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Chapter 5 - Ethical and Legal Guidelines

This chapter includes specific guidelines in the following areas: assessment of mothers and newborns; confidentiality of information about treatment for drug and alcohol abuse; issues arising during postneonatal followup of the drug-exposed infant; and training in ethical and legal issues. However, throughout this chapter, it should be kept in mind that AOD addiction is fundamentally a medical, not a legal, issue.

As a foundation for these guidelines, the following principles are enunciated:

1. The ethical principle of respect for persons makes the woman the autonomous decisionmaker for herself and her fetus, which is undeniably part of her body. A pregnant woman and her fetus ought to be thought of as a unit, or dyad, and intervention strategies during pregnancy ought to benefit both the woman and the fetus.

2. The ethical principle of beneficence requires an individual to act in a manner that maximizes good consequences and minimizes harm to another. Women who are pregnant have obligations of beneficence to their fetuses.

3. Society in general, and health care professionals in particular, have obligations of beneficence to both the woman and fetus as well as the preservation of the family. These obligations include provision of comprehensive, multiservice, community-based, gender-specific programs that are accessible and affordable.

4. Involuntary civil commitment, criminal prosecution, or use of civil child protective service interventions for a pregnant woman, ostensibly to benefit the fetus, should not be used. Decisions concerning the incarceration of a pregnant, substance-using woman should be made only on the basis of an offense, and should not be related to pregnancy and substance abuse. If a pregnant, substance-using woman is incarcerated, adequate drug treatment and all necessary medical care must be provided.

5. If a pregnant, substance-using woman is eligible for a diversion program for a crime unrelated to drug use during pregnancy, this alternative should be encouraged and should provide comprehensive, gender-specific, multiservice treatment to enhance the health of the woman and the development of the fetus.

6. After birth, intervention strategies should continue to be designed to benefit the mother-infant dyad. There should be a strong presumption in favor of maintaining the mother-child relationship, and the right of the mother as decisionmaker for the child, unless the mother is not acting in the best interest of the child.

7. Treatment for the father of a drug-exposed infant should be available in the same program when appropriate, or in a different program. It may be therapeutically contraindicated for the parents of the drug-exposed child to receive treatment in the same program. For example, if the mother is engaged in treatment and is drug free while the father continues to use drugs, it is probably more appropriate for the father to be in a different treatment program. If the father is substance-using himself, then treatment

should be made available to him as well. Every effort to strengthen and maintain the family as a unit should be considered in providing services to the pregnant, substance-using woman and the mother-infant dyad.

8. In designing programs and providing services, agencies and individual providers must adhere to Federal and State laws. Because these laws are subject to change, programs and services need to be reviewed periodically by the provider's legal counsel.

Assessment of Mothers and Infants for Drug Use / Drug Exposure

Mothers

Health care professionals, hospitals, and clinics have an obligation to identify and assess all women, optimally during prenatal care, but at least at the time of delivery, for substance use.

1. Assessment should include the father and the family context.
2. Identifying a woman as a substance user does not, by itself, imply an obligation to report to child protection or law enforcement agencies. (State laws may differ in this regard.)
3. Maternal use of a substance does not equate to child abuse *per se*.
4. Assessment should include providing the woman with information regarding her right to confidential or anonymous HIV counseling and testing. Providers involved with the substance use assessment process should receive initial and ongoing training in HIV concerns, and should be able to present the woman with arguments regarding why knowledge of her HIV status may be beneficial to herself and her child. However, assessors must also understand that HIV testing is voluntary, that women have the right to refuse to be tested for HIV, and that this right to refuse testing must be respected. (HIV testing of the infant involves medical and legal questions beyond the scope of this TIP. Suffice it to say that, when the mother has custody of her infant, her informed consent is required for the infant to be tested.)

Guidelines for urine toxicology were developed for a companion volume in this series, *Pregnant, Substance-Using Women*, and appear in Appendix C.

Infants

Health care professionals, hospitals, and clinics have an obligation to assess newborns who exhibit signs and symptoms of drug exposure, whose mothers have been identified as probable substance users, or whose mothers have signs and symptoms of drug use.

