

REPRODUCTIVE HEALTH IN CRISIS: A SPECIAL SERIES

# Unbiased Information on and Referral for All Pregnancy Options Are Essential to Informed Consent in Reproductive Health Care

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A patient’s ability to give informed consent to care is a bedrock principle of modern medical practice in the United States. The principle of informed consent centers on an individual’s well-being and right to self-determination, and requires that patients be given all relevant information on their condition and possible treatment options or outcomes in order to make voluntary decisions about their care, in conjunction with their health care providers.

Informed consent is deeply rooted in legal, ethical and medical standards developed over the course of decades. Major U.S. professional medical organizations have defined what informed consent means in practice. The American Medical Association, for example, states in its Code of Medical Ethics that clinicians should “present relevant information accurately and sensitively, in keeping with the patient’s preferences”<sup>1</sup> and asserts that “withholding information without the patient’s knowledge or consent is ethically unacceptable.”<sup>2</sup>

Policymakers and advocates opposed to abortion have long sought to undermine this fundamental standard of care, particularly when it comes to women’s right to complete, medically accurate and unbiased information and resources for all of their pregnancy options—often referred to as “nondirective pregnancy options counseling and referral.” Specifically, abortion foes aim to force clinicians to inappropriately withhold information about abortion and referral for abortion services. This means women would only receive information on and resources for carrying a pregnancy to

## HIGHLIGHTS

- *One aspect of ensuring informed consent in reproductive health care requires that women be offered complete, accurate and unbiased information on all pregnancy options—including parenting, adoption and abortion—and referrals for additional services as needed.*
- *The right to provide informed consent has long been threatened by antiabortion policymakers and advocates seeking to keep women from receiving factual information about abortion and referral for abortion services.*
- *Restricting comprehensive counseling and referrals for all pregnancy options seriously jeopardizes women’s health and well-being.*

term, and then choosing either parenting or adoption. Such ideologically driven interventions would clearly undermine women’s ability to provide truly informed consent to their own reproductive health care, with damaging consequences for their health and well-being.

### **Nondirective pregnancy options counseling and referral is essential for informed consent.**

The guidelines of a number of leading professional medical organizations specifically address the need for comprehensive, unbiased information on and referral for all of a woman’s pregnancy options—parenting, adoption or abortion—as a fundamental component of a patient’s right to self-determination.

In 2015, the American College of Obstetricians and Gynecologists (ACOG) reaffirmed a 2009 committee opinion stressing that patient autonomy

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is especially critical when it comes to women's sexual and reproductive health. ACOG asserts that all providers, even those who personally object to abortion, "must provide the patient with accurate and unbiased information about her medical options and make appropriate referrals."<sup>3</sup> ACOG further notes that "informed consent includes freedom from external coercion, manipulation, or infringement of bodily integrity." In its most recent Guidelines for Women's Health Care, ACOG expressly addresses nondirective options counseling for women experiencing unintended pregnancy, recommending that all patients, including adolescents, "should be counseled about [their] options: continuing the pregnancy to term and raising the infant, continuing the pregnancy to term and placing the infant for legal adoption, or terminating the pregnancy."<sup>4</sup> These guidelines also advise that providers follow a patient's wishes regarding any resources that should be offered to her partner and, if the patient is a dependent adolescent, what information should be shared with her parents (in accordance with relevant state law).

The American Academy of Pediatrics (AAP) is similarly explicit in its policy regarding counseling and referral for adolescents, which states that pediatricians "should be able to make a timely diagnosis and to help the adolescent understand her options and act on her decision to continue or terminate her pregnancy."<sup>5</sup> The organization further declares that practitioners are not entitled to let their own views diminish this standard of care, and that an adolescent who is pregnant deserves to be supported regardless of her decision.

The American Academy of Physician Assistants (AAPA) states in its Guidelines for Ethical Conduct that clinicians have a "duty to protect and foster an individual patient's free and informed choices," and to assist each patient "in making decisions that account for medical, situational, and personal factors."<sup>6</sup> Specifically on reproductive decision making, AAPA's guidelines state that clinicians "have an ethical obligation to provide balanced and unbiased clinical information about reproductive health care," even if that means referring the patient to another provider if the clinician's values conflict with the patient's care.

