Housekeeping

- Welcome!
- Announcements
  - Notes Box
  - Chat Box
  - Web Links Box
  - Registration Information
- Let’s get started!

Ethical Issues of FASDs and the Helping Professional Webinar
Sponsored by the Frontier Regional FASD Training Center
Presenters: Ruth Gerritsen-McKane Ph.D, Chris Gjesfjeld, Ph.D, Mahasin Saleh, Ph.D.
Polling Question 1

Polling Question 2
Prior Learning Goals and Outcomes  
(Introduction to FASDs Webinar – 1/30/13)

- Define the terminology related to FAS & FASDs
- Describe the prevalence & costs associated with FASDs
- List the effects of alcohol during the critical periods of embryo & fetal development
- Discuss fetal alcohol exposure and its impact on young children

Learning Goals and Outcomes

- Identify ethical issues related to FASDs
- Identify ethical principles in relation to FASDs
- Describe basic ethical principles for providers
- Recognize patient confidentiality in relation to FASDs
### Prevalence and Costs

<table>
<thead>
<tr>
<th>FAS</th>
<th>FASD</th>
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<tbody>
<tr>
<td>0.2 – 1.5 cases per 1,000 births</td>
<td>9 - 10 cases per 1,000 births</td>
</tr>
<tr>
<td>Translates to about 1,000 – 6,000 alcohol-affected births per yr</td>
<td>Translates to about 40,000 alcohol-affected births per year</td>
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<tr>
<td>Estimated lifetime cost per individual of $2 million</td>
<td>Estimated lifetime cost per individual of $1.4 – 1.5 million</td>
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Comparable to other developmental disabilities (e.g., Down syndrome, autism)
A Society with Discomfort

- **Drinking Safe?**
- **Friends**
- **How I Met Your Mother**
  - this video removed the part that Lily was told she could drink “just a little bit” during pregnancy
ALCOHOL and Fetal Impact

• Interferes with the normal proliferation of nerve cells
• Alters the ability of brain cells to produce or regulate cell growth, division, & survival
• Alters the expression of certain genes
• Alters the pathways of biochemical or electrical signals within the cells.

Polling Question 4
Ethical Issues
We all face Ethical Dilemmas during our Helping Profession Careers

Ethics and FASDs

- Bio-medical ethics
- Confidentiality
- Ethical framework
- Case study
Steps for Ethical Decision Making  
Anderson (1999)

- Determine the facts
- Analyze the ethical aspects/principles
- Make a decision
- Take action
- Evaluate the decision

Four Basic Principles  
(Beauchamp and Childress, 1983)

- **Autonomy:** Consider a person’s right to self-determination, the capacity for autonomous choice
  - Ability to reason
  - Ability to make a voluntary choice
  - Does alcohol dependence affect autonomy?

Four Basic Principles

• **Beneficence**: Asks us to seek the benefit of our patients
  — Goal of “Helping Professions”
  — Care for the well-being of the woman consuming alcohol
  — Care for the children impacted by FASDs (e.g. special education services)

Four Basic Principles

• **Nonmaleficence**: Responsibility to avoid causing harm and to minimize undue harm to others
  — Weigh the benefits vs. the risks
  — How is the fetus considered?
Four Basic Principles

• **Justice**: Fair distributions of social benefits and burdens and to promote and follow laws and practices in ways that are fair for all people
  – Can we be fair to clients with FASDs?
  – Can we be nonprejudicial to women with known alcohol use and abuse in pregnancy?
  – Do all women have access to alcohol treatment services?

