High Income Countries Issue Brief:

RIGHTS OF CHILDREN AND YOUNG PEOPLE TO ACCESS HIV-RELATED SERVICES

For the High Income Countries Dialogue of the Global Commission on HIV and the Law

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Global Commission on HIV and the Law

Oakland (CA), United States of America, 17 September 2011
## Contents

Acknowledgements........................................................................................................ 1

Abbreviations ................................................................................................................... 2

1. **Introduction** .............................................................................................................. 3
   Structure, Methodology and Limitations ........................................................................ 4

2. **International Standards Related to Children and HIV** ............................................ 7

3. **Sexual Health Information and Education** .............................................................. 10
   3.1 Legal and Policy Environment .................................................................................. 10
   3.2 Good Practice and Law Reform ............................................................................... 13

4. **Sexual and Reproductive Health Services** ............................................................... 4
   4.1 Legal and Policy Environment .................................................................................. 4
       *Contraception, Abortion and STI Treatment* ......................................................... 4
       *HIV Testing* ........................................................................................................... 4
   4.2 Good Practice and Law Reform ............................................................................... 4

5. **Harm Reduction and Drug Treatment Services** ....................................................... 23

6. **HIV Treatment and Medication Trials** .................................................................... 26

7. **Principles for Developing Legal Frameworks Respecting Children’s Capacity and Rights** ............................................................................................................. 4
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Abbreviations

AIDS  Acquired Immune Deficiency Syndrome
CRC  Convention on the Rights of the Child
HIV  Human Immunodeficiency Virus
ICESCR  International Convention on Economic Social and Cultural Rights
IPPF  International Planned Parenthood Federation
NSP  Needle and Syringe Programmes
OHCHR  Office of the High Commissioner for Human Rights
STI  Sexually Transmitted Infections
UN  United Nations
UNAIDS  Joint United Nations Programme on HIV and AIDS
USA  United States of America
USD  United States Dollars
WHO  World Health Organisation

Countries included in the High-Income Countries Dialogue:

Austria, Belgium, Canada, Denmark, Finland, France, Germany, Greece, Ireland, Iceland, Israel, Italy, Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, United Kingdom of Great Britain and Northern Ireland, and United States of America (USA/ US).
1. Introduction

Particular vigilance is required to ensure that the human rights of children are respected, protected and fulfilled.\(^1\) Children and youth in high-income countries have not borne the burden of the Human Immunodeficiency Virus (HIV) epidemic to the same extent as children in other regions. It is estimated that, as of 2009, there were approximately 6,000 children living with HIV in North America and Western and Central Europe. Rates of HIV among children in high-income countries are low when compared with other regions.\(^2\) The protocols used to prevent vertical transmission are widely employed, HIV incidence resulting from sex and shared drug equipment is relatively low among children, child-specific ARVs are available and there have not been a significant number of children orphaned by the HIV-related deaths of parents.

This brief focuses on the rights of children (minors under the age of 18 years) in high-income countries to access health services related to HIV prevention – in particular sexual and reproductive health services, and harm reduction services and drug treatment services. It will examine children’s right to access information, the age at which children can consent to sexual and reproductive health services and drug treatment services, the right to privacy of children’s health-related information, and the duty of confidentiality owed by health and social welfare providers to children in relation to health information. The brief will also examine the right of children to access HIV treatment and participate in clinical trials.

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\(^1\) There is no standard definition of “child,” “young person” or “adolescent” for the purposes of law and health. The Convention on the Rights of the Child (CRC) states in Article 1 that a “child” is “every human being below the age of 18 years,” unless applicable law provides for earlier attainment of majority status, such as on marriage. The World Health Organization (WHO) defines “adolescence” as occurring between the ages of 10 and 19 years. WHO (1993), The health of young people. The most recent UNAIDS report on the global HIV epidemic defines children as those people aged 0 to 14 years. UNAIDS (2010), *Report on the Global AIDS Epidemic 2010*.

Structure, Methodology and Limitations

The Issue Brief is based on a desk review of literature, United Nations (UN) and other international organisations’ policy briefs, reports and analytical papers, analyses of selected statutes, judicial precedents and law enforcement practices. It does not aim to provide a comprehensive overview of the legislation, policies and enforcement practices in all study countries. Rather, the aim of the Issue Brief is to provide examples of positive and negative legal regulations, policies and enforcement practices, which serve as illustrations of supportive or punitive legal environments, and point out challenges faced by the high income countries in relation to HIV, the law and human rights. An overview of why certain policies may be harmful for individual human rights and public health goals is provided, as well as links to international standards.
1. International Standards Related to Children and HIV

The International Convention on Economic Social and Cultural Rights (ICESCR) and the Convention on the Rights of the Child (CRC) define the human rights of children and young people. The CRC sets the upper limit of childhood at 18 years. It states that the best interests of the child shall be the primary consideration in all actions concerning children. The CRC sets out for children, among other rights, the right to non-discrimination, the right to life, survival and development, the right to have views affecting the child heard and given due weight, in accordance to age and maturity of the child, the right to privacy, the right to access information and material aimed at the promotion of their social, spiritual and moral well-being and physical and mental health, and the right to the highest attainable standard of health, which imposes upon the State an obligation to take appropriate measures to develop preventive health care, guidance for parents, and family planning education and services. The CRC does not state an age at which a child can fully exercise certain rights, without recourse to parental consent. The recognition of self-determination of minors in relation to parental authority (i.e. parental responsibilities, rights and duties) is based upon the concept of the “evolving capacities of the child”.

