and extent of these obstacles differ across political, economic, and legal contexts. A common thread throughout is the pervasive denial or discouragement of young people's sexuality, particularly where it occurs outside of marriage.[ii]

The aim of this paper is to provide an overview of relevant laws, policies, and practices that either obstruct or promote minors' access to health services and information. It considers the extent of minors' informed decision-making capacity regarding health services and information and explores how it can be fostered and developed. While its specific focus is decision-making in the health context, much of this paper is relevant to sexual decision-making generally.

The term 'minor' is used throughout this paper to refer to persons below the age of legal majority (usually 18 or 21). Many legal rules and policies continue to make sharp distinctions between minority and majority status. Internationally, the *Convention on the Rights of the Child* (CRC) defines a 'child' as every human being below the age of eighteen unless domestic laws specify that majority is attained earlier.[iii] I use the term 'young people' (10–24 years) when discussing broader social and cultural patterns concerning youth sexuality.[iv]

02 Health decision-making and international law and bioethics

Health decision-making

The ability of minors to access timely health services and information is dependent on the degree of equity in a health system's design, funding and clinical delivery.[v]

The UN Committee on Economic, Social and Cultural Rights emphasizes that sound individual and public health requires:

- the *availability* of public health and health-care facilities
- the *accessibility* of health facilities, goods and services (non-discrimination, physical accessibility, information and affordability)
- the *acceptability* of such services (respectful of medical ethics and culturally appropriate)
- *quality* of information and services (scientifically and medically appropriate).[vi]

It is beyond the scope of this paper to address health systems and educational infrastructure, upon whose existence individual decision-making is predicated. I do note, however, that publicly available health care remains inadequate in many countries in the Global South and some in the Global North. This is in part due to neoliberal economic policies, promoted by international financial institutions including the World Bank and the International Monetary Fund, which have urged and sometimes required states to reduce public funding of health services.[vii]

More recent conditional cash transfer programmes directly incentivize poor parents, specifically mothers, to protect their children's health by paying parents small sums of money when their children reach certain health milestones (e.g. immunizations, weight gain).[viii] However, because the health needs of younger children are distinct from those of older minors, directing money to parents (mothers) will not ensure the health of the latter. Particularly in the area of SRH, adolescent minors need to be able to access confidential, funded (publicly or by a service organization) health services and information.[ix]

Historical context: majority and minority medical decision-making

The rise of patient autonomy in the twentieth century was a response to prior conditions wherein "patients traditionally had few, if any, rights of self-determination: Doctors neither informed patients nor obtained their consent for treatment or for research."[x] In 1914, Justice Cardozo articulated a vision of bodily autonomy that has become a cornerstone of modern global bioethics. He held in *Schloendorff v. New York* that: "[e]very human being of **adult years** and **sound mind** has a right to determine what shall be done with his own body…".[xi] Majority age and cognitive faculties, however vaguely defined, would become indicative of patient rights.

Informed decision-making emerged as an ethical and legal principle requiring medical providers to obtain express, informed consent before treating patients. The doctrine of informed consent requires that a decider is competent, informed, and acting voluntarily.[xii] With the exception of medically emergent situations, a health provider who treats an individual without his or her informed consent commits the tort of battery in common law jurisdictions and contractual breach in civil law jurisdictions.[xiii]

Yet, even as adults were gaining rights of bodily autonomy throughout the twentieth century, parents and legal guardians remained the primary medical deciders for minors. Historically, the civil law protected parental rights and duties until majority was reached.[xiv] At common law, minors were incapable of providing informed consent to treatment.[xv] Common law courts routinely held that until a minor reached majority, only parents or legal guardians could provide consent to treatment.[xvi] This rule of parental consent accorded with historical "notions of family privacy, parental autonomy, and the importance of familial bonds."[xvii] It also accorded with "the narrower notion that parents are legally responsible for the care and support of their children".[xviii] In other words, the legal incapacity of minors was not predicated solely on an idea of natural *cognitive* deficiency, but more concretely on the economic imperative of fathers (and eventually mothers) to decide what services their child would receive.

Medical care for minors continues to operate against a set of background family law rules that impose varying levels of responsibility on parents to provide for the medical care and nurturing of their minor children.[xix] In its absolute form, the parental consent rule protected parents from having

to pay for unnecessary or risky treatment and from the financial burden of having to support a child if the unwanted treatment failed.[xx] Even as this rule has been modified through the 'mature minor' doctrine and the evolving capacities of the child, discussed below, parents' economic interest in minors' care continues to impact minority decision-making and medical privacy and confidentiality.

Parental obligation to provide necessary care can entitle parents to obtain information about treatment for which they are required to pay.[xxi] That said, where health providers do not directly bill parents for minors' care, they should not be legally obliged to disclose care; in fact, they have an ethical duty against disclosure.[xxii] In jurisdictions where adolescents are covered under their parents' public or private health insurance plans, health professionals and supporters of minors' rights should advocate for provisions that allow for payment while retaining confidentiality (for example, by not revealing the precise nature of the service).[xxiii] Countries with universal health care coverage, as well as organizations that provide care to minors without relying on parental payment, can resist the breaches of confidentiality that arise in jurisdictions that privatize responsibility for minors' care to parents.

While parental responsibility for *remuneration of care* remains an ongoing issue in many jurisdictions, the legal approach to *minority decision-making* has undergone significant transformation in recent decades in some jurisdictions. Some jurisdictions now employ age-based or competency-based approaches, or a mixture of both, that allows for a degree of autonomous medical decision-making by minors.

Even where rules for autonomous minority decision-making exist on the books – and especially where they do not – lower-level policies and gatekeepers at hospitals, clinics, and schools often have the greatest impact on access. Indeed, most countries do not have specific legislation regarding minors' access to health services.[xxiv] Where legislation does exist, advocates must still work for progressive interpretations of discretionary terms such as 'maturity' or 'competency'.[xxv]

Rules for informed decision-making: age and emancipation

Some civil law and common law jurisdictions have legislated a minimum age for medical decision-making by minors. The minimum age may vary depending on the nature or seriousness of the treatment. Some countries expressly allow minors to consent to abortion services, for example.[xxvi] Other jurisdictions allow minors to consent to treatment and testing for STIs, substance abuse, mental health and/or contraception services, but require parental involvement for access to abortion.[xxvii] Many countries also impose a minimum age for refusal of life-saving treatment. [xviii] Such age-based laws tend to either preclude consent by minors below the set age (therefore requiring parental or guardian consent) or require that these younger minors demonstrate maturity to overcome their presumed incompetency.

Minimum age laws are often defended on the ground that age is an efficient proxy for competency:[xxix]

> "…in a bureaucratized society, age has considerable practical advantages as an administrative and normative gauge. It is an easily measured, inescapable attribute and a quality that everyone has experienced or will experience."[xxx]

Age is a measure that, in turn, constitutes the subject.

In the medical context, however, such proxies are much less needed. In contrast to voting or purchasing alcohol, which are tied solely to age without any capacity testing, medical treatment already involves an individual assessment of voluntariness and capacity to satisfy the standard of informed consent.[xxxi] It is true that a competency analysis may be more fulsome, though this will depend on how a provider interprets 'maturity'. A provider may well conclude that a minor's request for SRH services to protect his or her health is indicative of maturity and competency.[xxxii] Where specific concerns about abuse or sexual violence arise, they can and should still be investigated as a separate line of inquiry.