Polling Question 5
Confidentiality

- Essential aspect of provider-client relationship
- More information known: Better ability to provide best care
- Legal and Ethical Consequences
  - HIPAA
  - No false impressions
  - Consistent with policy restrictions
  - Consistent with state laws

Issues to Consider

Dubovsky (2003)

- Confidentiality
  - Address issues of sharing information between you and the family
    - It is possible for the family to share information without your breaching confidentiality
    - You may not be able to acknowledge that you know the individual
    - If you can, talk about the possible need to share this information with the individual
    - If you can’t share information, explain why
Issues to Consider
Dubovsky (2003)

- Confidentiality
  - Do not talk about the individual or family with your family, friends, at the water fountain, in the elevator, or at the intake desk, even if you don’t use names
  - Be aware of talking in cubicles without full walls
- Keep open communication with the individual and family when appropriate
- Utilize informed consent
- Ensure that recommended services are needed

Issues to Consider
Dubovsky (2003)

- Confidentiality
  - Don’t fall into the “I trust you and want to tell you something but you must promise not to share it” trap

  - Discuss touchy situations with supervisors, being aware of possible confidentiality issues
Guidelines for Decision Making
Adapted from Curtis and Hodge (1994)

• Is there an existing code of ethics?
  – Are you familiar with it?
  – Does it inform you as to what to do?
• What are the treatment justifications?
  – What is your rationale for doing this?
  – What is the anticipated outcome
• Are there any other ways to do this?
  – Can the outcomes be obtained in any less problematic way?

Guidelines for Decision Making
Adapted from Curtis and Hodge (1994)

• Who benefits?
  – For whose benefit do you want to do this?
• Could this be a problem for the individual, family, staff or community?
  – If someone saw you doing this, would they have a problem?
  – Could you clearly explain your rationale?
• Would it be OK if you saw yourself in the headlines?
Polling Question 6

Intersections

- Policies related to drinking during pregnancy
- One resource State by State legislative chart.
- Where else would you look for state specific resources?

FASD Legislation by State

The Case of Claire

- Claire is a mother of 4 and is expecting her 5th baby in a few months. She lives in a isolated community. Her common-law partner has been very abusive and has recently been put in jail. She has no one to turn to, most of her friends are also his friends and have taken his side. And yet, in some ways, it was easier when he is home. He will buy groceries and bring in some money.
The Case of Claire

- Claire drinks alcohol to help her forget what is going on. Sometimes she drinks with her partner because he expects it. Other times she drinks small amounts throughout the day to take the edge off. She finds herself more easygoing with the kids when she is calmer.

Punitive Approaches

- Health Advocacy groups have issued strong concerns against punitive approaches towards women who expose their fetuses to harmful substances...
  - American Academy of Pediatrics
  - American Medical Association
  - American Nurses Association
  - American Public Health Association
  - March of Dimes (CDC, 2009)
Punitive Approaches

• “.....Might contribute to mistrust of health care providers by pregnant women who are need of trusted care” (CDC, 2009).

Revisit Four Basic Principles

• Analyze this in context of these principles: autonomy, beneficence, nonmaleficence, and justice

• For example: what case factors do we consider given the principle of autonomy?
Identifying Ethical Principles  
Case of Claire

• Which ethical principles seem most relevant to this case?
• What does she know about effects on the fetus? How might we evaluate her decision making?
• What access does Claire have to treatment services?

In Conclusion...

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References


• Case study adapted from: http://www.preventioninstitute.sk.ca/alcohol-tobacco-and-other-drugs/alcohol-risk-assessment

• Center for Disease Control Fetal Alcohol Spectrum Disorders: Competency-Based Curriculum Developmental Guide for Medical and Allied Health Education Practice (http://www.cdc.gov/noibodd/fasd/curriculum/fasadguide_web.pdf)


Additional Website Resources

• Fetal Alcohol Syndrome Consultation, Education and Training Services:
  – www.fascets.org

• Fetal Alcohol Syndrome: Support, Training, Advocacy, and Resources:
  – www.fasstar.com

• The Arc of the United States:
  – www.thearc.org

• The Arc’s Family Resource Guide:

• National Institute for Alcohol Abuse and Alcoholism (NIAAA):
  – www.niaaa.nia.gov

• Substance Abuse Treatment Facility Locator:
  – www.findtreatment.samhsa.gov

• Fetal Alcohol Syndrome Family Resource Institute:
  – www.fetalalcoholsyndrome.org

• FAS Diagnostic & Prevention Network:
  – www.depts.washington.edu/fasdpn