In General Comment 14 on the right to the highest attainable standard of physical and mental health, the United Nations Committee on Economic, Social and Cultural Rights states:

The Convention on the Rights of the Child directs States to ensure access to essential health services (and)... links these goals with ensuring access to child-friendly information about preventive and health-promoting behaviour and

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4 CRC, Article 3.
5 Ibid, Article 2.
6 Ibid, Article 6.
7 Ibid, Articles 12, 13.
8 Ibid, Article 16.
9 Ibid, Article 17.
10 Ibid, Article 24(1).
11 Ibid, Article 24(2)(f).
12 Ibid, Articles 5, 14.
support to families and communities in implementing these practices...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 counselling and to negotiate the health-behaviour choices they make. The realisation of the right to health of adolescents is dependent on the development of youth-friendly health care, which respects confidentiality and privacy and includes appropriate sexual and reproductive health services.

In General Comment 4, regarding adolescent health and development, the Committee on the Rights of the Child recognises that adolescence is a period characterised by rapid changes, including sexual and reproductive maturation, which can pose new challenges to their health and development owing to their relative vulnerability and pressures from society to adopt risky health behaviours, including the challenge of developing an individual identity and dealing with one’s sexuality. In this regard, the Committee calls on States to:

... ensure that appropriate goods, services and information for the prevention and treatment of STDs, including HIV/AIDS, are available and accessible. To this end, States parties are urged (a) to develop effective prevention programmes, including measures aimed at changing cultural views about adolescents’ need for contraception and STD prevention and addressing cultural and other taboos surrounding adolescent sexuality; (b) to adopt legislation to combat practices that either increase adolescents’ risk of infection or contribute to the marginalisation of adolescents who are already infected with STDs, including HIV; (c) to take measures to remove all barriers hindering the access of adolescents to information, preventive measures such as condoms, and care.

Guideline 8 of the International Guidelines on HIV/AIDS and Human Rights provides:

States, in collaboration with and through the community, should promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.

Girls are particularly vulnerable to violence, coercion and lack of control over their sexual and reproductive health. Therefore, policies and legislation must be attuned to

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15 Ibid.
the specific issues, differing vulnerabilities and needs of young women, and be equally approached for all youth - including young men, lesbian, gay, bisexual and transgendered youth, as well as marginalised groups such as street youth.
3. Sexual Health Information and Education

3.1 Legal and Policy Environment

There is little comparative data, or legal and policy analysis, on the sexual and reproductive health and rights of young people in Europe. One large-scale research and policy development project undertaken concluded that policies to protect the sexual and reproductive health rights of young people may not meet their needs and are not always consistent within and among European countries. The project report also noted that not only the most vulnerable youth in Europe (i.e., injecting drug users, school dropouts, ethnic minorities, young people living on the street), but less vulnerable youth attending school also suffer from poor sexual and reproductive health education.

In the USA, legislation has played a prominent role in the content of sexual health education. Federally, in 2010 the United States Congress passed two new evidenced-based sex education programmes: the Personal Responsibility Education Program (PREP), and the Teen Pregnancy Prevention (TPP) initiative. Prior to that, the federal government provided special grants to states for abstinence-only-until-marriage

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19 Ibid.

programmes. It has been reported that during the period from 1981 to 2007 more than USD 1 billion in funding was directed toward abstinence-only programmes. It has been argued that abstinence-only sexual health education programmes interfere with children’s right to the highest attainable standard of health because they withhold potentially life-saving information on HIV and other sexually transmitted infections.

All states in the USA have enacted legislation that touches upon sex education for public schoolchildren. As of February 2011:

- 20 states and the District of Columbia require public schools to teach sex education (including HIV education);
- 35 states and the District of Columbia require that students receive instruction about STIs and HIV/AIDS;
- 15 states require sex education curricula to be medically accurate and/or age appropriate. State policies vary in their determination of “medically accurate;” some require that state health departments review curricula, while others require that the facts taught come from “published authorities upon which medical professionals rely.”

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21 The program under Title V, Section 510(b) of the Social Security Act (now codified as 42 U.S.C, § 710(b)) is commonly known as Title V. It created specific requirements for grant recipients. Under this law, the term “abstinence education” means an educational or motivational program which:
- Has as its exclusive purpose teaching the social, psychological, and health gains to be realised by abstaining from sexual activity;
- Teaches abstinence from sexual activity outside marriage as the expected standard for all school-age children;
- Teaches that abstinence from sexual activity is the only certain way to avoid out-of-wedlock pregnancy, sexually transmitted diseases, and other associated health problems;
- Teaches that a mutually faithful monogamous relationship in the context of marriage is the expected standard of sexual activity;
- Teaches that sexual activity outside of the context of marriage is likely to have harmful psychological and physical effects;
- Teaches that bearing children out of wedlock is likely to have harmful consequences for the child, the child’s parents, and society;
- Teaches young people how to reject sexual advances and how alcohol and drug use increase vulnerability to sexual advances, and
- Teaches the importance of attaining self-sufficiency before engaging in sexual activity.

Title V-funded programs were not permitted to advocate or discuss contraceptive methods except to emphasise their failure rates.


25 Ibid.
Many of these statutes define parents’ rights concerning sexual education:26

- 37 states require school districts to allow parental involvement in sexual education programmes;
- 3 states require parental consent before a child can receive instruction; and
- 35 states and the District of Columbia allow parents to opt-out on behalf of their children.

A review of four abstinence-only programmes in school districts in the State of Texas documented that teachers in some districts were restricted or prohibited altogether from providing information about condoms, while in other districts the curriculum required teachers to teach that condoms were ineffective at preventing HIV.27 Concerns have been raised that the terms of federally and state-funded abstinence only programmes do not adequately support the need for accurate sexual health information among lesbian and gay students.28 The focus on abstinence-only-until-marriage does not adequately take into account the legal reality that in most jurisdictions in the US, same-sex couples are not legally permitted to marry.29 Some states’ legislation or policies in relation to education bar the discussion of homosexuality altogether except in the context of sexually transmitted diseases, ban instruction that homosexuality is acceptable, or require instruction that homosexuality is unacceptable and illegal.30

It has been argued that abstinence-only programmes are not supported by evidence of efficacy.31 An independent evaluation of the federally-funded abstinence only programme, several systematic reviews, and cohort data from population-based surveys have found little evidence of efficacy and have found evidence of possible harm.32 Studies have pointed to medical inaccuracy and the ethically untenable position of