In addition to age-based rules, some jurisdictions also provide for medical decision-making by 'emancipated minors'. The most commonly recognized grounds of emancipation are marriage, living separately and independently from one's parents, being a member of the armed forces, or having otherwise gained recognition by a court as an emancipated minor.[xxxiii] Greater legal and provider recognition of emancipation is especially crucial in developing countries where increasing numbers of minors are heading households due to parental death or separation.[xxxiv]

The advantage of age-based and emancipation rules is that they are certain and predictable.[xxxv] In jurisdictions that permit emancipated minors or minors of a certain age to consent to many or all medical procedures, they need not 'demonstrate' their maturity to service providers. Young people over the prescribed age are treated the same, for most or all purposes, as adults in providing informed consent to treatment. They are presumed to be competent. This avoids the serious problems that arise in discretionary systems where service providers are unwilling to recognize minors' competency, particularly in SRH decision-making. For these reasons, the Committee on the Rights of the Child

(CRC Committee) has "welcome[d] the introduction in some countries of a fixed age at which the right to consent transfers to the child."[xxxvi] The Committee "encourages States parties to give consideration to the introduction of such legislation…" The benefit of this approach is that "children above that age have an entitlement to give consent without the requirement for any individual professional assessment of capacity after consultation with an independent and competent expert."[xxxvii]

The downside of such rules is that they may preclude minors under the prescribed age from being recognized as capable to decide. Their care may be left to the determination of their parents or guardians, or in emergent cases to the medical provider or the state. Thus, the CRC Committee also "strongly recommends that States parties ensure that, where a younger child can demonstrate capacity to express an informed view on her or his treatment, this view is given due weight."[xxxviii]

Standards for informed decision-making: 'mature minor' and 'evolving capacities of the child'

In contrast to chronological age and emancipation-based *rules*, the common law 'mature minor' doctrine and the international law concept of the 'evolving capacity of the child' are *standards* that allow for discretionary assessments of decisional competency. The benefit of standards is that they allow for contextual factors to be weighed individually. The downside is that the outcome is more uncertain and subject to the biases of the service provider or adjudicator (e.g. the court).[xxxix] For some youth, then, discretion in the hands of gatekeepers will undermine their care; for others, it will provide an opening to receive care.

Many common law jurisdictions recognize some version of the 'mature minor' standard. According to this doctrine, minors who exhibit sufficient maturity to understand the nature, consequences, and potential risks of treatment can provide informed consent.[xl] The level of requisite maturity may differ according to the kind of treatment. An adolescent or younger child capable of consenting to dental treatment or treatment for a sports injury may nevertheless lack capacity to refuse life-sustaining care.[xli]

This modern instantiation of the mature minor doctrine is usually traced to the 1986 UK House of Lords decision of *Gillick v. West Norfolk and Wisbech Area Health Authority*.[xlii] *Gillick* involved a parental challenge of Health Authority guidance to physicians which stated that they could prescribe contraception to female patients under 16 without parental consent.[xliii] The House of Lords held in favor of the Health Authority.

The test for legal competency developed in *Gillick* is whether the young person shows "sufficient understanding and intelligence to enable him or her to fully understand what is proposed".[xliv] So-called *Gillick*-competency has been recognized in other Commonwealth countries.[xlv] The doctrine has also been extended by courts beyond the medical context, for example to the juvenile justice context.[xlvi]

At international law, the correlative legal concept is the 'evolving capacity of the child'. This concept recognizes childhood and adolescence as a gradual developmental phase. Like *Gillick*, it rejects a strict on/off approach to legal capacity and instead applies a sliding scale approach to minor competence. The 'evolving capacities of the child' is articulated in Article 5 of the CRC:

> "States Parties shall respect the responsibilities, rights and duties of parents or, where applicable, the members of the extended family or community as provided for by local custom, legal guardians or other persons legally responsible for the child, to provide, **in a manner consistent with the evolving capacities** of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention."[xlvii]

This provision limits the degree to which states must respect parental or community rights vis-à-vis minors, including in the health care context.[xlviii] The CRC provides that states do not have to respect parental or community rights or duties when these are exercised in a manner inconsistent with the evolving capacities of the child.

This concept of 'evolving capacities' should be read in conjunction with minors' right to express their views under Article 12 of the CRC. Article 12 of the CRC provides:

1. States Parties shall 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**.

2. For this purpose, the child shall in particular be provided the opportunity to be **heard in any judicial and administrative proceedings affecting the child**, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.[xlix]

Article 12 understands minors to be active subjects, rather than simply passive objects of state or parental authority.[l] The article reflects a compromise between using age as a proxy for competency and requiring an individualized maturity analysis. Article 12(1) states that "due weight" should be given to the child's views "in accordance with the

age and maturity of the child." This means that according to the Convention neither the child's age, nor her maturity, is determinative of the appropriate weight to be accorded her views; both are necessary and valid considerations.

The CRC Committee has emphasized the importance of minors' views in the health care context. In its General Comment on 'the Right of the Child to be heard', the Committee stated:

> "the realization of the provisions of the Convention requires respect for the child's right to express his or her views and to participate in promoting the healthy development and well-being of children. This applies to individual health-care decisions, as well as to children's involvement in the development of health policy and services." [li]

The views of young people are relevant not only for individual access, but also for program design. It is essential that young people are key participants in programs addressed to them.[lii]

Administrative policies and local practice for informed decision-making

International and domestic legal developments in minors' access to care are clearly significant. Legal reform remains imperative in many contexts, particularly where criminalization, lack of confidentiality, and stigma deter young people from seeking essential care and information. At the same time, it is essential to address informal policies and practices that continue to determine minors' access in many local settings. Where there are no specific laws on minority medical decision-making, where reform of restrictive laws appears unlikely, and even where progressive laws are in place, advocates must work to identify and engage local "gatekeepers" to improve minors' access to information and services.[liii]

Many states do not have specific legislation or case law regarding minors' access to care. In sub-Saharan Africa, for example, South Africa is exceptional in having legislation that specifically addresses medical decision-making by minors – the *Children's Act, 2003*.[liv] The majority of other African states regulate access to SRH services through non-legislative administrative policies and directives.[lv] The same is true for many countries in the Global South.

Health advocates should engage with stakeholders, including Health Ministry officials, administrators, and most importantly healthcare providers, clinic directors, and school officials about the importance of minors' access to confidential services and information. Providers and policymakers should be reminded that *requiring*, rather than *encouraging*, parental notice or consent has been shown to delay and deter minors from seeking care.[lvi] Advocates should also stress the cost-savings associated with SRH information and preventative services, including condom distribution and contraception.[lvii] Likewise, where there are legislative silences – for example on access to contraception, as is the case in most African states – providers should be advised to interpret such silence permissively.[lviii]

An important site of engagement is national HIV/AIDS strategies. In sub-Saharan Africa, where the HIV pandemic remains most prevalent, almost every state has a national HIV/AIDS policy.[lix] A majority of Asian and Latin American states also have such policies. Reproductive health organizations with a strong regional presence may be best situated to press for the inclusion of minors in these policies.[lx] This is especially important given the heightened vulnerability of young women aged 15–24 to HIV-infection in Africa.[lxi] In many contexts, it may prove easier and more effective to get minors' access rights recognized in HIV/AIDS guidelines than to engage the formal legislative process or conduct lengthy court challenges.

