Fetal Alcohol Spectrum Disorders

Competency-Based Curriculum Development Guide

for Medical and Allied Health Education and Practice

U.S. Department of Health and Human Services

Centers for Disease Control and Prevention

National Center on Birth Defects and Developmental Disabilities

FASD Regional Training Centers

National Organization on Fetal Alcohol Syndrome (NOFAS)

Competency VII: Ethical, Legal, and Policy Issues

The health care student or provider will be able to recognize ethical, legal, and policy issues related to FASDs.

Learning Goals

(Learning objectives for each goal can be found at the end of this section.)

VII-A Identify ethical issues related to FASDs.
VII-B Identify legal and policy issues related to FASDs.

Content Outline for Competency VII

I. **Ethical issues**
   A. Introduction
   B. Confidentiality

II. **Legal and policy issues**
   A. Fetal rights and the maternal-fetal relationship
   B. Limitations of coercive and punitive approaches
   C. A public health approach

Also included in this section are:

- Suggested learning activities.
- References.
- Chart of all learning goals and objectives for this competency.

I. Ethical Issues

Carolyn Szetela, PhD; Danny Wedding, PhD, MPH; Robert Levine, MD; and Margaret Stuber, MD

A. Introduction

All health care delivery involves ethical dimensions. Health care related to FASDs is laden with ethical issues such as weighing the rights of a pregnant woman and protecting the health of the fetus. Health practitioners are key players in advocating and delivering the best care to meet these needs. Those who carefully consider the ethical aspects of their work honor their patients and their larger communities, as well as maintaining their own integrity.

Four basic principles are commonly used to describe ethical challenges in health care settings (Beauchamp & Childress, 1983). These are autonomy, beneficence, nonmaleficence, and justice. As these principles are often in conflict with one another, none can be regarded as absolute. Health care providers might have to prioritize the principles in response to the unique situation in question.

Respect for autonomy asks health care providers to consider a person's right to self-determination in making health decisions. A well-known expression of the importance of autonomy in American medicine is the 1914 statement by Supreme Court Justice Benjamin Nathan Cordozo that "every human being of adult years and sound mind has a right to determine what shall be done with his body" (*Schloendorff v. Society of New York Hospital*, 1914). To have the capacity for autonomous choice, a person must have the ability to *reason* about his or her choices, as well as the ability to make a *voluntary choice*. Adults normally have the capacity for autonomy. However, fetuses, children, and adults with cognitive limitations such as can occur with FASDs are lacking or limited in the reasoning skills necessary to exercise full autonomy. Persons with alcohol dependence or addiction might also have limited autonomy because of impaired reasoning and/or compulsion.

Pregnant women, or adults caring for someone with an FASD, are ordinarily free to make autonomous personal health care decisions, as well as to make choices regarding care for the fetus or a child with an FASD. The mother, parent, or guardian is expected to be an advocate for the fetus or child's interests. At times the health care provider might question the reasonableness of a choice made on behalf of the fetus or child. In these cases, the provider might seek to influence the health decision through expanded education and informed consent processes. If such educational efforts are unsuccessful, the health care provider might consider available and legally permissible ways to limit the adult's decision-making authority in order to protect the fetus or child.

The principles of beneficence and nonmaleficence often go hand in hand. Beneficence asks health care providers to seek the benefit of their patients. Beneficence is an integral goal in the "helping professions." Nonmaleficence emphasizes the responsibility to avoid causing harm and to minimize undue harm to others. Together, these principles represent the weighing of benefits and risks of all reasonably considered health options. These principles apply when health care providers act to promote maternal and fetal health and prevent alcohol-related harms to women and fetuses, and when they provide competent, compassionate care for persons born with FASDs.

However, at times these principles might be in conflict when what would be of benefit to the fetus (such as restriction of the mother's access to alcohol by limiting her freedoms) might be harmful to the mother.

The principle of justice asks health care providers to consider fair distribution of social benefits and burdens (distributive justice), and to promote and follow laws and practices in ways that are fair for all people (procedural justice). Justice requires fairness to people who are affected by FASDs and to women with known alcohol use and abuse. Justice can be reflected in non-prejudicial attitudes and treatment of persons with FASDs and women who engage in at-risk or harmful drinking, and in promotion of access to the resources they need.