26 Ibid.
28 Ibid.
30 Ibid.
32 Underhill K, et al (2007), Abstinence-only programs for HIV infection prevention in high-income countries, Cochrane Database of Systematic Reviews, Issue 4 Art No CD005421. DOI: 10.1002/14651858.CD005421.pub2. According to the authors of the review, results showed no indications that abstinence-only programs can reduce HIV risk as indicated by self-reported biological and behavioral outcomes. Compared to various controls, the evaluated programs consistently did not affect incidence of unprotected vaginal sex, frequency of vaginal sex, number of partners, sexual initiation, or condom use. One study found a significantly protective effect for incidence of recent vaginal sex (n=839), but this was limited to short-term follow-up, countered by measurement error, and offset by six studies with non-significant results (n=2615). One study found significantly harmful effects for STI incidence (n=2711), pregnancy incidence (n=1548), and frequency of vaginal sex (n=338); these effects were also offset by studies with non-significant findings.
withholding potentially life-saving information. Reviews have found that abstinence-plus and comprehensive sexual health education and HIV prevention programmes apparently reduce in short-term and long-term HIV and sexually transmitted infections (STI) risk behavior among youth in high-income countries, and consistently show no adverse programme effects for any outcomes, including the incidence and frequency of sexual activity.\textsuperscript{33}

### 3.2 Good Practice and Law Reform

General Comment 3 of the Committee on the Rights of the Child specifically addresses HIV/AIDS and the rights of the child.\textsuperscript{34} It emphasises that effective HIV/AIDS prevention requires States to refrain from censoring, withholding or intentionally misrepresenting health-related information, including sexual education and information, and that, consistent with their obligations to ensure the right to life, survival and development of the child (article 6), States parties must ensure that children have the ability to acquire the knowledge and skills to protect themselves and others as they begin to express their sexuality.

In General Comment 4, the Committee on the Rights of the Child calls on States to:

\begin{itemize}
  \item … ensure that all adolescent girls and boys, both in and out of school, are provided with, and not denied, accurate and appropriate information on how to protect their health and development and practice healthy behaviours. This should include information on the use and abuse of tobacco, alcohol and other substances, safe and respectful social and sexual behaviours, diet and physical activity.\textsuperscript{35}
  \item … provide adolescents with access to sexual and reproductive information, including on family planning and contraceptives, the dangers of early pregnancy, the prevention of HIV/AIDS and the prevention and treatment of sexually transmitted diseases (STDs) … regardless of their marital status and whether their parents or guardians consent.\textsuperscript{36}
\end{itemize}

\textsuperscript{33} Ibid; See also Johnson BT et al (2011), \textit{Interventions to reduce sexual risk for human immunodeficiency virus in adolescents: a meta-analysis of trials, 1985-2008}, Archive of Pediatric Adolescent Medicine, 165(1) at pp.77-84.


\textsuperscript{36} Ibid, para 28.
The commentary to Guideline 8 (women, children and other vulnerable groups) of the International Guidelines on HIV/AIDS and Human Rights elaborate on the responsibility of States in relation to children:  

States should ensure the access of children and adolescents to adequate health information and education, including information related to HIV prevention and care, inside and outside school, which is tailored appropriately to age level and capacity and enables them to deal positively and responsibly with their sexuality. Such information should take into account the rights of the child to access to information, privacy, confidentiality, respect and informed consent and means of prevention, as well as the responsibilities, rights and duties of parents. Efforts to educate children about their rights should include the rights of persons, including children, living with HIV.

The SAFE Project, funded by the European Commission’s Health Strategy, created guidelines to assist policymakers and governments in the creation and improvement of policies and programmes that respond successfully to the sexual and reproductive health and rights of young people. In relation to information, education and communications, the SAFE Project recommended that governments ensure that comprehensive sexuality education be: a mandatory subject for both primary and secondary schools; based on clearly set minimum standards and teaching objectives; accompanied by necessary resources; made available in a variety of settings accessible to young people inside and outside of schools, and that specific action be taken to identify and reach vulnerable youth; and be monitored and evaluated. It is further recommended that governments ensure that the content of the programmes is comprehensive, covering a broad range of topics relating to physical and biological, emotional and social aspects of sexuality, including discussion of risk behaviour such as alcohol and drug use.

In Canada, the federal government has published national sexual health education guidelines. Under the Canadian constitution, provinces and territories have legislative jurisdiction over education. The guidelines are intended to: guide the efforts of professionals in the area of sexual health education and promotion; and to offer clear direction to assist local, regional and national groups and government bodies concerned with education and health. Five guiding principles are set out: (1) accessible health education for all Canadians; (2) comprehensiveness of sexual health education; (3) effectiveness of educational approaches and methods; (4) training and administrative support; (5) programme planning, evaluation, updating and social development.

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38 The SAFE project was a collaborative effort between IPPF European Network Regional Office and 26 of its Member Associations, together with Lund University and the WHO Regional Office for Europe.
39 Public Health Agency of Canada (2008), Canadian Guidelines for Sexual Health Education, Her Majesty the Queen in Right of Canada.
relation to legal concepts and frameworks, the guidelines include as a key concept “sexual rights,” which “embrace human rights that are already recognised in national laws, international human rights documents and other consensus statement.”\textsuperscript{40}