Moreover, even where restrictive laws or policies are in place, there is often room for progressive interpretation in "uncertain legal spaces."[lxii] In Mozambique, for instance, public hospitals have accepted requests for termination of pregnancy when pregnancy constitutes a risk to health or is the result of contraceptive failure.[lxiii] In Bangladesh, "menstrual regulation" has been used as a reason to provide abortion services in a country with a very restrictive abortion law.[lxiv] Women on Waves, a Dutch reproductive rights organization, provides online information for medical abortion, including advice for women and girls living in countries with restrictive abortion laws.[lxv] In the context of minors' access to information and services, discretionary terms such as 'maturity' or 'competency' can be interpreted progressively to cover minors seeking SRH services to protect their health.

Finally, it is important to recall that good laws mean little if minors cannot effectively access SRH services and information. Legal exceptions for abortion services or for minority decision-making are meaningless if providers are not trained in their application. Examples of efforts to give the law practical effect include projects that educate health providers on how to know when legal exceptions for therapeutic abortion are met,[lxvi] or that develop markers of minors' capacity for health decision-making.[lxvii]

Global human rights and bioethics

Non-discrimination in the provision of services and information

States and health care providers have a duty to ensure that persons seeking care are not discriminated against.[lxviii] It is impossible for a person to exercise her decision-making capacity if a medical provider discriminates by refusing treatment or providing suboptimum care. Most national constitutions and many health statutes and professional codes of conduct prohibit discrimination on the bases of sex, race, age, health status, disability, religion, ethnicity, and/or political affiliation.[lxix]

Non-discrimination is a foundational principle of international human rights law. All major international and regional human rights treaties require states parties to ensure that the rights articulated therein are enjoyed on the basis of non-discrimination. This includes the *International Covenant on Civil and Political Rights* (ICCPR),[lxx] the *International Covenant on Economic, Social, and Cultural Rights* (ICESCR),[lxxi] the *Convention on the Elimination of All Forms of Discrimination against Women* (CEDAW),[lxxii] the *Convention on the Rights of the Child* (CRC),[lxxiii] the *Convention on the Elimination of All Forms of Racial Discrimination* (CERD),[lxxiv] and the *International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*.[lxxv] Regional international human rights treaties, including the *American Convention on Human Rights*,[lxxvi] the *African [Banjul] Charter on Human and Peoples' Rights*,[lxxvii] the *Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa*,[lxxviii] the *African Charter on the Rights and Welfare of the Child*,[lxxix] and the *European Convention for the Protection of Human Rights and Fundamental Freedoms*[lxxx] all provide for equality and non-discrimination in rights protection.

Health systems that fail to provide necessary SRH services, including contraception and abortion services, directly undermine the health of minors. In such systems, moral judgment overrides the health needs of women and girls and men and boys. The CEDAW Convention specifically requires states parties to eliminate discrimination against women and girls in the provision of health services (art. 12). The CEDAW Committee has found efforts to eliminate discrimination inadequate where "a health care system lacks services to prevent, detect and treat illnesses specific to women."[lxxxi] The Committee considers it "discriminatory for a State party to refuse to legally provide for the performance of certain reproductive health services for women."[lxxxii]

Health systems must account for biological differences in reproductive capacity and health needs. This is especially crucial for young women for whom early pregnancy has serious physical, social and economic effects.[lxxxiii] The most significant of these – maternal mortality – remains the leading cause of death among women aged 15–49 globally.[lxxxiv] Ninety-nine percent of maternal deaths occur in developing countries, with two-thirds occurring in sub-Saharan Africa.[lxxxv] Adolescents have a markedly higher risk of death and complications as a result of pregnancy than older women.[lxxxvi]

In the context of health decision-making, the Committee on Economic, Social, and Cultural Rights (CESCR) has emphasized the importance of non-discrimination in access to healthcare. In its General Comment on the right to the highest standard of health, the Committee stated: "Health facilities, goods and services have to be accessible to everyone without discrimination, within the jurisdiction of the State party."[lxxxvii] Non-discrimination is a necessary condition for minors to access services and information. Health services and facilities "must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds."[lxxxviii] This includes all minors, but especially those at the greatest risk of stigma and discrimination, including young people living with HIV, pregnant minors who use drugs or alcohol, young people involved in sex work, gender non-conforming or LGBT youth, and poor and homeless young people.

Despite these global commitments, minors seeking SRH services regularly experience *de jure* (in law) and *de facto* (in fact) discrimination with respect to their sex/gender, sexuality, and age. The line between impermissible age discrimination and legitimate protection of minors can be difficult to draw and is often intensely political. I argue that where restrictive laws, health systems, or provider practices deny minors access to safe and confidential health services and counseling, without regard to their individual capacity, this constitutes age-based discrimination.[lxxxix] Likewise, involuntary parental notification constitutes discrimination against mature minors where adults can access such services confidentially.

In political struggles over minority decision-making, advocates should challenge the notion that protection necessarily means limiting minors' access to services (for example, through parental consent or notice requirements). Properly understood, *protection* should mean taking proactive measures to reduce harm to minors, particularly in view of their economic, political, legal and physiological vulnerabilities.

In *K.L. v. Peru* (2003), the Human Rights Committee found Peru in violation of its international obligations for failing to protect K.L., a minor, by preventing her from obtaining an abortion of an anencephalic fetus.[xc] As a result of Peru's

restrictive abortion laws, K.L. was forced to carry the fetus to term and to breastfeed the infant for four days before it died. K.L. experienced severe depression as a result. The Committee found, among other things, that Peru had violated its Article 24 obligations to provide measures of protection to a minor.[xci]

The right to the highest attainable standard of health

International human rights instruments recognize individuals' "right to the highest attainable standard of health." The ability of minors to access health services and information is a necessary condition for their enjoyment of this right.

The ICESCR imposes a positive duty on states parties "to recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."[xcii] States parties have a duty to take "deliberate, concrete and targeted… steps (art. 2.1) towards the full realization of article 12."

States' parties to the CRC have committed at international law to recognize "the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation."[xciii] Article 24(2) of the CRC further provides that "states parties shall strive to ensure that no child is deprived of his or her right of access to such health care services."[xciv] The Committee on the Rights of the Child has echoed the statement by the CESCR that:

> "States parties should provide a safe and supportive environment for adolescents that ensures the opportunity to participate in decisions affecting their health, to build life skills, to acquire appropriate information, to receive counseling and to negotiate the health-behaviour choices they make. **The realization of the right to health of adolescents is dependent on the development of youth-sensitive health care, which respects confidentiality and privacy and includes appropriate sexual and reproductive health services**."[xcv]

As such, the right to the highest attainable standard of health recognizes that effective and acceptable health services must be sensitive to the circumstances and capacities of young people.