An additional ethical principle, "respect for persons," encompasses aspects of all four of the principles just described. Respect for persons, as applied in a health context, asks care providers to honor each person's dignity and interests. People are to be treated as "ends in themselves" and not as mere means for achieving the goals of others. This principle asks health providers to show respect for people with FASDs and women with known alcohol use and abuse, and to address their health care needs and interests.

Good ethical decision making always includes consideration of relevant city, state, and federal laws. In some cases, however, ethical and legal strictures might conflict. For example, laws denying women the right to vote in the United States, until ratification of the 19th Amendment in 1920, would now be seen as violations of the ethical principles of autonomy, beneficence, nonmaleficence, justice, and respect for persons. When existing or proposed laws conflict with fundamental ethical values, they should be subject to review and revision (American Medical Association [AMA], Council on Ethical and Judicial Affairs, 1994).

B. Confidentiality

Confidentiality is an essential aspect of the health provider–patient relationship. Health providers learn personal information about their patients for the primary purpose of delivering health care that serves the patient's interests and preferences. Patients expect that the information they disclose will be held in trust, thus protecting their privacy and promoting their comfort in offering information.

The principle of confidentiality is not absolute. Among its possible exceptions are cases where health providers learn information that might, with reasonable probability, indicate serious bodily harm to the patient or others (AMA, 2006a). This includes learning of alcohol exposure by a pregnant patient who risks serious harm to herself and might also include risks to her fetus.

Care providers have a duty to honor patient confidentiality to the greatest degree possible, consistent with ethical, legal, and policy restrictions. While they seek to protect patient confidences, they should avoid giving a false impression that confidences might always be protected (AMA, 2007). Accordingly, care providers should inform patients about general limitations upon confidentiality in their setting, such as at the first health visit with the patient. When confidentiality must be breached, health providers should notify the patient of their need to disclose, unless impractical or inadvisable (AMA, 2006b). Care providers must stay informed of local, state, and federal laws impacting confidentiality.

II. Legal and Policy Issues

Carolyn Szetela, PhD; Danny Wedding, PhD, MPH; Robert Levine, MD and Margaret Stuber, MD

A. Fetal Rights and the Maternal-Fetal Relationship

Fetal rights can be considered from ethical and legal perspectives. We can ask distinctly, "What status does our ethical reasoning attribute to the fetus?", and "What status do legal precepts and practices attribute to the fetus?" Both regards must ultimately address the rights of the fetus in relation to the rights of the woman who carries the fetus.

The ethical status of fetuses is sometimes evaluated in terms of whether fetuses have "personhood." Personhood is a concept conferred upon an individual by its possession of select morally relevant characteristics that make it the proper recipient of human rights and obligations (Edwards & Graber, 1988). Just what these characteristics are is contested among philosophers and others. Proponents of competing theories consider personhood to begin at varying stages of fetal development, such as at conception, when the fetus develops a heartbeat, when it becomes viable (able to survive outside the mother's body), or at birth when physical separation from its mother occurs. Others posit personhood to begin after birth such as when the capacity for reasoning develops. Fetuses can be regarded as possessing some degree of ethical status before they achieve the full status of personhood. Although the appropriate ethical status of fetuses is not settled, people agree that the well-being of each person starts during fetal development, and that we should care for both fetuses and the mothers in whom they grow.

The legal status of fetuses is addressed by federal and state laws. In the United States, fetuses are not given the legal status of "persons," with rare exception. The legal status of fetuses is generally subordinate to that of pregnant women. A fetus' legal status might also increase over time with its continuing development in utero. The concept of expanded fetal rights at the stage of viability is seen in the U.S. Supreme Court ruling in *Roe v. Wade* (1973). This ruling permits states to restrict access to abortions in the third trimester of pregnancy, approximating the time of viability, except to protect the life or health of the woman. Prior to that point, a woman is conferred a right to abortion which states can limit only in the second trimester to protect a pregnant woman's health. States also, to varying degrees, impose civil and criminal protections of fetal life. For example, some states include fetuses, at varying stages of gestation, among those who can be victims of criminal homicide (Linder, 2005).

While a pregnant woman and her fetus can be considered separately in some ethical and legal respects, a woman and her fetus are ordinarily affected by the well-being of each other, possibly for as long as each lives. In cases where the well-being of a fetus and its mother appear to be in conflict, the ethical and legal issues are deeply challenging. Our society continues to struggle to identify a satisfactory framework for conceptualizing fetal and maternal status for cases where maternal interests or behaviors might put her fetus at risk. When maternal and fetal interests are distinct, any resolution might compromise the ethical interests of the woman, the fetus, or both.