\textsuperscript{40} Ibid, page 6.
Misconceptions regarding the legal standards regarding minors’ consent to medical services may act as a barrier to the realisation of their reproductive and sexual health rights.\textsuperscript{41} Health service providers may assume that minors (or those below the official age of consent in a given jurisdiction) require parental consent to obtain services or that parents must be informed when a minor accesses services. At times parental involvement is not a realistic or desirable goal as there may be competing interests between the adolescent and the parent.\textsuperscript{42} A majority of children report that confidentiality is the most important quality of a sexual health service.\textsuperscript{43} In order to avoid parental disclosure, children may forgo reproductive health care or may not be honest with healthcare providers when seeking services, which carry the potential for detrimental consequences for children’s sexual health.\textsuperscript{44} Another potential legal understanding conflict for service providers is between their obligations under child protection laws and their obligation to maintain client confidentiality. Under child protection laws, service providers often have a legal obligation to report cases where a child is at risk of harm. Domestic criminal laws often set out a legal age for consent to sex. When people below the age of consent access sexual health services, the service provider is put in a position to decide whether he or she has an obligation to report the situation to child protection authorities.\textsuperscript{45}

\begin{thebibliography}{9}
\bibitem{Cook2007b} Cook RJ et al, (2007), \textit{Respecting adolescents’ confidentiality and reproductive and sexual choices}, International Journal of Gynaecology and Obstetrics 2007;98(2):182-7, Faculty of Law, Faculty of Medicine and Joint Centre for Bioethics, University of Toronto, Canada.; See also Jones RK et al, (2005), \textit{Adolescents’ reports of parental knowledge of adolescents’ use of sexual health services and their reactions to mandated parental notification for prescription contraception}, JAMA 293(3):340-348; See also Thomas N et al, (2006), \textit{Confidentiality is essential if young people are to access sexual health services}, International Journal of STD AIDS.
4.1 Legal and Policy Environment

Over time the legal criteria for determining the competence of children to make medical decisions have moved from an age-based approach towards an assessment based on the individual child’s experience and understanding. The law regarding the age of consent to medical decision-making tends to be jurisdiction- and context-dependent, and different standards and approaches are evident across high-income countries. Under the CRC, States undertake to respect parental rights and duties to the extent that they are consistent with the “evolving capacities of the child”. The concept of “evolving capacity” envisions a point at which any conflict between parental rights to make decisions for a child and the child’s right to self-determine will be resolved in favour of the child; and the state’s obligation to respect, protect and fulfill the rights of the child is no longer balanced against parental authority. Under a human rights approach, in legal proceedings a child can assert her human rights and then the burden shifts to the parents to justify any limitation to the child’s rights.

The concept of the “mature minor” – a minor who is judged to have legal capacity to make a decision despite being under a certain fixed age – has received attention from courts, and in legislation and policy. A number of court decisions from domestic courts in high-income countries, which decisions will be examined below, have set forth standards for determining when a minor can obtain sexual and reproductive health services without recourse to parental consent.

There is substantial divergence across Europe regarding which decisions minors are competent to make and the rights afforded to adolescents. While many countries adopt an age-based approach, the age of consent to medical decisions varies among countries. The European Convention on Human Rights and Biomedicine leaves each


48 CRC, Article 5.

49 Ibid.


52 For example, the age at which a child can consent to medical treatment is 14 in Portugal, 15 in Denmark, 16 in Spain, 16 in the UK, and 18 in Greece. See Stultiens L et al, (2007), Minors and Informed Consent: A Comparative Approach, European Journal of Health Law.
State signatory to define when a minor is viewed as competent to give a valid consent.\textsuperscript{53} However, for those viewed in law as not capable of providing consent, according to the European Convention on Human Rights and Biomedicine the treatment must directly benefit the minor, the authorisation of a legal representative must obtained and the opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity.\textsuperscript{54} The European Parliament’s resolution on sexual and reproductive health and rights calls on States to improve and extend young people’s access to sexual and reproductive health services, and calls upon the governments to provide support for pregnant young women.\textsuperscript{55}

**Contraception, Abortion and STI Treatment**

In the United Kingdom, in the influential *Gillick* decision, the House of Lords abandoned the rule of parents’ absolute authority over a minor in favour of what is best for the welfare of the child according to general guidelines for determination of legal capacity in this context.\textsuperscript{56} A medical professional must consider: (a) the minor’s ability of the minor to understand the medical advice\textsuperscript{57} (b) the medical professional cannot persuade the minor to allow the minor’s parents to be informed (c) the minor is likely to have sexual intercourse with or without the contraception sought (d) the minor’s health is likely to suffer without medical advice and treatment (e) the minor’s best interests require the medical professional to give the minor contraceptive advice, treatment or both without the parental consent. The Court of Appeal for the Province of Alberta, Canada, has also considered the issue of minors’ consent to reproductive health services.\textsuperscript{58} The Alberta Court decided that minors are able to consent to an abortion if they have sufficient understanding and intelligence to enable them to understand fully what is proposed,

\textsuperscript{53} Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, Convention on Human Rights and Biomedicine, Oviedo, 4. IV 1 997. CETS No 164, article 6.

\textsuperscript{54} European Convention on Human Rights and Biomedicine, Article 6(2).

\textsuperscript{55} European Parliament resolution on sexual and reproductive health and rights (2001/2128 (INI)).

\textsuperscript{56} *Gillick* v West Norfolk and Wisbech Area Health Authority and another, [1986] 1 AC 112 (House of Lords), per Lord Fraser. The Family Law Reform Act 1969 provides that a minor who has reached 16 years of age can consent to any surgical, mental or dental treatment. Ms Gillick, who was under 16 years of age, has sought contraceptive advice and treatment. For a discussion of *Gillick* and the situation of minors’ consent in the UK, see Perera A (2008), *Can I Decide Please? The State of Children’s Consent in the UK*. European Journal of Health Law 15 (2008) at pp. 411-420.

\textsuperscript{57} In his reasons in *Gillick*, Lord Scarman supplemented the guidelines of Lord Fraser, as follows: “It is not enough that she should understand the nature of the advice which is being given: she must also have a sufficient maturity to understand what is involved. There are moral and family questions, especially her relationship with her parents long-term, problems associated with the emotional impact of pregnancy and its termination and there are the risks to health of sexual intercourse at her age, risks which contraception may diminish but cannot eliminate. It follows that a doctor will have to satisfy himself that she is able to appraise these factors before he can safely proceed on the basis that she has at law capacity to consent to contraceptive treatment.”

