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Association of Reproductive Health Professionals

Fetal Alcohol Spectrum Disorders (FASDs) Consensus Meeting

Meeting Report

Introduction

The message regarding alcohol use during pregnancy from the Centers for Disease Control and Prevention (CDC) and other federal agencies is that there is no known safe amount of alcohol use during pregnancy. However, health care providers in the US do not always provide this message consistently to their patients, instead suggesting that frequency, amount, type, and/or timing of the alcohol consumption may be taken into consideration in decisions about alcohol consumption during pregnancy.

A 2015 online survey of Association of Reproductive Health Professionals (ARHP) members[1] designed to gather information about members' current practices and educational needs related to educating and counseling women about alcohol use during pregnancy indicated that sexual and reproductive health care providers have a variety of approaches in discussing this issue with patients. The survey results also indicated providers could benefit from support in crafting and delivering more nuanced messages designed to meet patients "where they are" given that not all patients respond to the message that "no amount of alcohol is safe during pregnancy." Consistent, patient-centered messages regarding alcohol consumption during pregnancy is a key component in efforts to prevent FASDs. A summary of results from the online survey is included in Appendix A.

In response to current provider practice, the Association of Reproductive Health Professional (ARHP), with a grant provided by The Arc, convened a Consensus Meeting comprised of key thought leaders to develop guidance to

[1]ARHP members include health care professionals across disciplines who work in the area of sexual and reproductive health. For the survey referenced above, ARHP specifically surveyed frontline prenatal care providers.

Introduction

promote quality improvement for fetal alcohol spectrum disorders (FASDs) prevention within the clinical practice setting. The meeting goal was to develop expert guidance on patient-centered, culturally competent best practices for frontline providers in counseling patients to prevent FASDs. The recommendations from the meeting will inform the development of health professional educational interventions. This report summarizes the key themes and recommendations of this meeting.

ARHP held the Consensus Meeting at its Washington, DC, office on November 6, 2015. ARHP staff planned the meeting structure and content in conjunction with two meeting participants who served as Planning Committee Co-Chairs and the ARHP consultant who facilitated the meeting. ARHP recruited meeting participants with input from The Arc, Health Resources Services Administration (HRSA), CDC, Substance Abuse and Mental Health Services Administration (SAMHSA), and National Institute on Alcohol Abuse and Alcoholism (NIAAA), and included five leading clinical, research, and policy experts on FASDs.

The meeting began with a welcome and introduction section, a brief overview of the current state of FASD research and prevention messaging, and a short presentation highlighting the results of the previously mentioned ARHP member survey. The remainder of the meeting focused on generating recommendations from participants through two focused discussions. The following appendices provide additional information about the meeting:

Appendix A
ARHP Member Survey Results

Appendix B
Meeting Agenda

Appendix C
Participant List

Appendix D
Discussion Questions

Appendix E
Glossary (While the primary intended audience for this report is decision-makers and clinicians involved in FASDs prevention and continuing education for healthcare providers, the Arc and ARHP want to make sure that it is accessible to a broader audience. With this in mind, terms in italics are defined in the glossary.)

Findings and Recommendations

Included below are key points and recommendations from meeting participants, grouped by major theme.

The Current Message:
There is no known safe amount of alcohol use during pregnancy

All participants agreed that the current message for the general public— "No amount of alcohol is safe during pregnancy"—is accurate and consistent with scientific evidence. However, they also recognized the need for more nuanced messages for health care providers working with individual patients:

- "There is no known safe amount of alcohol use during pregnancy" is a factually correct statement, because we can't say for sure how much alcohol would be safe for any individual fetus. However, this message doesn't work or resonate with every woman and to all life situations.
- A technically more correct statement would be, "There is no known safe amount of alcohol for all fetuses." What is safe for one woman/fetus is not necessarily safe for all others. Studies of fraternal twins have shown that it is possible for fetuses to have profoundly different outcomes with the same alcohol exposure.
- People are inundated with mixed messages. Recently, social media have been reporting that 1–8 drinks a week is safe.
- The "no known safe amount" message also makes it difficult to explain to women who drank before they knew that they were pregnant that there is still an advantage to eliminating (or reducing) alcohol use for the remainder of the pregnancy. They often wonder if they've done irreparable damage and if they should terminate the pregnancy
- Discussions with patients should start before pregnancy—ideally when they become sexually active and certainly preconception.