Privacy and confidentiality

Legally, the concept of 'privacy' refers both to individuals' interests in preventing the state from interfering in the so-called private sphere of home and family (what I will call Privacy I) and the legal interest in keeping certain information private or secret from others (what I will call Privacy II). Confidentiality refers to the duty of providers to protect personal and confidential information.[xcvi]

Privacy I is typically articulated as a "right to private and family life," as contained in the ICCPR[xcvii] and the European Convention.[xcviii] Claimants have successfully relied on this notion of privacy to challenge state laws that interfere with private decisions, including laws prohibiting homosexual activity between consenting adults.[xcix]

The concept of Privacy II imposes positive obligations on the state and service providers to protect individuals' right to informational privacy and confidentiality. The aim of medical confidentiality "is to encourage communication between the patient and the provider; it is considered essential to a patient's trust in the health care system."[c] Confidentiality functions to promote access to care, and is also an ethical imperative in respecting individual autonomy over private information. Though confidentiality will yield to competing concerns in certain cases – child abuse and neglect[ci] or a minor's victimization by crime[cii] – these legal exceptions are narrow.

Confidentiality is critical to minors' ability to access timely, quality health services and information. Failures to protect confidentiality directly undermine young people's health. A recent editorial in the *Journal of Adolescent Health* emphasized that a lack of confidentiality deters some minors from seeking care altogether and undermines the level of care for those who do seek services:

> "Concerns about privacy can influence adolescents' use of health care by leading them to delay seeking care or to forgo care entirely, and affecting their choice of provider, their candor in responding to questions about sensitive topics, and their acceptance of certain interventions such as pelvic examines and testing for STIs and HIV."[ciii]

Respect for confidentiality is especially important in the case of young women. As the CEDAW Committee stated in its General Recommendation no. 24 on 'Women and Health':

> While **lack of respect for the confidentiality** of patients will affect both men and women, **it may deter women from seeking advice and treatment and thereby adversely affect their health and well-being**. Women will be less willing, for that reason, to seek medical care for diseases of the genital tract, for contraception or for incomplete abortion and in cases where they have suffered sexual or physical violence.[civ]

This notion of gendered deterrence was evidenced in a recent study of minors' access to contraception in Jamaica: "A lack of confidentiality [was] expressed by the respondents as a sore point, which discourages their seeking advice regarding sexual and reproductive health."[cv]

Legal rules or provider practices that mandate parental consultation as "desirable and in the best interests of the minor"[cvi] remain an obstacle to minors' confidentiality.

Requiring parental or guardian involvement is legally distinct from *encouraging* minors to discuss health decisions with their parent or guardian.[cvii] The CRC Committee has commented that parents and guardians "need to fulfill with care their right and responsibility to provide direction and guidance to their adolescent children in the exercise by the latter of their rights."[cviii] Here it is the minor who remains the primary agent with evolving capacities, with parents and guardians providing due guidance.

Harmful stereotypes that present youth as irresponsible and incompetent, and therefore properly under the totalizing governance of their parents, deprive young people of the ability to shape their own life course. As Rebecca Cook and Simone Cusack write in the gender context, when a stereotype interferes with persons' ability to "shape, or carve out, their own identities, when it lowers expectations of them, or, for example, negatively impacts their sense of self, goals, and/or life plans, it degrades them."[cix]

The right to life

States parties to international human rights instruments have positive obligations to protect minors' right to life in law and practice.[cx] Article 6 of the CRC states:

- States Parties recognize that every child has the inherent right to life.
- States Parties shall **ensure to the maximum extent possible the survival and development of the child**.[cxi]

A crucial element of ensuring the "survival and development" of young people is to enable their safe, confidential, and legal access to necessary health services.

Denials of access to effective and confidential health services directly contribute to loss of life, primarily as a result of untreated illness and maternal mortality, including recourse to unsafe abortion. In its Concluding Observations to Krygyzstan, the CRC Committee expressed concern "at the high and increasing rate of teenage pregnancies and the consequently high rates of abortions among girls under 18." The Committee commented that "various factors, including limited availability of contraceptives, poor reproductive health education and the requirements of parental consent have resulted in an increasing number of illegal abortions among girls."[cxii]

This confluence of factors – restrictive abortion laws, limited availability of contraception and sexual education for young persons, and parental consent requirements – make young women acutely vulnerable to unsafe abortion.[cxiii] It is estimated that 48% of all induced abortions globally are performed under unsafe conditions. This number jumps to approximately 95% of abortions in Africa and Latin America.[cxiv] Approximately 70,000 women die each year as a result of complications from unsafe abortion (13% of all maternal deaths globally).[cxv] Africa has the highest regional incidence of recourse to unsafe abortion by adolescents.[cxvi]

Faced with this "phenomenon of pandemic levels of unsafe abortion, … UN treaty bodies have read abortion rights into the broader fundamental rights."[cxvii] The CRC Committee has stressed that "States parties should take measures to reduce maternal morbidity and mortality in adolescent girls, particularly caused by early pregnancy and unsafe abortion…"[cxviii] While this internationalization of abortion rights has been incremental, it nevertheless constitutes a "chipping away at the wisdom of leaving domestic states sovereign over abortion."[cxix]

This chipping away is essential both at the state level, and most importantly at the level of health providers, educators and families.

Vulnerability to violence

Violence can be used to 'discipline' young people who transgress social norms, including compulsory heterosexuality and feminine chastity.[cxx] Where health providers fail to respect confidentiality, either because of age-discriminatory laws or paternalistic practices, this degrades and endangers the minor seeking care and may have a chilling effect on others. Minors who seek out services for LGBT health, general sexual and reproductive health care, or STI care may be subjected to stigma and violence if their autonomy and confidentiality is not respected.[cxxi]

Concerns about violence are especially pronounced in the context of HIV/AIDS. It is estimated that in sub-Saharan Africa, 3.5–14.6% of women who disclose their HIV-status report negative outcomes including blame, stigmatisation, abandonment and violence.[cxxii] This statistic does not include those women and girls who do *not* disclose their status, presumably those most in fear of violence. As health researcher Joanne Csete and others have noted, because domestic violence is typically hidden and under-prosecuted, the frequency of intimate partner or parental violence as a result of HIV-status disclosure will always be uncertain.123 Compounding this is the fact that measures of violence in clinical studies have often been under-inclusive by excluding non-physical aspects of abuse such as threats or controlling behaviour.[cxxiv]

Mediated disclosure – for example, where a counsellor or trusted family member or friend mediates disclosure in the home – can offer a culturally sensitive and effective means of supporting and protecting young people during partner or family disclosure.[cxxv] Counselling among sero-discordant

couples is particularly crucial for reducing violence and avoiding further transmission. It is important that partner or family disclosure is not treated as a once-off opportunity or event. Rather, it should be viewed as a process with multiple opportunities for counselling throughout. Ongoing social support groups and continued counselling may assist young persons living with HIV to overcome obstacles to disclosure and ensure that they can effectively follow treatment regimes.[cxxvi]

Education

Minors' ability to decide in health matters implicates, and in many ways is contingent upon, fulfillment of their right to education. Article 28 of the *Universal Declaration of Human Rights* (1948) states:

> Everyone has the right to education… Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms.