\textsuperscript{58} *C(JS) v Wren*, (1986) 35 DLR (4th) 419 (Alberta Court of Appeal). In Wren, the parents of a 16 year old pregnant girl sought to block her access to an abortion.
including an understanding of medical matters and obligations to their parents.

In the *Axon* case, the High Court of England and Wales was called upon to resolve a conflict between parents’ claim to be notified prior to an abortion and a minor’s right to consent to the procedure without such notification.\(^{59}\) That judgment confirmed the legality of the UK Department of Health’s Guidance to health professionals on the advice and treatment provided to under 16-year olds on contraception and sexual and reproductive health. The Guidance stated that health professionals have a duty of care and a duty of confidentiality to all patients, including those under 16, and that such a duty overrides parents’ right to be informed unless to do so was in the child’s best interests. Significantly, the High Court rejected the argument that the Guidelines, by permitting a medical professional to withhold information relating to advice or treatment of a young person on sexual matters, infringed the European Convention on Human Rights article 8 rights to privacy and family life of the parents of the young person. Moreover, even if that were the case, the High Court cited Strasbourg Court decisions establishing that a child’s article 8 rights override similar rights of a parent,\(^{60}\) and supporting the right to confidentiality of medical of health information.\(^{61}\)

Legislation pertaining to adolescent consent to access contraception and other sexual health services in the USA, if they exist, varies from one state to another.\(^{62}\) Over the past 30 years, states have expanded minors’ authority to consent to health care, including care related to sexual activity; however, many states allow physicians to inform parents that the minor is seeking or receiving STI services when they deem it in the best interests of the minor.\(^{63}\) A review of sexual health services and minors’ consent across the USA revealed that minors 12 years and older are legally permitted to consent to sexually transmitted disease services in 50 states and the District of Columbia (DC); and to contraceptive services in 25 states and DC; and to abortion in two states and DC. Regarding abortion services, the review indicated that seven states have no law, and in the remaining states the law required parental consent or notification.\(^{64}\)


\(^{60}\) Hendriks v Netherlands (1992), EHRR 223; Yousef v Netherlands (2003), 36 EHRR 345.


**HIV Testing**

While there is significant national, regional and international public health and policy-level guidance on HIV testing, there is a lack of up-to-date comprehensive information about legal and regulatory regimes applicable to testing across high-income countries. A lack of literature assessing legal and administrative barriers to HIV testing in Europe has been identified. Legislation pertaining to adolescent consent to HIV testing in the USA, if they exist, varies from one state to another. A review of sexual health services and minors’ consent across the USA revealed that minors 12 years and older are legally permitted to consent to HIV testing and treatment in 31 states, either under legislation specific to HIV testing or non-HIV-specific legislation.

### 4.2 Good Practice and Law Reform

In General Comment 3, the Committee on the Rights of the Child raises the issue of consent and access to health services in relation to HIV testing and counseling. It is not explicit about an age of consent; rather, following on the Convention it states that “the evolving capacities of the child will determine whether consent is required from him or her directly or from his or her parent or guardian.” The General Comment is silent regarding consent and access to HIV treatment and care, and access to harm reduction services. In respect to “substance abuse” it states: “State parties are obligated to ensure the implementation of programmes which aim to reduce the factors that expose children to the use of substances, as well as those that provide treatment and support to children who are abusing substances.”

In General Comment 3, the Committee encourages States to ensure that health services

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65 For an example of a survey of HIV testing and counselling see, Romanian Association Against AIDS (2008), HIV Counselling and Testing Services in Europe: Results of a European Seminar Pre-seminar Report, AIDS Action Europe. Survey data included the following high-income countries: Great Britain, France, Portugal and Sweden. Data regarding the legal framework for voluntary HIV testing and counselling demonstrated a range of source-documents, including HIV-specific laws, general laws related to health, health ministry orders, and working standards and procedures. The report does not deal with children’s consent to testing other than in the context of compulsory testing of children entering orphanages, principally in Central and Eastern Europe and countries of the former Soviet Union.


70 Ibid, para 39.
personnel fully respect the rights of children to privacy\textsuperscript{71} and non-discrimination.\textsuperscript{72} It also emphasises the general rule that confidentiality of HIV status of children must be respected in health and social welfare settings, and should not be disclosed to third parties, including parents, without the child’s consent.\textsuperscript{73} The General Comment lists the following services: HIV-related information; voluntary counselling and HIV testing; confidential sexual and reproductive health services; free or low-cost contraceptive methods and services; and HIV-related care and treatment if and when needed, including for the prevention and treatment of health problems related to HIV/AIDS.\textsuperscript{74}

In General Comment 4, the Committee on the Rights of the Child emphasises the importance of adolescent’s rights to privacy and confidentiality, and the issue of consent, in relation to access to health and medical services.\textsuperscript{75} Sexual and reproductive health services, including HIV and STD prevention, are listed.\textsuperscript{76} The Committee addresses law reform and training for health care providers:\textsuperscript{77}

With regard to privacy and confidentiality, and the related issue of informed consent to treatment, States parties should (a) enact laws or regulations to ensure that confidential advice concerning treatment is provided to adolescents so that they can give their informed consent. Such laws or regulations should stipulate an age for this process, or refer to the evolving capacity of the child; and (b) provide training for health personnel on the rights of adolescents to privacy and confidentiality, to be informed about planned treatment and to give their informed consent to treatment.

The International Guidelines on HIV/AIDS and Human Rights elaborate on the responsibility of States in relation to children’s access to services.\textsuperscript{78}

States should ensure that children and adolescents have adequate access to confidential sexual and reproductive health services, including HIV information, counselling, testing and prevention measures such as condoms, and to social support services if affected by HIV. The provision of these services to children/adolescents should reflect the appropriate balance between the rights of the child/adolescent to be involved in decision-making according to his or her

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\textsuperscript{71} Ibid, para 16.
\textsuperscript{72} Ibid, para 7 to 9.
\textsuperscript{73} Ibid, para 24.
\textsuperscript{74} Ibid, para 20.
\textsuperscript{76} Ibid, para 28.
\textsuperscript{77} Ibid, para 33.
\textsuperscript{78} OHCHR and UNAIDS (2006), International Guidelines on HIV/AIDS and Human Rights, consolidated version. HR/PUB/06/09, para 60(h).
evolving capabilities and the rights and duties of parents/guardians for the health and well-being of the child.