What the Scientific Evidence Tells Us about Dose-Response Effects Related to Alcohol Consumption

Providers and patients alike wonder about dose-response effects related to alcohol consumption in pregnancy—in addition to the role of timing of consumption (see Appendix E: Glossary). These are the points that the group agreed upon:

- The effect of alcohol on the fetus depends on quantity, frequency, and timing of alcohol consumption.
- There's no way to predict how alcohol will affect any particular fetus.
- Reducing drinking during pregnancy reduces the risk of adverse effects, but does not eliminate risk.
- Research is unlikely to ever pinpoint a threshold under which alcohol consumption during pregnancy is safe.

Key Points from the ARHP Member Survey

After reviewing data from the ARHP online member survey, meeting participants agreed on three key themes that emerged from survey participants' responses:

- Providers want evidence-based scripts that address a range of patient concerns.
- Key messages to patients should:
  - Include information that fetal brain development occurs throughout pregnancy.
  - Deemphasize timing of alcohol consumption.
  - Be available in basic and detailed versions.
- Messages to providers should also deemphasize timing and be available in basic and detailed versions.

A Harm Reduction Approach to FASDs Prevention

In other areas of public health, harm reduction approaches have been successfully employed to reduce—if not eliminate—risk of adverse outcomes. In discussing how such an approach might work in the area of FASD prevention, meeting participants made the following observations:

- There is a continuum. Less drinking means fewer adverse effects. Stopping at any point is going to be beneficial.
- The goal is to get as close to zero alcohol as possible.
- If you can't eliminate the risk, reduce it as much as possible. Reducing risk is better than no action at all.
- Consensus: No participants would be willing to tell a pregnant woman that even one drink is safe/okay.

Findings and Recommendations

Developing Rapport: Patient-Centered and Culturally Appropriate Communication

Meeting participants stressed the critical importance of developing rapport with patients. Hand-in-hand with rapport, successful clinicians must be patient-centered, respectful and culturally appropriate.

- Developing rapport takes time. Clinicians must make time in their schedules.
- Normalize instead of judging. For example:
  - Acknowledge that many women find themselves in the position of having had alcohol before they knew they were pregnant.
  - Say, "How much do you drink?" rather than, "Do you drink?"
  - Say, "How often do you party?" rather than, "Do you party?"
  - Say, "I'm here to help you have a healthy pregnancy."
- Approach patients from a stance of cultural humility—you can learn from your patient. For example:
  - Ask patients to explain their circumstances to you instead of making assumptions.
  - Ask yourself, "What does this person need?"
  - Be aware of your biases and "leave them outside" or be honest to yourself and your patients about them.
  - Tailor messages to individual patients.
  - Ask if you don't know.
  - Say, "Let me know if anything I say is off-base."
  - Ask, "What are your dreams/goals/plans for your baby?"
- Some patients may have FASDs (or other developmental delays) themselves, and will require tailored communication approaches to best support them and ensure understanding.

Practice Considerations and Recommendations

The group identified a set of practice-related issues that need to be considered in supporting frontline providers with FASDs prevention.