This early articulation of a right to education was followed up in a number of binding international and regional human rights conventions. Article 13 of the ICESCR provides:

> [States parties] agree that education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms.

In its General Comment on the right to education, the CESCR emphasized the importance of education for the empowerment of women and youth. "Education has a vital role in empowering women, safeguarding children from exploitative and hazardous labour and sexual exploitation, promoting human rights and democracy, protecting the environment, and controlling population growth."[cxxvii] In other words, education is a predicate to informed decision-making and self-protection and realization.

In his most recent report on comprehensive sexual education, the United Nations Special Rapporteur on the right to education emphasized: "education is the main fundamental tool for combating patriarchalism and generating the cultural shift so necessary for equality among individuals."[cxxviii] In this respect, education can foster informed decision-making for youth when it conveys accurate information, counteracts harmful gender stereotypes, and is accessible to all youth.[cxxix]

CSE policies frequently provoke intense political debate about the appropriateness of providing sexual information to minors. Some parents and many conservative and religious advocacy organizations argue that *exposure* to sexual knowledge will inevitably lead to an increase in sexual *behavior* and an earlier age of sexual debut.[cxxx] The empirical evidence on sexual education and contraceptive provision suggests the opposite, however. An American study measuring condom availability in high schools found that adolescents in schools where condoms were available were more likely to receive instruction on condom use and less likely to report recent or lifetime sexual intercourse.[cxxxi] The U.S. Children's Defence Fund states: "Teaching teens about sex has been found to increase their knowledge without increasing their sexual activity, despite assumptions to the contrary…."[cxxxii] This is not to suggest that reducing or eliminating adolescent sexual expression *per se* should be a policy goal. Rather, it is to highlight the speciousness of the claim that educational programs that promote positive and safer sexual activity necessarily contribute to an increase in sexual activity.

Youth advocates must work to counter the view that parents should have an automatic right to withdraw their children from such education. In the United Kingdom and most states in the United States, for example, parents are legally permitted to withdraw students from CSE classes.[cxxxiii] In France, parents can only remove elementary school age children from such classes.[cxxxiv]

Parental rights of withdrawal directly undermine the ability of some minors to access information. They also reinforce a broader ideology that views sexual health information as 'corrupting' innocent young people whose sexuality lies within the governance of the family. The U.N. Special Rapporteur on Education stressed in his recent report that:

> […] although fathers and mothers are free to choose the type of education that their sons and daughters will have, this authority may never run counter to the rights of children and adolescents… Particularly in the case of sexual education, people have the right to receive high-quality scientific information that is unprejudiced and age-appropriate, so as to foster full development and prevent possible physical and psychological abuse.[cxxxv]

In a recent case, the German Constitutional Court found against Baptist parents who wanted to remove their children from a theatrical school project intended to educate children about sexual abuse.[cxxxvi]

The European Court of Human Rights in *Kjeldsen, Busk Madsen and Pedersen v. Denmark* also upheld a mandatory sex education course in Danish schools, but did require some sensitivity to objecting parents' views.[cxxxvii] The Court held that the state must "take care that information or knowledge included in the curriculum is conveyed in an objective, critical, and pluralistic manner." The state is limited in that it cannot pursue "an aim of indoctrination that might be considered as not respecting parents' religious and philosophical convictions." The Court held that "the disputed legislation in itself in no way offends the applicants' religious and philosophical convictions."[cxxxviii]

03 Developing young people's capacities for informed decision-making

The following discussion applies the legal doctrine of informed consent to develop a general programmatic for promoting informed decision-making by minors. Each condition of informed consent – informed, voluntary, and competent decision-making – can be thought of in broader socio-political terms for promoting youth capacity.

Informed decision-making: the role of education and information

Accurate and positive information about sexual and reproductive health, sexual decision-making, diversity, and gender stereotyping is the cornerstone of informed decision-making. In 1992, the Supreme Court of Colombia recognized minors' need for sexuality education as part of modern schooling. The Court noted that sexuality education that provides students with timely, adequate and serious information is important for promoting young people's self-esteem, social sensitivity, respect for others' integrity and health identity.[cxxxix] In other words, CSE is essential to "positive youth development."[cxl]

'At-risk' programmes that focus solely on risk reduction have proven largely ineffective.[cxli] Programmes that fail to interrogate relations of power, risk, and desire limit the capacities of young people. When sexuality is equated only with danger, stigma, and victimization, young people's scope for critique, resistance and reporting of abuse, responsible engagement *and* enjoyment are all restricted.[cxlii] Studies have found that perceived stigma is negatively associated with adolescents' likelihood of being screened for STIs, for example.[cxliii] Retreat, rather than engagement with the health system, can be the response to negative messaging.

Successful interventions build instead "on the strengths and confidence of young people, creating meaningful roles and opportunities to contribute."[cxliv] An exemplary program in Nepal situates sexuality education as part of young people's life goals, visions for the future, and safer and pleasurable sexuality.[cxlv]

To be effective, sexual and reproductive health information must be accurate, widely disseminated and accessible to hard-to-reach youth. In a study of adolescent boys in Ghana, many adolescents reported significant barriers to accessing formal family planning services and education. Barriers included a lack of knowledge about the location and hours of services, staff disapproval of young people accessing contraceptives, and restrictions on access to unmarried persons.[cxlvi] In view of such obstacles, many youth seek reproductive health information and care from informal sources, including peers, pharmacies, chemists and traditional healers. Services that specifically address boys, including regional Planned Parenthood 'Young Men's Clubs' and 'Daddy's Clubs' can be especially useful in reaching adolescent boys.[cxlvii] Outreach work is especially important to reach youth who are not in school.[cxlviii]

Overcoming inaccurate information about modern contraceptives and condom use remains essential. Researchers have found that misinformation about hormonal contraception causing infertility and stigma around condom use and promiscuity contributes to the low level of modern contraceptive use among adolescents in developing countries.[cxlvix]

To promote young people's evolving capacities, medical providers should present information in a way that is comprehensible to young people. Reading material, for example, should be suitable to youth reading achievement and skills development.[cl] Even for adult patients, it is recommended that reading material be aimed at a pre-secondary school reading level in order to reach a broad range of literacy levels. Written handouts are more effective when discussed in-person with a health provider. Some youth who lack schooling or who are more responsive to media may be better informed through orally presented material or audio-video materials.[cli]

More generally, the following programmatic suggestions may lower barriers to counseling and health services: eliminating clinic requirements that minors bring their parents with them, extending or changing opening hours, employing male and female staff, providing condom dispensers in discrete locations, and providing formal consent forms that are in a language that is clear and accessible to young people.[clii]

Voluntary decision-making: familial, socio-political and economic contexts

Voluntariness in the clinical context usually refers to the lack of overt or tangible duress or coercion on a decision-maker. This coercion may emanate from a third party, including a spouse or family member, or may be the product of dire material circumstances, such as poverty. Studies of youth voluntariness in medical decision-making have

found that parents exert influence over medical decisions through young adulthood, though this influence tends to vary according to the type of treatment decision.[cliii] Minors tend to report parental influence in several forms: feeling directly coerced such that they had "no choice"; "needing parental support, whether emotional, financial, or physical"; respecting parental judgment and believing parents have greater knowledge in such areas; and a wish to avoid tension and conflict with parents.[cliv]

In order to foster informed youth decision-making and promote supportive parental involvement, it is important to address these multiple facets of voluntariness. The extent to which a young person is financially, socially, or emotionally dependent on his or her parents, in-laws, extended family, or peers may differ according to each young person, but also according to the social, political and economic context. In contexts where married adolescents leave their natal home to reside with their husband's family, for example, in-laws may exert significant influence or control over health decisions.[clv] Health providers and service organizations need to be attentive to the potential for coercion and should develop programmes that seek to engage extended families in discussing the importance of medical care for all persons.