The World Health Organisation (WHO) and the Joint United Nations Programme on HIV and AIDS (UNAIDS) encourage countries to provide adolescents with independent access to HIV prevention, treatment, care and support.\(^79\)

WHO guidance on HIV testing distinguishes between children (sometimes the term “young children” is used) and adolescents.\(^80\) WHO and WHO Europe recommend that countries adopt policies to offer HIV testing and counselling to all adults, adolescents and children presenting at health facilities with signs and symptoms of underlying HIV infection, and to children known to be perinatally exposed to HIV.\(^81\) Legal and policy requirements for HIV testing and counselling of young children, and the age that defines a child, vary by country.\(^82\)

WHO guidance on provider-initiated testing in healthcare settings addresses informed consent and assent of adolescents to HIV testing.\(^83\) It takes as a starting point that “national and local laws may or may not stipulate precisely the age of majority for independent access to health services, or the age at which adolescents are allowed to give their own consent may vary for different procedures.” It calls on governments to develop and implement clear legal and policy frameworks that stipulate: (1) the specific age and/or circumstances in which minors may consent to HIV testing for themselves or for others (as in the case of child-headed households); and (2) how the assent of and consent of adolescents should best be assessed and obtained. Regarding the second point, the guidance states that where domestic law does not allow a “sufficiently mature adolescent” to consent, the health care provider should provide the adolescent opportunity to assent to HIV testing and counselling in private, without the presence or knowledge of his or her parents or legal guardians, and if the adolescent assents only then seek the consent of the parent of guardian. The guidance also calls for training and supervision for health care providers on laws and policies governing the consent for minors to access clinical services.

\(^79\) WHO, UNAIDS (2007), Guidance on provider-initiated HIV testing and counselling in health facilities.
\(^80\) Ibid; See also WHO Europe (2010), Scaling up HIV testing and counseling in the WHO European Region as an essential component of efforts to achieve universal access to HIV prevention, treatment, care and support: Policy Framework. See also: WHO Regional Office for Europe (Copenhagen, Denmark) (2011), HIV Testing in Young Children: Technical Briefing Paper, WHO/HIV/11.2.
\(^81\) WHO, UNAIDS, (2007), Guidance on provider-initiated HIV testing and counselling in health facilities; See also WHO Europe (2010), Scaling up HIV testing and counseling in the WHO European Region. See also European Centre for Disease Prevention and Control (2010), HIV testing: increasing uptake and effectiveness in the European Union.
\(^82\) WHO (2011), HIV Testing in Young Children.
\(^83\) WHO, UNAIDS (2007), Guidance on provider-initiated HIV testing and counselling in health facilities.
Recognising that abortion is a sensitive issue in many European countries, the SAFE Project’s legislative and policy recommendations to governments include:\textsuperscript{84}

- ensure that abortion legislation is integrated into an overall strategy of prevention which includes comprehensive and rights-based sexuality education and the provision of contraception, emergency contraception and youth-friendly services;
- ensure that parental/adult consent is not part of a legal framework and that an exception to regular procedures of public hospitals should be stipulated to protect the right to confidentiality of a minor seeking an abortion; and
- ensure that young women are able to access abortion services in a mix of medical settings to increase accessibility and quality of care a pre-determined period for reflection should not be made mandatory and should not be included in the legislation but left to the judgment of counselors or service providers.

The United Kingdom has policy and practice guidance for the management of sexually transmitted infection and provision of sexual health services to children and youth, both of which provide a legal framework and guidance for consent, confidentiality and child protection.\textsuperscript{85}

Sweden has sought to create a policy environment supportive of youth access to health services.\textsuperscript{86} The principal institutional iterations of the policy have been twofold. First, youth health centres were created throughout the country in the 1970s, in response to increasing substance use (i.e., alcohol, tobacco and illegal drugs) and rising abortion rates among young women. Second, in 1993 the Children’s Ombudsman was created pursuant to the \textit{Children’s Ombudsman Act}. The Children’s Ombudsman is charged with representing the rights and interests of children and young people against the background of Sweden’s commitments under the CRC. Some of the policy features of the Swedish environment in relation to the sexual health and reproductive health of youth include:

- Sex education and family life skills are a mandatory part of the school curriculum;
- Condoms are freely available in schools and youth health centres;
- Contraceptive medication is generally subsidised, as is the morning after pill for those under 20 years of age;

\textsuperscript{85} Department of Health (UK) (2004), Best practice guidance for doctors and other health professionals on the provision of advice and treatment to young people under 16 on contraception, sexual and reproductive health.; See also Clinical Effectiveness Group, British Association for Sexual Health and HIV, (2010), United Kingdom National Guideline on the Management of Sexually Transmitted Infections and Related Conditions in Children and Young People – 2010, \url{http://www.bashh.org/documents/2674}.
\textsuperscript{86} Baltag V, Mathieson A (eds) (2010), Youth-friendly health policies and services in the European Region, Copenhagen, Denmark: WHO Regional Office for Europe.
• Promotion of the human rights of children, based on a framework of social connectedness grounded in children’s need for security, communication and participation.
There is a paucity of recent literature about laws and policies affecting access to harm reduction and drug treatment services for minors in high-income countries. This may reflect the general lack of attention in policy and programming to harm reduction for youth, combined with a focus on recreation drug use among youth (often related to cannabis and alcohol) rather than on reducing harms associated with injection drug use, including the transmission of blood borne infections. A recent survey revealed a lack of disaggregated data regarding youth and drug use, few youth-specific policies and programmes, and the lack of youth involvement in policy and programme design. This situation suggests that an opportunity exists to further research the issue of youth and drug treatment and the engagement of youth in policy and programming in order to devise appropriate responses specific to their needs. The UNAIDS Programme Coordinating Board has called upon Member States and civil society organisations to develop, in addition to specific interventions that target injecting drug users, guidance and programme models to respond to the needs of other sub-groups of drug users, including underage and young drug users. 