B. Limitations of Coercive and Punitive Approaches

Preventing the harms of prenatal alcohol use carries great ethical urgency, as prevention serves to benefit fetuses throughout their lives and avoid possible great disruption and distress to the

mother. A common consideration for preventing prenatal alcohol exposure is to physically bar a woman who poses a high risk to her fetus from accessing alcohol during her pregnancy, such as by criminal or civil commitments. For example, the state of Wisconsin enacted a statute allowing pregnant women whose habitual drinking exposes a fetus to substantial risks of physical harm to be taken into custody and undergo involuntary inpatient alcohol treatment (Linder, 2005). Other states have proposed or enacted bills that respond to women who expose a fetus to the harms of alcohol in pregnancy by means such as requiring involuntary civil commitment of the woman, requiring health practitioners to report newborns demonstrating prenatal exposure, expanding definitions of child neglect to include neonatal harm or prenatal damage to a child, and defining such acts as criminal mistreatment in the first degree (Substance Abuse and Mental Health Services Administration [SAMHSA], 2006).

Many previous efforts to apply law enforcement measures to restrain women from exposing fetuses to damaging drugs involve cocaine, particularly in the form of crack. A prominent case is *Whitner vs. State of South Carolina* (1997). Cornelia Whitner was charged with criminal child neglect for exposing her fetus to cocaine, residues of which were found in her newborn when he was drug tested after birth. In 1992, she was sentenced to 8 years in prison by a South Carolina court, which found her viable fetus to be protected under the state's child endangerment statute. Her sentence was affirmed in 1997 by the Supreme Court of South Carolina, holding the viable fetus to be a person, and the U.S. Supreme Court declined a petition for writ of certiorari (review of the case). Currently, South Carolina remains the first and only state whose law recognizes the viable fetus as a person and accordingly permits criminal prosecution of women for endangerment of a fetus (Linder, 2005).

A second prominent case, reviewed by the U.S. Supreme Court, is *Ferguson v. City of Charleston* (2001). In 1989, as a result of concerns about the incidence of cocaine use among pregnant women, a public hospital in Charleston, South Carolina, began to implement a policy of selectively drug testing women who presented for prenatal care or delivery, without their informed consent. Initially, women with a positive drug test would be turned over to the police for arrest without opportunity to seek treatment instead. The policy was modified in 1990 to allow women to avoid arrest if they entered a drug treatment program, attended all counseling appointments, and passed their subsequent drug tests. Ten of the women arrested as a consequence of positive cocaine tests responded by suing the hospital and the state. In 2001, the U.S. Supreme Court ruled in favor of the women, holding that the drug tests were an unconstitutional search because the hospital was acting as an arm of law enforcement without obtaining a search warrant or informed consent before conducting the drug tests. They held, "A state hospital's performance of a diagnostic test to obtain evidence of a patient's criminal conduct for law enforcement purposes is an unreasonable search if the patient has not consented to the procedure" (*Ferguson v. City of Charleston*, 2001). This decision sets limits on how health care providers at public hospitals can intervene to prevent fetal alcohol exposure.

Evolving opinion on ethical practices, policies, and laws regarding women who might risk alcohol- or drug-related harm to their fetuses is expressed by the American College of Obstetrics and Gynecology Committee on Ethics in their Opinion, *Maternal Decision Making, Ethics, and the Law* (American College of Obstetricians and Gynecologists [ACOG], 2005). The committee offers six objections to coercive and punitive responses to these women (See Table 7.1). Among them are considerations of women's autonomy regarding the primacy of their decisions

about their individual situations and health; considerations of outcomes such as the adverse consequences of coercive or punitive approaches upon individual women, and upon public health by discouraging women from seeking prenatal and health care (Poland, Dombrowski, Ager, & Sokol, 1993); and considerations of procedural justice regarding the strikingly disproportionate applications of coercive and punitive practices upon disadvantaged and vulnerable groups of women.