Overt coercion in the form of violence remains a pressing issue for autonomous youth decision-making. In a study of psychosocial influences on adolescent sexuality and identity in rural Kenya, many adolescent males reported experiencing pressure from peers and adults to 'prove' their masculinity by having sex with females. This coercion was especially pronounced during the time period after they had undergone adolescent circumcision – a marker understood to correlate with physical maturity.[clvi] In their study on coerced forced intercourse and reproductive health among adolescent women in Uganda, Michael A. Koenig and colleagues emphasized the importance of addressing sexual coercion and violence as an integral component of reproductive health programs.[clvii]

Competent decision-making: cognitive and psychosocial skills development

Competency in medical decision-making refers to individuals' ability to understand and appreciate relevant treatment information, including consequences, risks, and alternatives, and "to use the information to weigh the risks and benefits of different options while making a choice."[clviii] Competency therefore requires some ability to reason abstractly, to consider multiple alternatives, and to combine variables to examine information systematically.

Studies comparing adolescent and adult decision-making processes have found few, if any, differences in cognitive abilities between adults and adolescents aged 14 and over.[clix] Psychologist Tara Kuther concludes on her review of the psychology literature that "many adolescents are as able as adults to conceptualize and reason about treatment alternatives, and, therefore, to make healthcare decisions."[clx]

A participatory approach to care is essential for fostering and developing the necessary skills for competent health decision-making. Even where a young child may not meet the capacity measures required to give informed consent, he or she should still be informed about and encouraged to *assent* to basic care (e.g. childhood injections).[clxi] Such participation might be as simple as asking the child which arm he or she wishes to be injected in. In cases where a young child is only being offered the opportunity to *assent*, not to *refuse* care, however, the provider should make this clear to the child.

Moreover, confidential advice and counseling should be available to children of any age and capacity. The legal standard for informed consent, required in the treatment and care context, is not required for a person to receive advice or counseling by a medical provider. The CRC Committee emphasized this in its General Comment no. 12 on "the right of the child to be heard":

> States parties need to introduce legislation or regulations to ensure that children have **access to confidential medical counselling and advice without parental consent, irrespective of the child's age, where this is needed for the child's safety or well-being**. Children may need such access, for example, where they are experiencing violence or abuse at home, or in need of reproductive health education or services, or in case of conflicts between parents and the child over access to health services. **The right to counselling and advice is distinct from the right to give medical consent and should not be subject to any age limit**.[clxii]

Thus, even where a child may not qualify as a competent decider, he or she should nevertheless be able to access confidential advice or counseling, particularly where he or she is at risk of abuse or exploitation. Early advice and counseling will also contribute to a better sense of participation in later medical decision-making.

03 Conclusion

- States parties have an obligation under international law to ensure that health services and counseling are provided on an equal basis and free from discrimination.
- Advocates should use states' reporting obligations under the respective international human rights treaties as an opportunity to address young people's access to timely, quality health services. 'Shadow reports' to the relevant treaty bodies can be a useful mechanism to highlight access problems and suggest areas of reform.
- Even as adults have gained rights of bodily autonomy and medical decision-making throughout the twentieth century, minors continue to face significant *de facto* and *de jure* obstacles to autonomous decision-making.
- Both the mature minor doctrine and the evolving capacities of the child standard recognize childhood and adolescence as a period of gradual development. They reject a strict on/off approach to social or legal capacity.
- Where there are no specific laws on minority medical decision-making, where reform of restrictive laws appears unlikely, and even where progressive laws are in place, advocates must work to identify and engage local gatekeepers to improve minors' access to information and services.
- States and health care providers have a duty to ensure that persons seeking care are not discriminated against. Where restrictive laws, health systems, or provider practices deny minors access to safe and confidential health services and counseling, without regard to their individual capacity, this constitutes age-based discrimination. Involuntary parental notification constitutes discrimination against mature minors where adults can access such services confidentially.
- The right to decide and effectively access health services is a necessary condition for young people to enjoy their highest attainable standard of health.
- Autonomous decision-making by competent minors includes the right to maintain privacy and confidentiality over that decision. Confidentiality is essential to promote access to care. It is also an ethical imperative in respecting individual autonomy respecting the uses of private information.
- Denials of minors' right to decide and to maintain confidentiality can directly violate their right to life and their right to be free from violence, particularly where they are denied confidential access to sexual and reproductive health services.
- The right to decide is interconnected with and often contingent upon young people's ability to receive and impart information and enjoy their right to education.
- Young people's capacity for autonomous decision-making can be fostered by ensuring they have access to comprehensive information, including sexual education, adequate social and economic supports, and the opportunity to develop the cognitive skills necessary to partake in decision-making.

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lix. Ibid. at 157–158 citing: Ethiopia: Health Policy of Transitional Government of Ethiopia (1993); Kenya: National Population Policy for Sustainable Development (2000); National Reproductive Health Policy (2007); Family Planning Guidelines (2005); Adolescent Reproductive Health and Development Policy (2000); National HIV/AIDS Strategic Policy; Lesotho: National AIDS Policy; Malawi: Reproductive Health Policy (2002); Reproductive Health Strategic Plan; National AIDS Policy; Nigeria: National Policy on HIV/AIDS; National Policy on Health and Development of Adolescents and Young People in Nigeria (2007); South Africa: Operational Plan for Comprehensive HIV/AIDS Care, Management and Treatment for South Africa (2003); Tanzania: National Population Policy (2006); Uganda: National Adolescent Health Policy for Uganda (2004); Zimbabwe: National HIV/AIDS Policy; National HIV/AIDS Strategic Plan (2006).

lx. It is clear that non-governmental organisations (NGOs) do face resistance in influencing national HIV/AIDS strategies. Various NGOs working on HIV and men who have sex with men in Latin America have noted the challenges they face in shaping HIV/AIDS strategies. Each context will differ politically and advocates should still work for inclusion of young people in such policies. UNAIDS, 'Regional Consultation on HIV/AIDS prevention, care and support programmes in Latin America and the Caribbean for men who have sex with men', (Geneva, Switzerland: UNAIDS, 1999).

lxi. UNICEF, 'Girls, HIV/AIDS, and Education', available online: www.unicef.org/lifeskills/index_8657.html (last accessed Apr. 1, 2011).

lxii. Rebouché, 'Parental Involvement Laws and New Governance', supra note 25 at 209.

lxiii. Faundes, A. and Hardy, E. 'Illegal abortion: consequences for women's health and the health care system', 58 *Int'l J. of Gynecology & Obstetrics* 77 (1997) at 80.

lxiv. Ibid.

