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Schapiro, Naomi A

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Corresponding Author: Ms. Naomi A. Schapiro, PhD Candidate

Corresponding Author's Institution: University of California, San Francisco

First Author: Naomi A. Schapiro, PhD Candidate

Order of Authors: Naomi A. Schapiro, PhD Candidate

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Confidentiality and Access to Adolescent Health Care Services

Naomi A. Schapiro, RN, PhD (c), CPNP
Associate Clinical Professor
Department of Family Health Care Nursing
University of California, San Francisco

naomi.schapiro@nursing.ucsf.edu

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6 2338 McGee Avenue
7 Berkeley, CA 94703
8 October 30, 2009
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11 Sarah A. Martin, MS, RN, CPNP-PC/AC
12 204 W. Fremont Street
13 Arlington Heights, IL 60004
14 E-mail: smartin@childrensmemorial.org
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17 Dear Ms. Martin,
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19
20 Please accept my submission for the Health Policy column, Confidentiality and Access to
21 Adolescent Health Care Services.
22

23
24 Karen Duderstadt, the column editor, has already reviewed the manuscript and made
25 some editorial suggestions. This article is over 1500 words, as you and Karen had
26 discussed.
27

28
29 There are more than 10 references, which was the limit I had been given, though the total
30 is under 1700 words. Let me know if you want me to try to pare them down. I thought,
31 given the nature of the policy issue, that readers might want references for some of the
32 facts and assertions in the column.
33

34
35 This article has not been submitted nor is it under consideration for any other journal. The
36 article is adapted from a talk I gave in Spanish at a Colombian-Venezuelan health
37 conference and has a different focus from that talk.
38

39 Please let me know if you have any questions.
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42 Sincerely,
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50 Naomi A. Schapiro
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1 Confidentiality and Access to Adolescent Health Care Services

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10 3 Adolescent birth rates in the U.S. declined steadily from the 1950s until 2005, but
11 4 increased 3.5% in 2006. While there are multiple factors at play in this reversal, the
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14 5 increases were largest in states with the most limited access to confidential adolescent
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16 6 health services and contraception (Child Trends Data Bank, 2007).

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19 7 Adolescent childbearing has been linked to poorer health outcomes for both
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21 8 mother and child, and maternal mortality is the third leading cause of death for
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24 9 adolescents internationally (World Health Organization, 2009). Access to confidential
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26 10 reproductive health services for adolescents is an important policy issue for pediatric
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29 11 health care providers (HCPs). This article will discuss the scope and implications of
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31 12 confidentiality in adolescent health care services in the U.S., discuss recent controversies
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34 13 and policy reversals in this area, and compare approaches within the U.S. to international
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36 14 policies, specifically the *United Nations Convention on the Rights of the Child* (UNCRC).

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39 15 Evolution of Adolescent Confidentiality Rights

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41 16 Privacy and confidentiality rights for adolescents as well as adults have gradually
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43 17 evolved in the U. S. since the 1960s. While not specifically guaranteed in the
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46 18 Constitution, court decisions have affirmed that the Bill of Rights implicitly protects
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48 19 confidentiality. Until 1965, individual states had the right to regulate the availability of
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51 20 contraception, even for married couples. In the case of *Griswold vs. Connecticut*, the
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53 21 Supreme Court ordered the State of Connecticut to allow prescription of contraception to
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56 22 married couples, affirming their rights to make private decisions about birth control. In
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58 23 1973, privacy rights were extended by the Supreme Court to allow a woman to make a

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4 24 decision about abortion with her physician, overturning state laws outlawing abortion
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6 25 (Luker, 2006).

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8
9 26 The decade of the 1970s saw a progression of laws regarding adolescent access to
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11 27 contraception, testing and treatment of sexually transmitted infections (STIs), and
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14 28 pregnancy management including abortion. By the 1980s, there was a backlash from
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16 29 conservative and religious groups who objected to adolescent access without parental
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18 30 permission to contraception and abortion, as well as to public funding for these services
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20
21 31 for women of all ages. Some of these controversies spread to public schools, specifically
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23 32 regarding the provision and content of sex education (Luker, 2006; Santelli et al., 2006).

24 33 Adolescent Confidentiality & Reproductive Health

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28 34 Starting in the 1980s, there were dramatic changes in policies regarding national
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31 35 and international reproductive health, including adolescent access, depending on the
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33 36 administration in the White House. President Reagan instituted a “gag rule” that
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35 37 prohibited U.S. aid to international programs that mentioned abortion when counseling
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37 38 about sexual harm reduction. The gag rule was lifted during the Clinton administration,
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39 39 replaced during the administration of President George W. Bush, and lifted once more as
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41 40 one of President Obama’s first acts in 2009.