- Clinician education programs should address providers' apprehension about bringing up this topic.
- Some providers don't ask because they don't know what to do if a patient says she drinks. However, it's important to document her drinking in her health record, and there's some evidence that just asking a pregnant woman about her drinking may have a positive impact on her behavior.
- Education and counseling are not a one-time event. It's a process. And you can't make anyone do anything. Frontline providers need to be educated about Prochaska and DiClemente's Stages of Change Theory (Transtheoretical Model).
- Providers should use an evidence-based screener with patients at least once a trimester.
- Screening questions should be embedded into electronic health records (EHRs).
- Support should be integrated into the clinical care team, and may include a substance abuse counselor, social worker, and others.
- While motivational interviewing (MI) is the gold standard for working with women to eliminate risk, effective MI requires extensive training and practice. We need to think about if and how this type of intensive support fits with the typical frontline prenatal care provider's practice. It is important to acknowledge that many providers may need to refer patients out for this type of intensive work.
- Providers are often faced with a lack of local treatment options—especially for pregnant women. At the very least, providers should be made aware of these resources:
  - SAMHSA's National Helpline: 1-800-662-HELP (4357); TTY: 1-800-487-4889; www.samhsa.gov/find-help/national-helpline
  - SAMHSA's Behavioral Health Treatment Services Locator: https://findtreatment.samhsa.gov/
  - National Organization on Fetal Alcohol Syndrome's Resource Directory: http://www.nofas.org/resource-directory/

Findings and Recommendations

Using Tailored Messages

In keeping with the idea of patient-centered care, the theme of applying tailored messages was salient throughout the meeting. Below are several approaches for tailoring messages and examples of messages.

Approaches to tailored messages:

- Clinicians must understand the population(s) with whom they are working including their motivations and challenges.
- When working with women from cultures in which alcohol has cultural importance/meaning, look to other health promotion activities that have successfully helped individuals retain cultural meanings and rituals.
- "It takes a village." Include partners, friends, and family in supporting the woman.
- Enlist partners' help in encouraging the woman to abstain from or reduce alcohol consumption.
- Many women are more likely to make sacrifices during pregnancy than at other times in their lives. Capitalize on this tendency.
- Regularly check for true understanding of the issues you're discussing.

Specific messages:

- "Drinking while pregnant is like riding a motorcycle. Sure, you went riding yesterday, and didn't get hurt. But the more times you ride, the chances you have of getting into an accident."
- "Would you put alcohol in your baby's bottle? That's exactly what you're doing if you're drinking during pregnancy."
- Consider using images of "normal" and FAS-affected brains to show the tangible effects of alcohol on brain development.
- "You're a mother now." (Tap into the nurturing mindset to help the woman do what's best for her baby.)

Summary

The wide-ranging discussion of this group of policy experts, researchers, and frontline clinicians offered an array of valuable perspectives. Most importantly, they offered a set of guiding principles and specific examples to guide the development of additional clinical education activities and resources. For example, to be effective, clinical education approaches and materials should acknowledge and address the following:

- While scientifically valid, the "there is no known safe amount of alcohol use during pregnancy" message designed for the general public will not be effective for every individual woman seen in a clinical setting. Messages and educational approaches must be tailored for specific patients.
- Establishing rapport, including demonstrating respect and cultural sensitivity, is essential in the clinician-patient relationship. Otherwise, patients will not feel comfortable being honest about their drinking habits.
- Provider realities, including anxiety about addressing alcohol use, the nature of behavior change, time constraints, and barriers/facilitators within the practice setting must be addressed.
- Providers have a responsibility to ask patients about alcohol use at regular intervals and ensure understanding.
- Providers should be encouraged to help patients get as close to no drinking as possible, and must be "given permission" to refer patients for more intensive treatment—and provided with available treatment referrals—when necessary.

More specifically, the group recommended developing a screening and education algorithm like the following one to assist clinicians in discussing this topic.