lxv. *Women on Waves*, available at: www.womenonwaves.org/set-397-en.html (last accessed Mar. 20, 2011).

lxvi. See e.g., Cook, R.J., Ortega-Ortiz, A., Romans, S. and Ross, L.E. 'Legal abortion for mental health indications', 95 *Int'l J. of Gynecology and Obstetrics* 185 (2006).

lxvii. For a discussion of the importance of guidelines for courts and practitioners, Rhonda Gay Hartman, 'Coming of Age: Devising Legislation for Adolescent Medical Decision-Making'. 28 *Amer. J. of Law & Med.* 409 (2002).

lxviii. World Medical Association Declaration of Lisbon on the Rights of the Patient, art. 1(a): "**Every person is entitled without discrimination to appropriate medical**

care. (Emphasis added) (adopted 1981) (amended 1995; editorially revised 2005); International Federation of Gynecology and Obstetrics: art. 3: "Adhere to the principle of non-discrimination in order to assure that **every woman is treated respectfully regardless of age, marital status**, ethnicity, political affiliation, race, religion, economic status, disability, or other status. Women should be treated with respect for their individual judgment and not that of their partners or family" (Emphasis added).

lxix. In the United States context, for example, the *Health Security Act* provides that anti-discrimination is a duty of health alliances. Health alliances cannot discriminate against health plans on the basis of race, gender, ethnicity, or religion, among other grounds. For discussion, Chapman, A.R. *Health Care Reform: A Human Rights Approach*, (Georgetown University Press, Washington D.C., 1994) at 299.

lxx. *International Covenant on Civil and Political Rights*, GA res. 2200A (XXI), 21 UN GAOR Supp. (No. 16) at 52, UN Doc. A/6316 (1966); 999 UNTS 171; 6 ILM 368 (1967), art. 2(1): "Each State Party to the present Covenant undertakes to respect and to ensure to all individuals within its territory and subjects to its jurisdiction the rights recognized in the present Covenant, without distinction of any kinds, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status."

lxxi. *International Covenant on Economic, Social and Cultural Rights*, GA res. 2200A (XXI), 21 UN GAOR Supp. (No. 16) at 49, UN Doc. A/6316 (1966); 993 UNTS 3; 6 ILM 368 (1967), art. 2(2): "The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status."

lxxii. *Convention on the Elimination of All Forms of Discrimination against Women*, GA res. 34/180, 34 UN GAOR Supp. (No. 46) at 193, UN Doc. A/34/46; 1249 UNTS 13; 19 ILM 33 (1980), art. 1 defines "discrimination against women" for the purpose of CEDAW: "For the purposes of the present Convention, the term "discrimination against women" shall mean any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field."

lxxiii. *Convention on the Rights of the Child*, GA res. 44/25, annex, 44 UN GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989); 1577 UNTS 3; 28 ILM 1456 (1989), art. 2: "(1) States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.
(2) States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members."

lxxiv. *International Convention on the Elimination of All Forms of Racial Discrimination*, 660 UNTS 195; G.A. res. 2106 (XX), Annex, 20 UN GAOR Supp. (No. 14) at 47, U.N. Doc. A/6014 (1966), art. 1 defines "racial discrimination" for the purpose of the Convention: "In this Convention, the term "racial discrimination" shall mean any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life."

lxxv. *International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, G.A. Res. 61/106, Annex I, UN GAOR, 61st Sess., Supp. No. 49, at 65, U.N. Doc. A/61/49 (2006), entered into force May 3, 2008, art. 5.

lxxvi. *American Convention on Human Rights*, OAS Treaty Series No. 36; 1144 UNTS 123; 9 ILM 99 (1969), art. 1(1).

lxxvii. *African [Banjul] Charter on Human and Peoples' Rights*, adopted June 27, 1981, OAU Doc. CAB/LEG/67/3 rev. 5, 21 I.L.M. 58 (1982), art. 2.

lxxviii. *Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa*, Adopted by the 2nd Ordinary Session of the Assembly of the Union, Maputo, CAB/LEG/66.6 (Sept. 13, 2000); reprinted in 1 Afr. Hum. Rts. L.J. 40, *entered into force* Nov. 25, 2005, art. 2.

lxxix. *African Charter on the Rights and Welfare of the Child*, OAU Doc. CAB/LEG/24.9/40 (1990), *entered into force* Nov. 29, 1999, art. 3.

lxxx. *Convention for the Protection of Human Rights and Fundamental Freedoms*, 213 UNTS. 222, *entered into force* Sept. 3, 1953, as amended by Protocols Nos. 3, 5, 8, and 11, which *entered into force* on 21 September 1970, 20 December 1971, 1 January 1990 and 1 November 1998 *respectively*, art. 14.

lxxxi. Committee on the Elimination of All Forms of Discrimination against Women, *General Recommendation 24: Women and Health*, UN Doc. A/54/38/Rev. 1, chapter I, para. 11.

lxxxii. Ibid.

lxxxiii. Cook, R.J., Dickens, B.M. and Fathalla, M.F. *Reproductive Health and Human Rights: Integrating Medicine, Ethics and Law*, (Oxford, UK: Oxford University Press, 2003) at 279-281.

lxxxiv. Asamoah, B.O. et al., 'Distribution of Causes of Maternal Mortality Among Different Socio-Demographic Groups in Ghana: A Descriptive Study', 11 *BMC Public Health* 159 (2011) at 159.

lxxxv. WHO, 'Trends in Maternal Mortality: 1990 to 2008 – Estimates developed by WHO, UNICEF, UNFPA and the WB', (Geneva: WHO, 2010) at 17.

lxxxvi. World Health Organization, 'Maternal Mortality', Fact Sheet No. 348 (WHO: November, 2010).

lxxxvii. Committee on Economic, Social and Cultural Rights, "General Comment No. 14, The right to the highest attainable standard of health (article 12 of the *International Covenant on Economic, Social and Cultural Rights*)", UN Doc. E/C.12/2000/4, 11 August 2000, para. 12(b).

lxxxviii. Ibid. at para. 12(b)(i).

lxxxix. For discussion in the context of abortion services, Cook, R.J. and Dickens, B.M. 'Human Rights Dynamics of Abortion Law Reform', 25 *Hum. R. Q.* 1 (2003) at 41. Also Packer, C. 'Preventing Adolescent Pregnancy: The Protection Offered by International Human Rights Law', 5 *Int'l. J. Children's Rights* 46 (1997).

xc. *K.L. v. Peru*, U. Doc. CCPR/C/85/D/1153/2003, 22 November 2005 at para. 7.

xci. Ibid.

xcii. ICESCR, supra note 71, art. 12.

xciii. CRC, supra note 73, Art. 24(1).

xciv. Ibid.

xcv. Committee on the Rights of the Child, *General Comment No. 4: Adolescent health and development in the context of the Convention on the Rights of the Child*, UN Doc. CRC/GC/2003/4 (2003), para. 40 (emphasis added).

xcvi. Cook, Dickens and Fathalla, *Reproductive Health and Human Rights*, supra note 83 at 120–121.

xcvii. Article 17 of the ICCPR states that "no one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation."

xcviii. *European Convention on Human Rights*, Article 8(1): "Everyone has the right to respect for his private and family life, his home and his correspondence."