An ethical and effective response to the risks of FASDs must also account for contributing factors in maternal drinking. While health professionals now recognize that alcohol and drug addiction are illnesses that usually require effective treatment to overcome, beliefs persist that women who abuse alcohol or drugs in pregnancy could readily stop and are morally culpable for continued use (Marshall, Menikoff, & Paltrow, 2003). Women ordinarily do not intend to expose themselves and their fetuses to the risks of compulsive and abusive drinking. Alcohol abuse is frequently associated with unresolved medical and mental health problems (Mertens, Lu, Parthasarathy, Moore, & Weisner, 2003) and difficult social circumstances such as sexual, physical, or emotional abuse (Amaro, Fried, Cabral, & Zuckerman, 1990; Rosenbaum, 1997) and economic stress (Sheehan, 1998). Treatment programs for alcohol and drug abuse that address these underlying factors produce better outcomes (U.S. Department of Health and Human Services, 1999). Threatening and incarcerating women who live with these burdens do not produce a lasting reduction in their risk exposure (ACOG, 2005).

Table 7.1. Six Objections to Punitive and Coercive Legal Approaches to Maternal Decision Making

1. Coercive and punitive legal approaches to pregnant women who refuse medical advice fail to recognize that all competent adults are entitled to informed consent and bodily integrity.
2. Court-ordered interventions in cases of informed refusal, as well as punishment of pregnant women for their behavior that might put a fetus at risk, neglect the fact that medical knowledge and predictions of outcomes in obstetrics have limitations.
3. Coercive and punitive policies treat medical problems such as addiction and psychiatric illness as if they were moral failings.
4. Coercive and punitive policies are potentially counterproductive in that they are likely to discourage prenatal care and successful treatment, adversely affect infant mortality rates, and undermine the physician-patient relationship.
5. Coercive and punitive policies directed toward pregnant women unjustly single out the most vulnerable women.
6. Coercive and punitive policies create the potential for criminalization of many types of otherwise legal maternal behavior.

Source: American College of Obstetricians and Gynecologists. (2005). ACOG Committee Opinion No. 321: Maternal decision making, ethics, and the law. Obstetrics and Gynecology, 106, 1127–1137.

A reasonable legal or policy response to drinking during pregnancy should also stand in balance with responses considered appropriate for other pregnancy behaviors that pose serious and sometimes equally likely risks to the fetus. These include many relatively common pregnancy behaviors, such as using tobacco, becoming pregnant during very early or late stages in one's childbearing years or with health conditions that pose fetal risks, and using reproductive technologies that increase the likelihood of multiple births. Also male behaviors such as exposure to toxins that can damage sperm might harm the fetus. Indeed, each serious health risk warrants a response specific to its unique causes and solutions. However, recognition that these behaviors have not fuelled commensurate efforts to restrict and punish women or men as has occurred with pregnant women who use alcohol and drugs serves as a caution to ensure that strategies to prevent FASDs are both effective and fair (Eckenwiler, 2004).

Punitive laws used to prevent women from exposing fetuses to drugs present a number of serious ethical concerns. Autonomy and justice are compromised when unwarranted rules and restrictions are imposed upon women because they are pregnant. When the legal system is used to enforce such restrictions within the relatively short duration of pregnancy, women are at risk of too little time to prepare their cases, and court decisions are likely rendered too late to adequately protect the fetus. Forcing restraint from alcohol upon individual women does not optimize

benefit (beneficence) and the avoidance of undue harm (nonmaleficence), and it might contribute to mistrust of health care providers by pregnant women who are in need of trusted care. ACOG and a host of health advocacy groups have issued strong concerns or recommendations against punitive approaches, including the American Academy of Pediatrics, the American Medical Association, the American Nurses Association, the American Public Health Association, the National Council on Alcoholism and Drug Dependence, and the March of Dimes.

C. A Public Health Approach

As an alternative to punitive interventions, education and drug and alcohol abuse treatment are proactive measures to prevent the harms of prenatal alcohol exposure. Health care providers can send the message to women of childbearing age that "when you drink, your baby drinks," and encourage effective use of contraceptives as well as preconception abstinence from alcohol. As Floyd, Ferguson, and Hungerford (1999) stated, "public health measures needed to reduce these potentially harmful exposures include alcohol assessment, education, and counseling for women of childbearing age, with referral sources for problem drinking, and family planning services for pregnancy postponement until problem drinking is resolved" (p. 101). Many women do not recognize the dangers of alcohol to a fetus, and social and cultural norms often tolerate or even encourage drinking in pregnancy. Health care providers are often reluctant to address alcohol use with their female patients, expressing barriers such as lack of training, discomfort talking about women's alcohol use in pregnancy, and a lack of time during health visits (Gahagan et al., 2006; Nevin, Parshuran, Nulman, Koren, & Einarson, 2002). Training in time-effective ways to talk with patients about alcohol in pregnancy will help health care professionals and the public become better informed in how to prevent FASDs. When health providers include preventive interventions in their routine practices, they might gain satisfaction in preventing and minimizing health problems before they arise.