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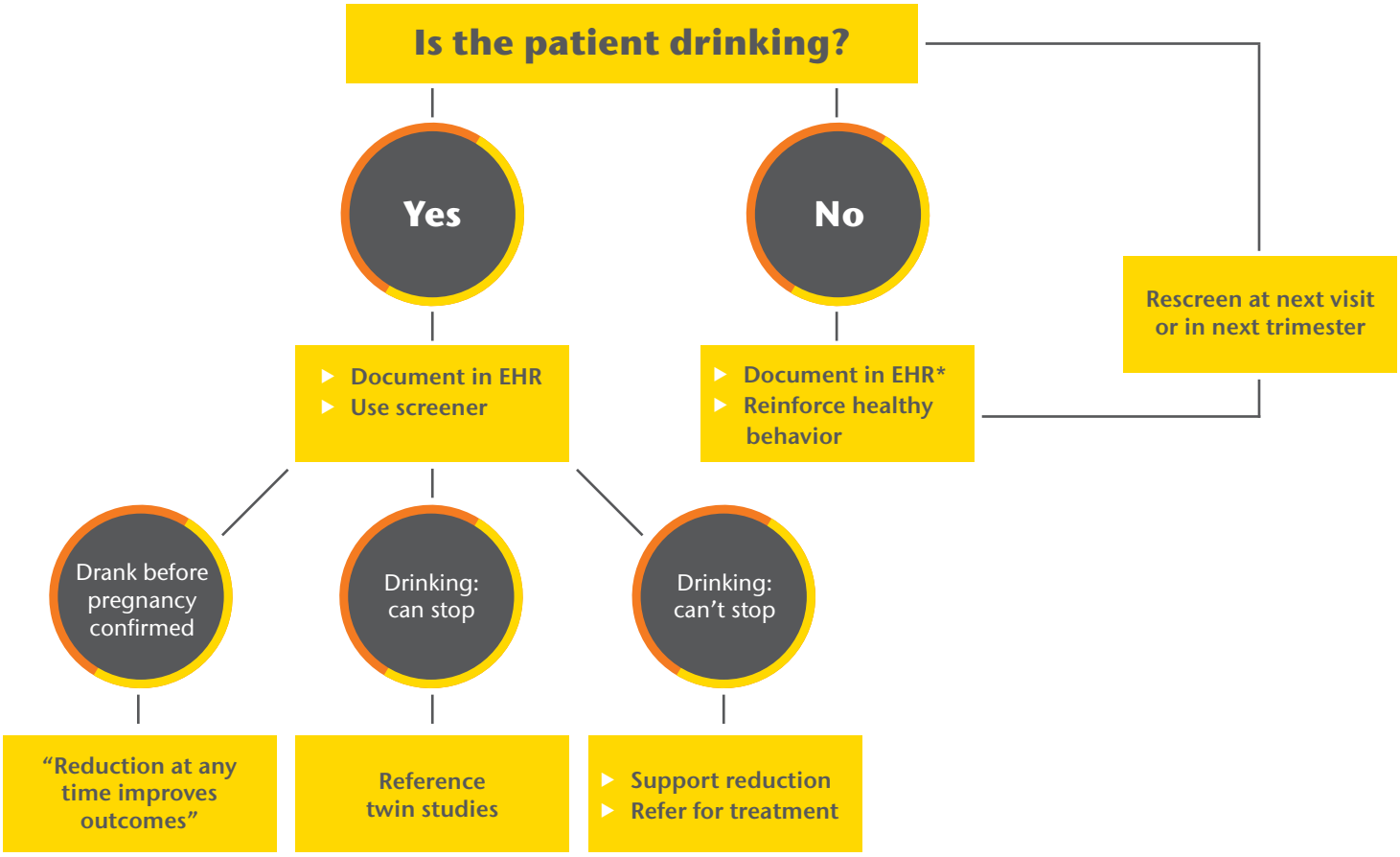
FASDs Screening & Education Algorithm



Additionally, the group recommended that organizations like The Arc and ARHP develop scripts to aid clinicians in their discussions and educational efforts. Scripts would provide various strategies for addressing patient concerns such as, "But my mother drank when she was pregnant with me and I turned out fine" and "Do I need to terminate if I had drank before I found out I was pregnant?" The more concrete the tools and job aids are, the better.