88 See for example, Rhodes T, Hendrich D (2010), Harm reduction: Evidence, impacts and challenges, EMCDDA Monograph 10, Lisbon, Portugal: European Monitoring Centre for Drugs and Drug Addiction, which includes a section on “Young people, recreation drug use and harm reduction.” See also, Poulin C (2006), Harm Reduction Policies and Programs for Youth, Ottawa, Ontario: Canadian Centre on Substance Abuse, for a review of Canadian harm reduction laws, policies and programs for youth—in relation to alcohol, tobacco and cannabis—found that laws support abstinence as the desired stance for prevention efforts and identify youth as being, in a real way, a vulnerable sub-group of the population. The review identified federal and provincial legislation as well as formal school board policies that support abstinence as a goal, whereas harm reduction is supported by various non-binding statements of principle at the national and provincial levels, primarily from a health perspective.


drug education for young people is lacking, and in many countries, there are age thresholds for participating in harm reduction interventions.\(^91\)

Article 33 of the CRC addresses the rights of the child in the context of illicit drugs:

States Parties shall take all appropriate measures, including legislative, administrative, social and educational measures, to protect children from the illicit use of narcotic drugs and psychotropic substances as defined in the relevant international treaties, and to prevent the use of children in the illicit production and trafficking of such substances.

Article 33 has received little attention and has appeared rarely in academic literature.\(^92\) This suggests an opportunity to clarify the obligations of state parties in relation to children and harm reduction: (1) the publication of a General Comment from the Committee on the Rights of the Child on article 33; (2) the publication of a supplementary commentary on the drug conventions read in the light of the CRC could be collaboratively drafted by a number of UN organisations and committees and offices; and (3) the formation of an interagency group at the UN around children and drugs.\(^93\)

In a number of the high-income countries reviewed, there is no legal prohibition on minors’ access to opiate substitution treatment: Canada\(^94\), UK\(^95\), and Switzerland\(^96\). In

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\(^93\) Ibid.

\(^94\) In Canada, prescribing opiate substitution treatment (i.e., methadone and buprenorphine) is subject to more legal regulation than the prescription of most other drugs, under the Controlled Drugs and Substances Act. To prescribe methadone for the treatment of opioid dependence, physicians must be exempted under section 56 of the Act, and support of the physician's licensing body is normally required. Federal guidelines are silent on, or contemplate, access by minors. See: Health and Welfare Canada (1992), The use of opioids in the management of opioid dependence, Ottawa: Minister of Supply and Services; and, Health Canada (2002), Best Practices: Methadone Maintenance Treatment, Her Majesty the Queen in Right of Canada, represented by the Minister of Public Works and Government Services Canada, which provide specific guidance in relation to adolescents. Three of four provincial guidelines do not establish age-related criteria for admission to treatment. See also The College of Physicians and Surgeons of Ontario (2011), Methadone Maintenance Treatment Program Standards and Guidelines, 4th ed, College of Physicians and Surgeons of Saskatchewan, Saskatchewan Health, (2008), Saskatchewan Methadone Guidelines for the Treatment of Opiate Addiction; College of Physicians and Surgeons of British Columbia, (2009), Methadone Maintenance Handbook. However, Quebec requires that patients be 14 years or older to receive methadone for detoxification, a parental authority must be notified when a youth between 14 and 18 years is hospitalised, and the consent of a person in parental authority should be obtained if possible. See Collège des médecins du Québec, Ordre des pharmaciens du Québec (2000), The Use of Methadone in the Treatment of Opiate Addiction, Updated 2004.

\(^95\) In the UK, the Medicines Act 1968 and the Misuse of Drugs Act 1971 cover many aspects of the production, prescribing, possession, supply, administration and disposal of methadone and buprenorphine. According to guidance, at 16 young people can be presumed to have capacity to consent
the USA, there is a wide variety of state legislation applicable to substance abuse treatment for youth.\textsuperscript{97}

Several barriers to needle and syringe programmes (NSP) access have been reported, including strict drug and paraphernalia laws leading to a fear of arrest, distance from service, limited opening hours, limits on the injecting equipment provided per visit and concerns over confidentiality. It has also been reported that NSP staff are sometimes reluctant to provide young people (under eighteens) with injecting equipment.

At the regional level, the European Union’s drug strategy and action plan for 2009 to 2012 emphasises harm reduction as a key component within the drug response. On evaluating progress on the previous action plan (2005 to 2008), which also included harm reduction, the European Commission concluded that ‘further improvements are still needed in [the] accessibility, availability and coverage’ of harm reduction services across the region. It also highlighted shortcomings of current responses in addressing the needs of subpopulations such as women, young people, migrants and specific ethnic groups.

to treatment; children under 16 may have capacity to consent, depending on their maturity and ability to understand what is involved; and, a person with parental responsibility can consent on behalf of a child who lacks capacity to consent themselves. See Department of Health (England) and the devolved administrations (2007), Drug Misuse and Dependence: UK Guidelines on Clinical Management, London: Department of Health (England), the Scottish Government, Welsh Assembly Government and Northern Ireland Executive. See also Gillvary E, Britton J (2009), Guidance for the pharmacological management of substance use among young people, Department of Health (England).