A position statement issued in 1989 and reaffirmed in 2016 by the Association of Women's Health, Obstetric and Neonatal Nurses supports and promotes a patient's right to "evidence-based, accurate, and complete information and access to the full range of reproductive health care services," and specifically opposes policies that limit health care professionals' ability to counsel patients on their pregnancy options and to provide referrals if needed.<sup>7</sup>

Collectively, these organizations echo the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, which consisted of leading experts in research, law, medicine and medical ethics. The commission issued a seminal 1982 report on the ethical and legal implications of informed consent that concluded patients must be able to make decisions voluntarily and must be provided with "all relevant information regarding their condition and alternative treatments." Moreover, the commission advised health care professionals not to withhold or distort information with the intent to influence patients' decisions: "A choice that has been coerced, or that resulted from serious manipulation of a person's ability to make an intelligent and informed decision, is not the person's own free choice."<sup>8</sup>

**Federal guidelines uphold nondirective pregnancy options counseling and referral.** The most notable example is the Title X national family planning program. Administered by the U.S. Office of Population Affairs (OPA), Title X has been the only federal program dedicated to advancing the availability of high-quality family planning services in the United States since its inception in 1970. The statute, regulations and programmatic guidelines that govern Title X effectively set the standard for publicly funded family planning care across the country.

Voluntary participation and freedom from coercion—key aspects of informed consent—are cornerstones of the Title X program. Sites supported by Title X funding are explicitly required to offer any client who needs it "neutral, factual information and nondirective counseling" on any of the full scope of pregnancy options, including "prenatal care and delivery; infant care, foster

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care, or adoption; and pregnancy termination.”<sup>9</sup> Title X providers must also offer “referral upon request” for services related to any of these options. Only the client gets to decide which pregnancy options she wants to learn more about and which ones do not match her needs. Informed consent in the Title X context also includes providing patients with access to a broad array of contraceptive methods (see “Why Family Planning Policy and Practice Must Guarantee a True Choice of Contraceptive Methods,” 2017).

In practice, this means that Title X providers must offer comprehensive counseling and resources that are responsive to each client’s needs. According to clinical recommendations on providing quality family planning services—published in 2014 by the Centers for Disease Control and Prevention and OPA—family planning providers (including but not limited to those funded by the Title X program) should follow the most current recommendations on pregnancy testing and counseling from leading medical associations, specifically citing ACOG and AAP (see above).<sup>10</sup> The family planning guidelines additionally recommend that these discussions address the client’s medical history and her personal goals about whether and when to have children, and advise that a client’s confidentiality must be guaranteed upon her request. Staff must also be knowledgeable about other providers or organizations to which they can refer clients for services ranging from abortion to prenatal care to adoption services, and do everything possible to expedite those referrals, including making provider listings available and contacting the referral site on the client’s behalf, if so requested. In order to provide such client-centered care, staff must be trained and able to have conversations on all pregnancy options that are respectful, nonjudgmental and based on the medical evidence, and work collaboratively with the client to establish a plan that matches her decision.

**Abortion foes have long attacked women’s right to nondirective pregnancy options counseling and referral.** The most significant federal-level attack targeted Title X–supported providers and the women who rely on them. Even though grantees have been prohibited from using Title X funds to pay for abortions since the program was enacted,

President Reagan and his administration were moved by antiabortion activists’ unfounded but sustained allegations of misuse of Title X dollars. In response, the administration issued regulations, finalized in 1988, that were designed to prohibit clinicians at any Title X–funded site from providing abortion counseling or referral—even when expressly requested by a client.<sup>11</sup>

Commonly referred to as the “domestic gag rule,” this administrative rule—which was held up in court for years—would have made receipt of Title X funds contingent on clinicians providing incomplete and biased information to their patients. While barred from discussing abortion, they would have been expressly required to provide information on and referral for prenatal care. The rule also included detailed requirements to financially and physically separate Title X–supported activities from abortion-related services, and restricted Title X–funded sites’ ability to advocate for or “promote” abortion access. Collectively, these regulations would have forced safety-net family planning providers to choose between receiving Title X funding and providing high-quality services that uphold the principles of informed consent.