Taken together, the insights and recommendations that resulted from the FASDs consensus meeting provide a valuable blueprint for moving into a new phase of patient-centered, culturally competent training for frontline prenatal providers to reduce the risk of FASDs.

The Arc's FASD Prevention Project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) through a $1.3 million cooperative agreement (Grant No. U1HMC26371). This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government.

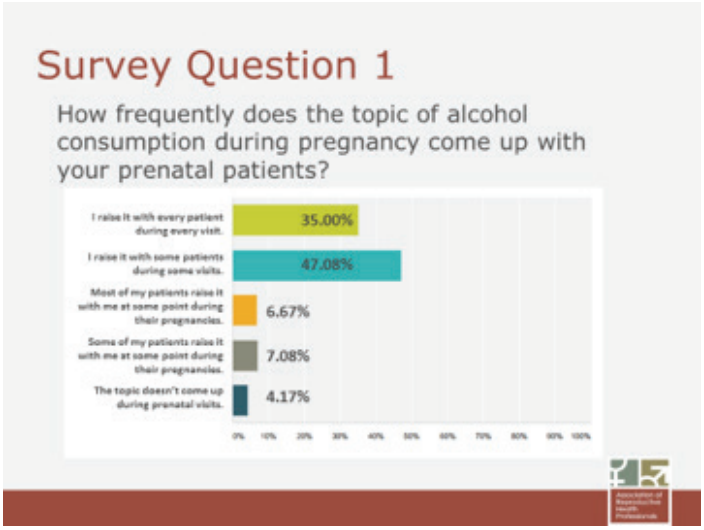
Appendix A: ARHP Member Survey Results

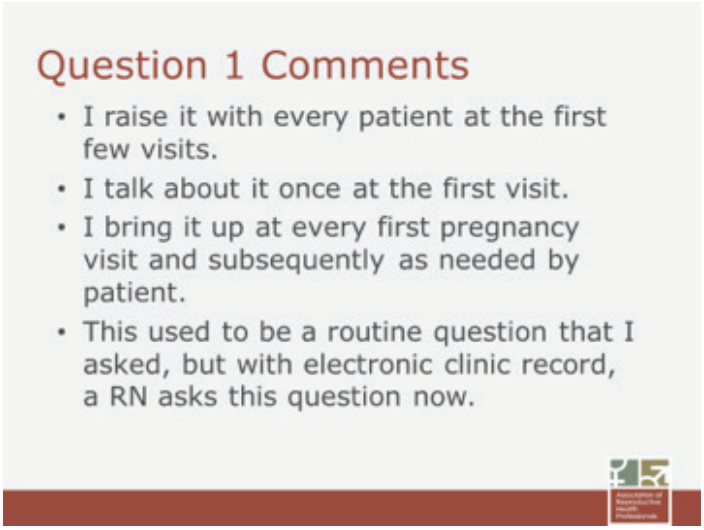
In planning for the November 6, 2015 FASDs Consensus Meeting, the Association of Reproductive Health Professionals (ARHP) conducted an informal online survey of its members designed to assess frontline sexual and reproductive health care providers' current practices and educational needs related to educating and counseling woman about alcohol use during pregnancy.

ARHP sent an invitation to participate to all ARHP members, including non-clinician members. 258 members responded, providing a "snapshot" of members' current practices. ARHP recognizes that results are neither generalizable to all ARHP members nor all practicing prenatal care providers. Respondents' practice categories were as follows:

- Obstetricians/Gynecologists: 14.04%
- Family Physicians: 17.02%
- Certified Nurse-Midwives: 20.43%
- Nurse Practitioners: 24.68%
- Registered Nurses: 10.21%
- Other: 11.92%
- Not in Clinical Practice: 1.7%

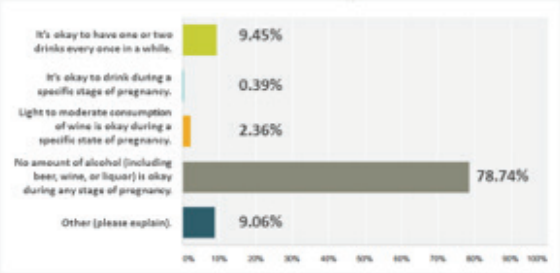
We presented and discussed survey results in the consensus meeting. The PowerPoint slides summarizing results are included below and on the pages that follow.