\textsuperscript{96} In Switzerland the Loi fédérale sur les Stupéfiants contains no age restriction. Société Suisse de Médecine de l’Addiction (2007), Recommandations médicales pour les traitements basés sur la substitution des patients dépendants aux opioïdes provides: “Un seul critère suffit pour poser l’indication d’un TBS: la dépendance aux opioïdes. Le diagnostic repose sur les critères de la CIM 10 (ou DSM IV). Ni les limites d’âge, ni la condition d’une durée minimale de la dépendance, souvent mentionnées dans des guidelines pour poser l’indication au TBS, ne reposent sur de s preuves...Au cas où des mineurs sont inclus dans un traitement basé sur la substitution, requérir l’avis des spécialistes de ce groupe d’âge.”

6. HIV Treatment and Medication Trials

In the USA, the laws regulating minors’ consent to HIV treatment have been described as heterogeneous, complex and lacking in clarity. Among those states with HIV-specific laws that permit minors to consent to HIV testing, only some explicitly permit minors to consent to HIV/AIDS treatment; while some states permit adolescents to consent to HIV testing, however do not allow these young people to independently obtain treatment. In states without HIV-specific laws, the common law and a range of other laws will determine whether and when a minor can consent to HIV-related medical treatment. For example, state statutes that allow minor parents, married minors, or runaway minors to consent to care do authorise minors to consent to HIV/AIDS treatment.

In the USA, a model of delivering legal services, in partnership with health services, has been developed to promote the right to health of minors. Close to 50 medical–legal partnerships in clinics and hospitals now rely on lawyers to assist pediatric teams in dealing with the health concerns of low-income populations. The fundamental objective of a medical–legal partnership is to radically change healthcare delivery for vulnerable children by having lawyers help medical teams deal with the non-biological factors that exacerbate health problems. Medical–legal partnership involves three core activities: (1) training and education for healthcare workers; (2) direct legal assistance to patients; and (3) systemic advocacy. Such medical-legal partnerships may provide an important model for addressing the significant social, legal and medical complexity often faced by children at risk or and infected with HIV.

Promoting biomedical research involving children living with HIV is consistent with article 15(1)(c) of the ICESCR, given the right of all people to benefit from scientific developments.

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99 Ibid.
100 Ibid.
102 Zuckerman B et al (2007), From principle to practice: moving from human rights to legal rights to ensure child health, Archives of Diseases in Childhood, 92(2) at pp.100–101.
progress and research.\textsuperscript{103} Children’s consent in research - as with vulnerable people of all ages, such as prisoners and migrants – can raise extra ethical dilemmas.\textsuperscript{104} It has been recommended in the Canadian context that a provincial legislature recognise that for children living with HIV the right to the highest attainable standard of health requires that they be a prominent concern in biomedical research.\textsuperscript{105} This can be achieved, in part, by clarifying the consent requirement for children’s enrollment in clinical trials.\textsuperscript{106} In Europe and the USA there have been a number of regulatory and legislative attempts to increase children’s access to clinical trials as a means of increasing access to pediatric formulations of medication.\textsuperscript{107}

\begin{thebibliography}{10}
  \bibitem{Ibid} Ibid. A similar call for clarification in the law of UK is articulated in Alderson P (2007), \textit{Competent children? Minors’ consent to health care treatment and research}, Social Science and Medicine.
  \bibitem{EURegulation} EU Regulation on Medicinal Products for Paediatric Use Regulation (E.C.) No. 1901/2006. The Regulation aims to reduce the use of unlicensed medicines in children and to improve information on the use of medicines in children without subjecting them to unnecessary research. In addition, the Regulation provides rewards, incentives and obligations for pharmaceutical companies. In the USA, see Pediatric Research Equity Act of 2003, Pub Law No 108-155, 117 Stat 136 (2003).
\end{thebibliography}
UNICEF has published guidance for developing legal frameworks regulating children’s legal capacity to make decisions. The guidance is grounded in concept of the “evolving capacities of the child” used in Article 5 of the CRC. This concept recognises the changing relationship between parents and children as the children grow up, focusing on capacity rather than age as the determining factor in the exercise of rights and decision-making in matters concerning the child. A number of the principles suggested by UNICEF might usefully inform the High-Income Dialogue:

- Legislators and judicial decision makers should be fully conversant with the CRC and its implications for children.
- Relevant legislation should be examined to ensure appropriate protection for children and in consideration of the evolving capacities of children.
- Legislation that sets age-limits should include opportunities for children to exercise rights on their own behalf, consistent with their capacities and the right to protection.
- Legislation should take into account research regarding children’s evolving capacities, bearing in mind the applicability of research to the context.
- Effective coordination between government ministries should be facilitated to promote coherency and consistency in the application of age-limits.
- Children should be consulted in the development of legislation.

WHO Europe has identified a number of features of effective services for vulnerable youth:

- provide services in a way that fully respects their best interests and rights.
- ensure the involvement of all relevant layers of the health system (including primary health care facilities, family doctors and community-based youth-oriented and specialist services) in service design and delivery.
- provide not only structured treatment for those who are already engaging in high-risk practices, but also early interventions focusing on prevention of high-risk behaviours.

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109 Baltag V, Mathieson A (eds) (2010), Youth-friendly health policies and services in the European Region, Copenhagen, Denmark: WHO Regional Office for Europe.
• ensure close links, good coordination and bilateral referral systems between government-provided services and services from civil society organisations that are in contact with vulnerable youth through outreach mechanisms.

In this context, vulnerable youth refers to homeless or institutionalised children, those working in the sex industry, or those coming from disadvantaged communities such as Roma and Aboriginal youth—many of whom exist outside the mainstream social, education and health sectors.
“Every day, stigma and discrimination in all their forms bear down on women and men living with HIV, including sex workers, people who use drugs, men who have sex with men, and transgender people. Many individuals most at risk of HIV infection have been left in the shadows and marginalised, rather than being openly and usefully engaged... To halt and reverse the spread [of HIV], we need rational responses which shrug off the yoke of prejudice and stigma. We need responses which are built on the solid foundations of equality and dignity for all, and which protect and promote the rights of those who are living with HIV and those who are typically marginalised.”

- UNDP Administrator Helen Clark