xcix. See e.g. *Dudgeon v. United Kingdom* (1981), 4 EHRR 149 (European Court of Human Rights); *Norris v. Ireland* (1988) 13 EHRR. 186 (European Court of Human Rights); *Modinos v. Cyprus* (1993) 16 EHRR 485 (European Court of Human Rights); *Toonen v. Australia* UN GAOR, Human Rights Committee, 15th Sess., Case 488/1992, UN Doc. CCPR/C/D/488/1992, Apr. 1994 (UN Human Rights Committee).

c. Weisleder, P. 'The Right of Minors to Confidentiality and Informed Consent', 19 *Journal of Child Neurology* 143 at 143.

ci. Diaz, A. et al., 'Legal and Ethical Issues Facing Adoelscent Health Care Professionals', 71 *The Mount Sinai J. of Med.* 181 (2004) at 183.

cii. Ibid.

ciii. English, A. 'More Evidence Supports the Need to Protect Confidentiality in Adolescent Health Care', 40 *J. of Adol. Health* 199 (2007) at 199. also Bitler, M. and Zavodny M., 'The effect of abortion restrictions on the timing of abortions', 20 *J. of Health Econs.* 1011 (2001) (A US study found a higher percentage of abortions after the first trimester in states with parental involvement laws); Colman, S. and Joyce, T. 'Minors' Behavioral Responses to Parental Involvement Laws: Delaying Abortion Until Age 18', 41 *Perspectives on Sexual and Reproductive Health* 119 (2009); Meehan, T.M., Hansen, H. and Klein, W.C. 'The impact of parental consent on the HIV testing of minors', 87 *Am. J. Public Health* 1338 (1997) (finding that the number of adolescents visiting test sites and obtaining an HIV test increased after the parental consent requirement was abolished); Jackson, S. and Hafemeister, T. 'Impact of Parental Consent and Notification Policies on the Decisions of Adolescents to Be Tested for HIV', 29 *J. of Adolescent Health* 81 (2001).

civ. Committee on the Elimination of Discrimination against Women, 'General Recommendation 24, Women and Health' (Twentieth session, 1999), UN Doc. A/54/38 at 5 (1999) (emphasis added).

cv. Crawford, T.V., McGrowder, D.A. and Crawford, A. 'Access to contraception by minors in Jamaica: a public health concern', 1 *North Am. J. Med. Sci.* 247 at 253.

cvi. *Bellotti v. Baird*, 443 U.S. 622 (1979) at p. 640: "As immature minors often lack the ability to make fully informed choices that take account of both immediate and long-range consequences, a State reasonably may determine that parental consultation often is desirable and in the best interest of the minor."

cvii. See e.g., *R. (on the application of Axon) v. Secretary of State for Health & Another*, [2006] E.W.H.C. 37 (Admin.) (upholding the right of competent young people under the age of 16 to receive confidential sexual and reproductive health care, including abortion care). For a discussion of this case, Erdman, J. 'Moral Authority in English and American Law', in Williams, S. ed., *Constituting Equality: Gender Equality and Comparative Law* (Cambridge: Cambridge University Press, 2009), 107–133.

cviii. CRC Committee, *General Comment No. 4 (2003): Adolescent Health and Development in the Context of the Convention on the Rights of the Child*, 33rd Sess., para. 31, UN Doc. CRC/GC/2003/4 (2003) at para. 7.

cix. Cook, R. and Cusack, S. *Gender Stereotyping: Transnational Legal Perspectives* (Philadelphia: University of Pennsylvania Press, 2010) at 64.

cx. *Universal Declaration of Human Rights*, G.A. res. 217A (III), UN Doc A/810 at 71 (1948), art. 3, supra; ICCPR, supra note 70, art. 6(1); CRC, supra note 73, art. 6(1), (2); Disability Rights Convention, supra note 75, art. 10.

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cxviii. CRC Committee, *General Comment No. 4 (2003): Adolescent Health and Development in the Context of the Convention on the Rights of the Child*, 33rd Sess., para. 31, UN Doc. CRC/GC/2003/4 (2003).

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cxxi. For a discussion of stigma and the law, Burris, S. 'Stigma and the law', 367 *The Lancet* (2006) 529.

cxxii. World Health Organization, 'HIV Status Disclosure to Sexual Partners: Rates, Barriers and Outcomes for Women' (Geneva: WHO, 2004) at 19.

cxxiii. Csete, J.. Schleifer, R. and Cohen, J. '"Opt-out" testing for HIV in Africa: a caution' (2004) 363 *The Lancet* 493.

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cxxvi. Ibid.

cxxvii. ICESCR, *General Comment 13, The right to education* (Art.13), 21st Sess., UN Doc. E/C.12/1999/10 (1999), at para. 1.

cxxviii. Report of the United Nations Special Rapporteur on the right to education, Sixty fifth session, UN Doc. A/65/162, para. 8.

cxxix. CSE programmes that perpetuate discrimination on the basis of sex, sexuality, and gender non-conformity violate minors' right to health protection. *International Centre for the Legal Protection of Human Rights (INTERRIGHTS) v. Croatia*, Complaint no. 45/2007, decided on 30 March 2009 (European Committee of Social Rights) (finding that "certain specific elements of the educational material… are manifestly biased, discriminatory and demeaning, notably in how persons of non-heterosexual orientation are described and depicted…"; States parties have a positive obligation under the Social Charter to ensure the effectiveness of the right to protection of health by way or non-discriminatory sexual and reproductive health education).

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cxxxi. Blake, S. et al., 'Condom Availability in Massachusetts High Schools: Relationships with Condom Use and Sexual Behavior', 93 *Am. J. Pub. Health* 955, 957 (2003). Also Baldo, M., Aggleton, P. and Slutkin, G. 'Does Sex Education Lead to Earlier or Increased Sexual Activity in Youth?', *Int'l Conf. AIDS* (1993) (abstract no. PO-D02-3444): "In response to policy maker's objection that sex or AIDS education may encourage sexual activity in young people, a review of studies on the effect of sex education in schools was carried out. Most of these studies are restricted to changes in students' knowledge or attitudes. Out of eighteen studies reviewed, only seven had evaluated sexual practices of students exposed to sex education. These seven studies, all from the USA, indicate a clear trend: **In no study was there evidence of sex education leading to earlier or increased sexual activity in the young people who were exposed to it**…" (emphasis added).

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cxxxvi. Bundesverfassungsgericht Az:1 BvR 1358/09, 21 July 2009, as cited and discussed in Baer, S. 'A closer look at law: human rights as multi-level sites of struggles over multi-dimensional equality', 6 *Utrecht Law Review* 56 (2010) at 66. Also, a Hamburg Administrative Court rejected a claim by a Turkish mother to withdraw her daughters, age 14 and 15, from sex education in biology classes, Verwaltungsgericht Hamburg 2004, Az: 15 VG 5827/2003).

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cxxxviii. Ibid.

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This Right to Decide series of papers was initiated by IPPF to learn more about young people, autonomy and sexual rights from experts working on these topics in various fields. We wanted to understand the theory behind the laws, policies and practices that both facilitate and restrict young people's autonomy as well as the key factors contributing to the development of young people as autonomous decision-makers.