Survey Question 2

Which of the following best describes your basic message to patients about drinking alcohol during pregnancy?



Question 2 Comments

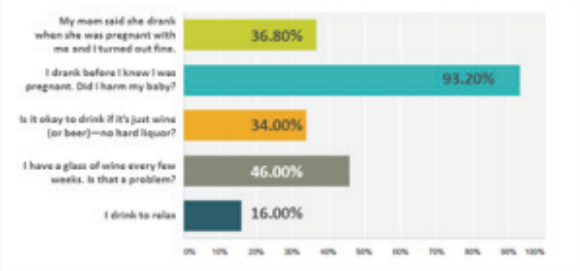
- We do not know if there is a safe level of alcohol consumption during pregnancy; therefore it is best to avoid it entirely.
- We don't know what amount of alcohol is a safe amount to consume during pregnancy. If you had 1 drink every once in a while, that would probably be OK, but I cannot make any guarantees.
- One drink per week after first trimester.
- Light consumption in the 3rd trimester is okay.

Question 2 Comments (cont.)

- One drink per week after first trimester. Sometimes recommend a glass of wine in term patients to help relax and to facilitate sex with partner to promote labor.
- I also try to minimize worry for women who drank in first trimester and didn't know they were pregnant.

Survey Question 3

Which of the following comments or questions do you hear from prenatal patients?

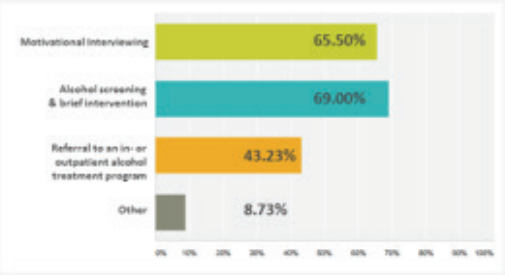


Question 3 Comments

- We have heard all of these comments. Most are concerned that they did drink before knowing they were pregnant in the first 6-8 weeks and want to know if that has caused a problem. We tell them that now that they are aware and that they have hopefully stopped we advise them that no amount is safe. We don't discuss if any damage was already done since we really don't know.

Survey Question 4

Which of the following techniques have you used in working with patients whose amount of drinking concerns you?



Question 4 Comments

- I just keep advising them at each visit.
- Harm minimization (for heavy drinkers, substance abusers).
- Referral to outpatient support program.
- Finding an alcohol treatment program in my area that accepts pregnant women is very difficult.

Survey Question 5

What is your biggest challenge with educating and counseling patients about alcohol use during pregnancy?

- Patients know to deny alcohol. Not sure I get accurate reporting.
- Noncompliance/low support systems.
- Continual misinformation/miseducation coming from patients and their social support networks.
- The few patients who most need to stop drinking are the hardest ones to convince.

Survey Question 5 (continued)

- Reports in the media/news at times that has physicians saying 1-2 glasses of wine during pregnancy is ok.
- Trying to convince someone of a potential risk when many family members drink and apparently had no fetal effects.
- Time and limited referral options.
- I don't feel like I have an effective way to talk about it.

Survey Question 6

How could ARHP support you in educating and counseling patients about alcohol use during pregnancy?

- Having job aids will be good.
- Creating modules to use in interaction.
- Targeting education to younger audiences.
- Providing support materials to guide interviews, counseling and possible interventions.

Survey Question 6 (continued)

- Patient education materials--low literacy.
- Video simulations-pt/provider with best practices using concepts of motivational interviewing and patient engagement.
- Local referral options.