42
43 41 Adolescent confidentiality rights have been affected by a series of Presidential
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45 42 Executive Orders. President Clinton extended the privacy rights of adolescents seeking
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47 43 confidential care in federally funded family planning clinics. While President George W.
48
49 44 Bush maintained adolescents’ ability to consent to confidential contraceptive care, he
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51 45 allowed parental access to these records, unless a given state had a more comprehensive
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53 46 privacy policy. By the end of 2008, the Federal Government extended regulations about
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4 47 conscience, greatly expanding the rights of employees of a clinic or pharmacy, including
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6 48 cashiers, to refuse to participate in filling a prescription or selling contraceptives to any
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9 49 individual if this action violated the employee's conscience. The Obama administration
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11 is in the process of modifying this regulation (Cohen, 2009; Kulczycki, 2007).
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14 51 Access to Confidential Health Services

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16 52 The ability of an adolescent to access confidential services varies from state to
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18 53 state, and specific access in a given state may be controversial and in flux; the following
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20 54 figures were accurate as of November, 2009 (Guttmacher Institute, nd). Twenty-one
21
22 55 states and the District of Columbia offer contraception for all adolescents, while 25 more
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24 56 allow adolescents to consent to contraception under specific circumstances, such as age,
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26 57 marriage or past pregnancy. Three states and the District of Columbia explicitly allow
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28 58 adolescents access to abortions, while laws mandating parental involvement in six more
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30 59 states are currently on hold because of Court decisions. Twenty-eight states and the
31
32 60 District of Columbia allow the minor unrestricted consent to her own prenatal care. In
33
34 61 contrast, all 50 states allow adolescents to consent for testing and treatment of STIs
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36 62 (Guttmacher Institute, nd), although some states exclude HIV testing and some allow the
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38 63 HCP to inform the parent of the tests.
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45 64 Adolescent Confidentiality & Parental Rights: The Ethical Underpinnings

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47 65 Medical ethics are based on principles such as autonomy, nonmaleficence and
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49 66 beneficence (Beauchamp & Childress, 2001). Autonomy supports the right of individuals
50
51 67 to make decisions about their own care. Nonmaleficence involves the basic duty to avoid
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53 68 harming patients, and in the case of adolescent care, the clinician must balance the harm
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55 69 of disclosing sensitive topics to the adolescent's parent with the potential harm of
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4 70 keeping important health information from the parent. Beneficence involves actively
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6 71 promoting good in addition to preventing harm, and it can be difficult to balance with
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9 72 respect for the individual's autonomy. In the case of adolescent health care services,
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11 73 beneficence might include increasing access to health care by removing barriers such as
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14 74 parental disclosure (Lehrer, Pantell, Tebb & Shafer, 2007).

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16 75 Privacy rights also allow parents to make decisions about their children's health
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18 76 care, including the decisions to refuse vaccination and life-saving medical treatments if
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21 77 these treatments conflict with personal or religious beliefs (Miller, 2006). Laws about
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24 78 child maltreatment in many states specifically allow parental exemptions from medical
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26 79 care on the grounds of personal or religious beliefs (Child Welfare Information Gateway,
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29 80 2007). Conversely, adolescents have been allowed to make decisions about their own
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31 81 medical treatment that conflict with their parents, for example in refusing another round
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33 82 of chemotherapy for cancer. While 14 has often been cited as an age at which adolescent
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36 83 cognitive skills are sufficiently developed to make independent decisions, 12 years of age
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38 84 is often used as the cutoff for confidential decision-making.

40 85 Adolescent Right to Privacy & Health Outcomes

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43 86 In delivering confidential services to an adolescent, the pediatric HCP may not be
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46 87 permitted to disclose information without the youth's consent, even to the parent. Why
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48 88 provide this level of privacy? Traditionally, HCPs have used a utilitarian approach
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50
51 89 (Beauchamp & Childress, 2001), in that teens are likely to do without health care if their
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53 90 confidentiality is not maintained (Lehrer et al., 2007). For example, most adolescents
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55 91 attending one family planning clinic stated that their parents were aware of their visits
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58 92 (Jones & Boonstra, 2005). However, while the teens who had not informed their parents
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4 93 stated that mandatory parental notification would be a barrier to their continued use of the
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6 94 clinic, they also stated that a lack of access to contraception, STI testing and treatment
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9 95 would not prevent them from continuing to engage in sexual activity.
10