Ultimately, however—following years of lawsuits, congressional intercession and a reinterpretation of the rules under President George H.W. Bush—these harmful restrictions were in effect for only a few months, and confusion surrounded their implementation.<sup>12</sup> President Clinton suspended the restrictions almost immediately after taking office,<sup>13</sup> and the Reagan-era regulations were formally reversed through subsequent federal agency rulemaking.<sup>14</sup>

At the state level, policymakers have long tried to restrict women’s right to full and unbiased information when it comes to abortion. A small number of court decisions have struck down state laws prohibiting providers’ use of public funds for abortion counseling and referral as part of nondirective pregnancy options counseling.<sup>15,16</sup> Still, some states have been able to enact restrictions: Four (Arkansas, Michigan, Ohio and Wisconsin) currently prohibit the use of public funds for abortion counseling and referral, although all make exceptions for the nondirective care required under

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Title X.<sup>17</sup> Lawmakers in other states have proposed similar policies as part of a broader resurgence of state-based family planning funding restrictions (see “Recent Funding Restrictions on the U.S. Family Planning Safety Net May Foreshadow What Is to Come,” 2016).

**Restricting pregnancy options counseling and referral harms women.** Biasing the information and resources available on pregnancy options could coerce women into unwanted medical decisions and care, and it ultimately threatens their health and well-being in a number of ways.

First, forcing clinicians to deny patients the full scope of information and referral represents unacceptable and damaging governmental interference in the provider-patient relationship, and stands in sharp conflict with women’s right to self-determination—and to abortion, as articulated in *Roe v. Wade*. ACOG describes informed consent as a communicative process ultimately “governed by the ethical requirement of truth-telling.”<sup>3</sup> ACOG also points to “the historical imbalance of power in gender relations and in the physician-patient relationship...and the intersection of gender bias with race and class bias” that are particularly present in obstetrics and gynecology, and in reproductive health care broadly.<sup>3</sup> Forcing providers to sabotage the rapport they have built with patients may cause those patients to retreat, possibly from seeking health care for other needs; this may be particularly true for women of color, low-income women and others who have historically experienced coercive treatment in the context of reproductive health care.<sup>18,19</sup>

Second, limiting information and referrals only to those related to carrying a pregnancy to term misleadingly suggests that pregnancy and childbirth are a woman’s safest options. In fact, pregnancy and delivery are decidedly riskier than abortion.<sup>20-22</sup> Being able to appropriately compare the safety of one’s medical options is a central component of informed consent.

Third, denying a woman information about and access to the full range of options once she knows that she is pregnant interferes with her ability to obtain additional services in a timely manner.

Women choosing to carry pregnancies to term benefit from initiating prenatal care early on, in order to promote healthy pregnancies and births. For women who choose to terminate, abortion is particularly safe when obtained in the first trimester of pregnancy.<sup>23</sup> Moreover, it often becomes more difficult for a woman to obtain an abortion as pregnancy progresses due to a lack of providers and increased cost, and her mental health may suffer as she undergoes forced delays in care.<sup>24-26</sup>

Fourth, denying or delaying a woman’s decision to terminate a pregnancy can be particularly harmful for women with certain medical conditions. For instance, in statements opposing the Title X gag rule, a number of professional medical associations described how not being able to make a fully informed decision on how to proceed with a pregnancy would be especially harmful for women with severe diabetes, heart conditions, HIV/AIDS and estrogen-dependent tumors—all conditions that could be exacerbated by continuing a pregnancy.<sup>27</sup> In the words of an ACOG statement decrying such obstruction of care: “That’s unethical. It’s bad medicine. And it’s inhumane.”<sup>28</sup>

Finally, limiting pregnancy options counseling and referral in the context of publicly funded programs would further entrench existing health disparities. Women who rely on publicly funded programs are disproportionately low-income, young or otherwise underserved,<sup>29</sup> and forcing subpar care on them is unethical—a point that many policymakers made in opposing the domestic gag rule. In 1992, for example, former Senate Majority Leader George Mitchell said, “A society like ours, based upon the fundamental principle of equality, ought not tolerate, let alone encourage, even less insist upon a system in which there are two standards of care: One for the wealthy, the affluent, the powerful; and another, lower standard, for the poor.”<sup>30</sup>

And yet, such ideologically motivated threats persist today. The Trump administration, Congress and state governments across the country are controlled by antiabortion policymakers intent on limiting access to unbiased information on and resources to obtain abortion services. These attempts clearly go against ethical and legal requirements on informed consent. Pregnancy

options counseling does not—and should not—involve advocacy of any one option. Rather, clinicians are obligated to assist and support all women in exploring all options so they can make their own, fully informed reproductive health choices free from coercion. Ensuring this standard of care is essential to advancing women’s right to self-determination, healthy reproductive lives and overall well-being. ■

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