1. Identifying an infant as drug exposed should not, by itself, imply an obligation to report to child protective services or law enforcement agencies. (State laws may differ in this regard.)
2. The finding of substances in the newborn's urine does not equate to child abuse by his or her mother. (State laws may differ in this regard.)
3. Screening of the newborn's urine should be done only for purposes of medical diagnosis and treatment, and should be accompanied by communicating with and informing the mother. As discussed in Chapter 2, in certain circumstances testing infants is medically necessary for the proper and safe care of the infant. Specific informed consent of the mother is not required because of the importance of the medical information to the care

of the infant and the fact that delay in obtaining the specimen would cause invalid results due to the short time in which drugs may be detected in the urine.

Reporting Laws And Laws Governing Confidentiality

Many jurisdictions require that drug abuse by pregnant women and / or substance exposure in an infant be reported to authorities. This sometimes poses a dilemma to hospitals, clinics, and treatment programs, which must also follow Federal regulations concerning the confidentiality of alcohol and drug abuse patient information (42 CFR Part 2). Federal laws take precedence over State laws, except in cases where child abuse is concerned. Since 1986, a law has been in effect declaring that the State's child abuse laws should be adhered to in the area of child abuse. Hospitals, clinics, and treatment program staff must be aware of their State's laws, regulations, and reporting requirements (e.g., with respect to mental health, HIV, and child protection). Likewise, patients in treatment programs should be told what confidentiality protection their program offers, and when these protections may be suspended. For instance, a program can be subpoenaed to release confidential treatment records or be required by State law to report drug use by a pregnant woman or the mother of a drug-exposed infant.

Confidentiality and reporting laws and regulations have a significant impact on service providers. The challenge is to design a treatment program that complies with Federal and State laws and regulations, and at the same time provides services that are responsive to the special needs of pregnant, substance-using women and families of drug-exposed children. Treatment program staff must be trained to deal with the conflicts between confidentiality and reporting issues, and to recognize how these conflicts affect their ability to deliver services.

Impact of Reporting Laws On Substance-Abusing Women

State and local laws requiring that maternal substance abuse and / or fetal drug exposure be reported to authorities have a significant impact on pregnant women, mothers, and their children. Such a report could provide impetus for removing children from their mother's care and putting them in protective custody or in foster care. Knowing that such a report was in the offing, the woman might forego her prenatal care or the followup care provided to her and her infant.

The following guidelines explain Federal regulations on confidentiality of drug and alcohol referral and treatment information and can assist programs in their efforts to design effective and appropriate procedures for treating pregnant, substance-using women and mothers of drug-exposed infants.

1. Prohibition of Disclosure - What follows is a summary explanation of the Federal confidentiality regulations, called the General Rule Prohibiting Disclosure:
    - Except under certain limited conditions, Federal confidentiality regulations prohibit the disclosure of records or other information concerning any patient in a Federally assisted alcohol or drug abuse program (42 CFR, Secs. 2.12; 2.13(a)).
    - This prohibition of unauthorized disclosure applies whether or not the person seeking information already has the information, has other means of obtaining it, enjoys official status, has obtained a subpoena or warrant, or is authorized by State law (42 CFR, Secs. 2.13(b); 2.20).
    - Any State provision that would permit or require a disclosure prohibited by the

Federal rules is invalid. However, States may require greater confidentiality than the Federal regulations (42 CFR, Sec. 2.20).

2. Exceptions - Although the general rule is that patient-identifying information may not be disclosed, the regulations set out a number of conditions permitting limited disclosures upon patient consent, and a few circumstances in which disclosures may be made without patient consent. Each of these conditions or circumstances has its own requirements and limitations. In general, permitted disclosures fall into the following categories:

    - Disclosures made with written informed consent of the patient
    - Disclosures made pursuant to internal program communications
    - Disclosures made in response to a court order
    - Disclosures made pursuant to a crime at the treatment program or against program personnel
    - Disclosures made for research or audit purposes
    - Disclosures made when an individual is obligated by State law to report reasonable suspicions of child abuse or neglect
    - Disclosures made pursuant to a qualified service organization agreement
    - Disclosures made pursuant to a medical emergency.

    A medical emergency is defined as a situation in which:

    - The individual's life is in immediate danger without emergency treatment, and
    - He or she is unable (for example, unconscious) or incompetent to give consent, and
    - The person authorized by law to give consent for the individual is unavailable.

State Laws on Confidentiality

A variety of State confidentiality laws may affect the provision of services and treatment to substance-abusing pregnant women, mothers, and drug-exposed infants. These may include, for example, laws that control the release of medical records, limit the ability of persons to testify in court based on information obtained when providing professional services (testimonial privilege), or prohibit disclosure of information regarding specific diseases (such as drug addiction and HIV). Service and treatment providers should consult with local counsel to determine which State confidentiality laws most directly affect their practices, and develop protocols and training programs that will help ensure that the provisions of these laws are followed.