For women with alcohol dependence and abuse, prevention messages alone fall short. Health care providers must screen women for alcohol use, and be able to supply referral options for women needing specialized treatment (ACOG, 2004). Unfortunately, there are often few treatment options available for pregnant women and women with dependent family members. According to ACOG (2005), "despite evidence-based medical recommendations that support treatment approaches to drug use and addiction, appropriate treatment is particularly difficult to obtain for pregnant and parenting women and the incarcerated." (Page 1134)

Many states have proposed or enacted public health interventions for FASDs. Such interventions include allocations of funds for prevention, diagnosis and registries, alcohol and drug recovery awareness events, increased access to addiction treatment, signage requirements, and community grants (SAMHSA, 2006).

Even if they were effective, efforts to legally restrain women from exposing fetuses to the harms of alcohol could be imposed, in practice, only on small numbers of women. Also, such efforts would likely begin when a pregnancy is underway and fetal harm might have already occurred. A public health approach incorporating prevention and treatment could have a far greater impact, by preventing rather than punishing harmful behaviors. Studies show that pregnant women who use alcohol and drugs want to protect their fetus and are motivated to make changes (Murphy & Rosenbaum, 1999). Referrals and access to excellent treatment programs that do not pose

undue disruptions upon the present needs of women are a constructive direction for preventing the harms of fetal alcohol exposure. Furthermore, such interventions serve to reduce, rather than increase, stigma and shame for women and their children.

Summary

Health care providers seek to provide ethical care for the women, fetuses and children they serve. When drinking during pregnancy poses risk to a fetus, providers can express their respect for both woman and fetus by working to address the woman's needs so that she might better care for her developing fetus.

Prevention education is a health care provider's first responsibility to reduce FASDs. For women who might not respond to prevention messages because of alcohol dependence or addiction, health care providers and society have an ethical role in facilitating help, both to benefit the woman and her child or children.

The personal toll of living with an FASD, as well as the toll upon the affected individual's family, can be devastating. Ethical care and well-informed and constructive policies and laws must strive for a day when prevention measures are universal, and people affected by FASDs will benefit from the best health practices and the full support of their communities.

Suggested Learning Activities

- Use *Law and Order* video for discussion. [Harbinson, P. (Writer), & Platt, D. (Director). (2003). Choice [Television series episode]. In D. Wolf (Producer), *Law & Order: Special Victims Unit*. Los Angeles: NBC Universal Television Studio.]
- Use case studies to generate discussion.
- Use the "Mistakes I Have Made…" (Boulding, 2001) article for discussion.

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Learning Goals and Related Objectives

Goal VII-A: Identify ethical issues related to FASDs

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Describe basic ethical principles for health care. (K) ▪ Identify ethical principles in relation to FASDs. (K, A) ▪ Recognize patient confidentiality in relation to FASDs. (K, A)	▪ Discuss the importance of ethics in working with persons with FASDs, their caregivers, policy makers, and other health professionals. (A) ▪ Evaluate and discuss ethical issues with patients, caregivers, policy makers, and health professionals. (A, S) ▪ Discuss confidentiality issues with patients and their families. (S)	▪ Describe ethical issues related to FASDs to other health professionals. (S) ▪ Describe confidentiality issues related to FASDs to other health professionals. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.

Goal VII-B: Identify legal and policy issues related to FASDs

Learning Objectives

Level 1 The learner will be able to…	**Level 2** The learner will be able to…	**Level 3** The learner will be able to…
▪ Discuss fetal rights and the maternal-fetal relationship. (K,A) ▪ Discuss limitations of coercive and punitive approaches toward alcohol and drug use in pregnancy. (K, A) ▪ Identify elements of a public health approach to FASDs. (K, A)	▪ Evaluate and discuss key legal and policy issues with patients, caregivers, policy makers, and health professionals. (A, S)	▪ Educate colleagues and staff about key legal and policy issues related to FASDs. (S)

A=Attitude-based objective; K=Knowledge-based objective; S=Skill-based objective

Level 1. Medical and allied health students or professionals who need basic background information on FASDs for their education, work, or both.
Level 2. Medical and allied health practitioners who need to use the information to provide services.
Level 3. Medical and allied health professionals who educate and train other professionals about FASDs.