11 96 Access to confidential reproductive health services should be viewed in the
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14 97 broader context of adolescent risk. In the U.S., the leading causes of death for adolescents
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16 98 are unintentional injury, suicide, and homicide. Internationally, the World Health
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18 99 Organization (2009) lists road accidents, self-inflicted injury and violence as first, second
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21 100 and fourth leading causes of death, with adolescent maternal mortality ranked as third.
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23 101 These causes are connected to psychosocial issues and behaviors, which are often, in
24
25 102 turn, connected to developing adolescent sexuality, depression and substance use (Eaton
26
27 103 et al., 2008). With mental health problems affecting up to 20% of the world's youth,
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29 104 addressing confidentiality and mental health access is becoming an international priority.
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32 33 105 Limits to Confidentiality

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36 106 There are limits to confidentiality, in order to ensure that the health care provider
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38 107 protects adolescents from harm. All 50 states in the U.S. have laws that mandate the
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40 108 reporting of child abuse and neglect (Child Welfare Information Gateway, 2007).
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42 109 Although these laws vary considerably from state to state, they usually include a
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44 110 provision for reporting consensual sexual activity between young adolescents and adults
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46 111 and may affect access to care. Some states, such as California, do not allow either the
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48 112 teen or the health care provider to withhold the report, while others allow the health care
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50 113 provider to use his or her best judgment. New York State prohibits reporting without the
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52 114 adolescent's consent unless sexual assault was committed by a parent or parental figure.
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4 115 Other limits to confidentiality involve protecting the adolescent from self-harm and
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7 116 protecting the intended victim if the adolescent intends harm to others.

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9 117 Two categories of minors (under 18 years of age) in the U.S. can consent to full
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11 118 scope medical treatment: emancipated minors and “mature minors,” with the latter
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14 119 category applying to adolescents who have run away or are living on the streets (National
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16 120 Center for Youth Law Teen Health Rights).

19 121 Confidentiality & Access to Reproductive Health Services Internationally

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21 122 The *United Nations Convention on the Rights of the Child* (UNCRC) is a legal
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23 123 document asserting a broad range of rights that are inherently due to children, including
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26 124 protection from harm, attainment of the highest possible state of health, and freedom of
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29 125 thought and expression appropriate to the child’s maturity (UNICEF, nd). International
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31 126 support for increased adolescent access to health care and adolescent confidentiality are
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33 127 implied in the UNCRC, especially Articles 12, 14, 16, 19 and 24 (see Box 1). Twenty
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36 128 years after its initial adoption, the only countries in the world that have not ratified the
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38 129 UNCRC are the U.S. and Somalia. The World Health Organization’s *Child and*
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41 130 *Adolescent Health Progress Report 2008* also highlights the importance of community
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43 131 support for safe, accessible and confidential adolescent services (World Health
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46 132 Organization, 2009).

47 48 133 Policy Imperative

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50 134 There is broad legal and ethical support for the delivery of confidential health
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53 135 services to adolescents, both in the U.S. and internationally. Access to confidential
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56 136 health services can increase adolescents’ access to care, with the potential to decrease
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58 137 both their use of risky behaviors and the impact of these behaviors on their long term
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4 138 physical and psychosocial health. Pediatric and adolescent HCPs can lead the charge to
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6 139 ratification of the United Nations Convention on the Rights of the Child by the U.S.
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9 140 government and contribute to improved access to health care for all adolescents.
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16 143 Note: This article has been adapted from a presentation given by the author at the Third
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18 144 National Colombian-Venezuelan Public Health Conference, Cúcuta, Colombia, June 27,
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21 145 2009 (Schapiro, 2009)
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45 181 Colombian-Venezuelan Public Health Conference, Cúcuta, Colombia.
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47 182 United Nations Children's Fund (UNICEF) Convention on the Rights of the Child. Retrieved
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49 183 from <http://www.unicef.org/crc/>
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Box 1

United Nations Convention on the Rights of the Child (UNCRC)	
Article 12	Children have the right to express their views freely in all matters affecting them, in accordance with their age and maturity.
Article 14	Children have the right to freedom of thought, conscience and religion, respecting the rights of parents and legal guardians “to provide direction to the child in the exercise of his or her right in a manner consistent with the evolving capacities of the child.”
Article 16	Children will be protected from “arbitrary or unlawful interference with ... privacy, family, home or correspondence,” and from attacks on their honor and reputation
Article 19	Children will be protected from all forms of physical or mental violence, neglect or maltreatment, including sexual abuse. Protective measures should also provide support for the child and caretakers, as well as prevention measures.
Article 24	Children have the right to the “enjoyment of the highest attainable standard of health” and no child should be deprived of access to health, including disease prevention and treatment, environmental health or adequate prenatal and postnatal care. Traditional practices harmful to the health of children should be abolished.

Adapted from United Nations Children's Fund (UNICEF) Convention on the Rights of the Child. Retrieved from <http://www.unicef.org/crc/>