Training on Confidentiality - All individuals who provide services to pregnant, substance-using women and mothers of drug-exposed infants must understand Federal regulations on confidentiality and must receive training on State and local laws, regulations, and reporting requirements.

- Providers of health care and social services include, but are not limited to, physicians,

social workers, nurses, psychologists, psychiatrists, child protective services workers, foster parents, teachers, child care workers, and drug and alcohol counselors.

- Providers of health care and social services must be trained to understand the differences among Federal, State, and local laws regarding confidentiality of information on drug and alcohol abuse treatment and other information on physical and mental health.
- Providers of health care services must know the relevant reporting laws pertaining to child abuse and neglect. They should know who is mandated to report child abuse and neglect, under what circumstances, and the penalty for not reporting such abuse and neglect.
- Programs serving pregnant, substance-using women or mothers of drug-exposed infants are often part of community-based organizations or health care clinics. Staff of these programs must be aware of confidentiality and the right to informed consent as it relates to drug treatment confidentiality laws.
- Cross-training concerning confidentiality and reporting should be given to individuals who may not understand Federal and other drug treatment confidentiality laws. This includes individuals involved in medical, legal, drug treatment, educational, and social service fields.

Patient Records and Courts - Service providers; pregnant, substance-using women; and mothers of drug-exposed infants should be concerned with how courts handle patient records, and under what circumstances courts can order medical and psychiatric evaluations.

- Once records go to adult court, they become public record. Individuals concerned about court records and subpoenas need to understand State laws. It should be noted that in most but not all States, juvenile records are confidential.
- Courts can order an evaluation to determine if a woman needs treatment for substance abuse, to make a diagnosis, and to make a referral for treatment or services. If the court orders the evaluation, the information cannot be kept from the court because of confidentiality regulations. (However, the information is still confidential to all other individuals and institutions.)

Communicating with Patients about Confidentiality - Providers of health care and social services should be concerned with how they communicate with the recipients of their services regarding confidentiality and reporting, and how they share information about a patient with other programs or individuals. This information needs to be presented to the woman at the initial point of drug treatment and / or prenatal care.

- Pregnant, substance-using women and mothers of drug-exposed infants should be informed by providers about the various Federal, State, and local laws and how such laws affect individuals receiving services. Relevant areas of law may include, but are not limited to, the reporting of child abuse to appropriate authorities, custody consequences, and issues of records once they reach the courts.
- Pregnant, substance-using women and mothers of drug-exposed infants must be informed of their right to confidentiality, and should be provided information about laws related to reporting and court involvement.
- Confidential information concerning the status of a woman in drug treatment cannot be

discussed with individuals or organizations outside of the drug treatment facility without written informed consent unless a legally recognized exception to confidentiality, such as a medical emergency, applies.

- When informed consent is obtained, it must be time-limited, content-specific, person-to-person, signed, and witnessed, in keeping with the requirements of Federal drug treatment confidentiality laws. A copy of the written informed consent document must be offered to the woman.

Confidentiality of Information on Infants - A parent or legal guardian has the right to control the release of confidential records and information pertaining to her or his infant.

- In order to release such information, the informed consent of the parent or legal guardian must be obtained. As noted earlier, although informed consent of the legal guardian is not required for drug testing of the infant, the law is much clearer that medical information of the infant cannot be released without the guardian's consent.
- The consent must conform to legal requirements controlling the release of the particular information (for example, in writing, time-limited, and witnessed).
- If a parent refuses to give consent, is incompetent to give consent, or cannot be found, the court may be requested to appoint a legal guardian for the infant. This guardian is authorized to make medical decisions for the infant, including release of confidential information.
- Parental consent is not necessary where excused by law, which may vary by State. In many States, exceptions to blanket rules requiring parental consent are made for medical emergencies and reporting of child abuse.

Unauthorized Release of Information - Release of confidential information without consent may harm the child or mother and may subject the health care and social services provider to civil or criminal liability. To avoid this, the hospital and social services agency should develop protocols and procedures governing the release of information and train employees in their use. Access to counsel knowledgeable in the area of confidentiality should also be provided to employees. The following information, at a minimum, should be covered in protocols and training:

- Elements and procedures for obtaining informed consent.
- Situations where consent for the release of information is not necessary.
- Whether to notify the mother when information is released without her consent.
- How to respond to a request for information (for example, in denying a request, making sure that the denial does not itself confirm the existence of a medical or substance abuse condition).
- How to limit disclosures to information necessary and relevant for providing services to the mother or child.
- How to satisfy the law when making disclosures without consent.