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Appendix B: FASDs Consensus Meeting Agenda

Friday, November 6, 2015
9:00 am – 2:00 pm
Association of Reproductive Health Professionals
Washington, DC

Meeting Goal
To develop expert guidance on patient-centered, culturally competent best practices for frontline providers in counseling patients to prevent FASDs

9:00 am – 9:45 am	Welcome and Introduction	Melissa Werner & Emily Kane Lee
9:45 am – 10:15 am	The FASDs "Landscape"	Susan Astley
10:15 am – 10:45 am	Provider Perspectives	Anne Moore
10:45am – 11:00 am	Break	
11:00 am – 12:15 pm	Discussion 1: Nuanced Messages for Providers: Meeting Patients "Where They Are"	Melissa Werner
12:15 am – 12:30 pm	Break	
12:30 am – 1:45 pm	Working Lunch and Discussion 2: Recommendations for Provider Support and Education	Melissa Werner
1:45 am – 2:00 pm	Summary and Closing	Melissa Werner

Appendix C: FASDs Consensus Meeting Participant List

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Appendix D: FASDs Consensus Meeting Discussion Questions

Discussion 1: Nuanced Messages for Providers: Meeting Patients "Where They Are"

1. What do the ARHP member survey responses tell us about where we need to go at this point in the discussion about FASDs prevention?

2. What does the evidence tell us about dose-response effects related to alcohol consumption?

3. What does/should a harm reduction approach to FASDs prevention look like?

4. What lessons can we glean from prevention messages and approaches used in other health areas (e.g., HIV prevention, injection drug use)?

5. What are evidence-based messages that providers can share with individual patients that incorporate a harm-reduction approach?

6. What does it mean to be patient-centered and culturally appropriate when it comes to FASDs prevention?

Discussion 2: Recommendations for Provider Support and Education

1. What tools or messages can providers use to help patients distinguish between population-based and individual risk?

2. How can providers establish rapport and trust with clients so that clients will be honest about alcohol consumption during pregnancy?

3. What tips do we have for providers when a patient who is an alcoholic (or heavy drinker) is unwilling or unable to change her behavior?

4. What can we recommend as effective approaches to providers for working with different types of patients?
   - The woman who wants to have a glass of wine "to relax"
   - The woman who wants to have a couple of drinks at a celebration (e.g., a wedding)
   - The woman whose family norm is to drink during pregnancy?
   - Other patients?

5. What are some effective ways that providers can respond to these situations?
   - Explaining that a woman doesn't need to terminate because she drank before she knew she was pregnant, and yet you're recommending that she doesn't drink any more now that she knows.
   - "But my mom drank when she was pregnant with me, and I'm fine."
   - Other situations?

Appendix E: Glossary

While the primary intended audience for this report is decision-makers and clinicians involved in FASDs prevention and continuing education for healthcare providers, the Arc and ARHP want to make sure that it is accessible to a broader audience.

Algorithm A flowchart or other aid designed to help clinicians make decisions

Cultural humility An approach that involves recognizing one's own cultural perspective through self-awareness and reflection in order to provide better care for people from diverse backgrounds

Dose-response effects Describes when a little bit of something has a small effect and more has a bigger effect; for example, the greater the exposure to lead a child has, the greater the negative health effects

Evidence-based screener A tool for assessing someone's drinking habits that has research showing its effectiveness, such as the TWEAK, AUDIT, CAGE, and T-ACE screeners

Harm reduction A public health approach that focuses on reducing risks when eliminating risks is not possible

Normalize To help someone see their experience as normal instead of judging them

Stages of Change/Transtheoretical Model A model developed by researchers Prochaska and DiClemente that describes a series of steps people go through in making changes to their behavior

Threshold The minimum or smallest amount needed to create an effect; in this case, there is no known smallest amount of alcohol that is safe to drink during pregnancy

Timing of consumption When in pregnancy a woman drinks alcohol; there is no known time during pregnancy during which it is safe to drink