Issues Arising During Postneonatal Followup

During postneonatal followup of the drug-exposed infant, the following should be noted:

1. Caregivers need to be aware of their own attitudes and feelings regarding substance-using women of childbearing age, because attitudes and feelings may hinder the ability of the provider to form a therapeutic alliance. A successful treatment intervention for the mother of a drug-exposed infant demands a therapeutic alliance between mother and provider, and should include: a nonjudgmental, nurturing approach; honest and open communication; and clear and concise shared expectations. Moreover, the provider of care should be aware of the complex psychosocial environment of drug-using women. This environment may include poverty, domestic violence, sexual abuse (including incest), homelessness, depression and other coexisting psychiatric disorders, intergenerational history of substance use, and the absence of healthy parenting.

2. Since chronic substance use is recognized as a relapsing disorder, programs and providers should:

    - Develop policies and procedures to keep patients in treatment, work with relapsing mothers, and foster the mother-infant dyad.
    - Recognize critical periods and issues of relapse and develop strategies to support the mother and protect the infant through relapse episodes. Relapse alone should not be grounds for reporting to a child protection agency, or for placing the child in foster care.
    - Be aware that the safety and well-being of the infant need to be protected. Notwithstanding the confidentiality requirements and the therapeutic alliance with the mother, a report to child protective services may be necessary and even legally required if the mother's substance use is seriously impairing her parenting ability. [1]

3. In dealing with drug-exposed infants, successful treatment of the mother-infant dyad requires that agencies and providers of care:

    - Establish interactive working relationships in order to coordinate all aspects of care.
    - Develop mechanisms so that case-specific information can be shared while respecting confidentiality and with appropriate informed consent.
    - Provide comprehensive services that include, but are not limited to:
        - Medical care for mother and infant, including acute care, well baby screens, immunizations, developmental assessment and followup, preconception counseling, and necessary medications.
        - Mental health care including alcohol and other substance use treatment, family therapy, and identification and treatment of coexisting psychiatric disorders.
        - Psychosocial interventions including parenting training, child development education, anticipatory guidance, assistance in obtaining public benefits, protection from domestic violence, child care, education, and vocational and job training.

Training in Legal And Ethical Issues

Groups, agencies, and individuals caring for a drug-exposed infant must clearly understand and address all aspects of the complex legal and ethical issues involved, so as to achieve the best possible care and positive outcome for the infant.

In order to ensure a positive outcome, all staff involved with a drug-exposed infant should participate in comprehensive and continual training that covers every aspect of the recommendations presented in the preceding sections. This training should be developed at the Federal level in collaboration with the States, and should include specific examples illustrating how the recommendations can be applied in a variety of environments and circumstances.

1. The first level of training should be provided by the Federal Government to staff of State health and social services departments. Once trained, these staff will become better able to evaluate and recommend improvements to institutions and programs serving drug exposed infants.
2. The next level of training will be delivered by States to local municipalities, so as to inform local service providers of new or clarified guidelines concerning the care of substance abusing women and their infants. In addition to providers of health and social services, persons who interface with and are involved in the court process should receive training. Judges are a priority target group for training. Attorneys, probation officers, and other court personnel should be encouraged to participate in training. Training should be made available to any person involved in making decisions for drug-exposed infants and their families. Cross-training of groups encompassing health professionals, child welfare specialists, and judges and attorneys involved in family law is particularly encouraged.
3. The final level of training must occur at the local level and target specific agencies involved in the care of substance-abusing women and their drug-exposed infants. This training must also include the necessary tools for documenting overall compliance with the guidelines.
4. Training at all levels must be ongoing and updated at regular intervals to provide the most up-to-date information - including any changes that may occur in the law and these guidelines - to all groups, agencies, and individuals involved with care of substance-abusing women and their infants.
5. New training dollars should be made available at the Federal level to ensure compliance with these guidelines.

Footnotes

1 The Panel on Psychosocial, Legal, and Ethical Issues suggests that these recommendations be added to the draft *TIP on Pregnant, Substance-using Women,* Chapter 2, Postpartum Guidelines.

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