

*Fetal Alcohol Spectrum Disorders  
Prevention Project*

## The Arc's Needs Assessment Report on Fetal Alcohol Spectrum Disorders

February 6, 2015

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Department of  
Social Work

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## Executive Summary

This report was prepared to fulfill an agreement between The Arc of the United States (The Arc) and the representatives from the Department of Social Work at George Mason University (Mason). This initial phase focused on data cleaning and analysis for a needs assessment conducted under the three-year Fetal Alcohol Spectrum Disorders Prevention Project (FASDs) funded by the US Health Resources and Services Administration (HRSA). The project is currently in its second year of funding.

The methods used to analyze the data included bivariate inferential statistical procedures based on the scaling of the variables. Initial questions included

- ▶ Whether differences occurred in providing information on alcohol use during pregnancy by health professions?
- ▶ If health care professionals/providers did not provide a consistent message on the benefits of alcohol abstinence during pregnancy, during which trimester did this occur?
- ▶ Whether other factors (e.g., region of the country, years of health care professional/provider experience, or size of community) accounted for significant differences in information dissemination.

Findings indicated that overall, health care professionals and providers appear to be providing good information to their clients/patients to avoid the potential for FASDs; however, a few exceptions did exist. Physicians and midwives were not as consistent as other professions (Registered Nurses, Licensed Practical Nurses, Nurse Practitioners, Mental Health and Substance Abuse Therapists and Community Health Representatives) in recommending total abstinence from alcohol during pregnancy. This was especially true during the third trimester when physicians and midwives believed that some amount of alcohol was safe.

It is recommended, based on the findings that The Arc continue their efforts to work closely with national physician and midwife organizations to better assure the consistent messaging that no alcohol consumption during pregnancy at any time provides the best way to prevent FASDs.

To better understand The Arc's future educational efforts we suggest engaging in an evaluability assessment to assure that:

- ▶ The education program is based on a consistent and coherent program theory.
- ▶ Evaluation procedures and measures are consistent with HRSA reporting requirements.
- ▶ Information is collected so key stakeholders' questions can be answered. Key stakeholders include The Arc, Health Resources and Services Administration (HRSA), Centers for Disease Control and Prevention (CDC), National Institute on Alcohol Abuse and Alcoholism (NIAAA), Indian Health Service (IHS), Substance Abuse and Mental Health Services Administration (SAMHSA), and National Institute of Health (NIH).

## Background on the Project

In the fulfillment of an agreement between The Arc of the United States (The Arc) and the Department of Social Work at George Mason University (Mason), we conducted the following work activities related to the three-year Fetal Alcohol Spectrum Disorders Prevention Project (FASDs). The project was funded by HRSA and awarded to The Arc and is currently in its second year of funding. This Phase I contract covered the period of August 2014 through January 2015.

The tasks provided during the Phase I contract included:

1. Cleaning and preparing the FASDs dataset for analysis
2. Conducting bivariate and multivariate analysis of the FASDs dataset
3. Providing summaries, tables and charts of significant findings for use by the Arc in their print and online publications
4. Preparing one manuscript for submission to an appropriate peer-reviewed journal

This project, and the related data analysis, is based on numerous evidence-based studies, that abstinence from consuming alcohol during an entire pregnancy provides the only assurance of avoiding having a child born free of FASDs (Sokol, Delaney-Black, & Nordstrom, 2003). The consistent messaging of this fact by health care professionals and providers to women who are either pregnant, planning on becoming pregnant, or of childbearing age remains essential to reducing the risk of FASDs (Zoorob, Aliyu, & Hayes, 2010).

Phase I data analysis included a needs assessment in order to identify trends and inform The Arc, and document needs and develop an education plan to inform health care professionals and providers. This is consistent with Rossi, Lipsey and Freeman's (2003) approach of using an evaluation pyramid in which need is first identified.

## Methods

The dataset was collected and compiled by The Arc during the first year of the project. The sample was purposive, with most respondents reached through mailing lists purchased or obtained from national organizations representing physicians, nurses, and midwives and federal departments that fund FASDs prevention programs.

### **Purchased Email Lists**

- ▶ Association of Women’s Health, Obstetric and Neonatal Nurses (AWHONN)
- ▶ Medical Marketing Service, Inc.

### **Obtained Email Lists**

- ▶ Association on American Indian Affairs
- ▶ Association of Reproductive Health Professionals
- ▶ National Association of County and City Health Officials
- ▶ The Centers for Disease Control and Prevention FASDs Listserv
- ▶ Substance Abuse and Mental Health Services Administration FASD Center for Excellence Listserv
- ▶ National Institutes of Health Listserv
- ▶ National Association of FASD State Coordinators Listserv
- ▶ Maine Department of Health and Human Services Listserv
- ▶ New York City Health and Hospitals Corporation

The initial dataset of respondents (n=460) was cleaned to assure that responses did not exceed the range of possible scores. Some of the values in the categorizing variables (e.g., profession) were combined in order to improve the robustness of the data analyses (Cohen, 1988). For example, all physicians such as internists, pediatricians, family practitioners, and obstetricians and gynecologists are combined into one group. A variety of bivariate analyses were conducted, based on the levels of measurement used and the types of questions being asked.

The data was first analyzed to identify some overall initial trends by professions. There are six categories for profession: physicians, nurse practitioners, registered nurses, counselors/therapists, midwives, and all other professions (i.e., dietitians and administrators). This was followed with a meeting of representatives of Mason and The Arc to identify additional relationships between variables for analysis that included:

- ▶ Which health care professional/provider is responsible for educating clients/patients regarding alcohol use, asking clients/patients about their alcohol use during pregnancy, and screening clients/patients for alcohol use during their appointment?
- ▶ What do health care professionals and providers say to pregnant clients/patients who report consuming alcohol during pregnancy versus which trimester of pregnancy?
- ▶ What do health care professionals and providers say to pregnant clients/patients reporting heavy drinking versus who is responsible to educate, ask, and screen clients/patients?
- ▶ How well do health care professionals and providers feel they are prepared to discuss alcohol abstinence during pregnancy versus other professionals?

## Findings

This section is organized by bullet points in order to increase the use and dissemination of the findings by The Arc program. The initial review of the dataset for how different health care professionals and providers disseminated information on alcohol use during pregnancy revealed the following results:

- ▶ Some obstacles for discussing alcohol use with clients/patients are reported by health care professionals/providers. Identified obstacles are as follows:
  - Time constraints
  - Client/patient denial of alcohol use
  - Discomfort with the issue
  - Unsure who is responsible for screening/discussing issue
  - Need more training
  - Lack of referral sources
  - Lack of financial reimbursement
  - Unsure about the research on FASDs

*Figure 1 (Appendix A) summarizes obstacles for discussing alcohol use. Each percentage represents persons who agreed with the stated obstacle.*

- ▶ For physicians, the odds of answering alcohol consumption is safe during any period of pregnancy are 4 times larger than the odds for other professions ( $p=0.004$ ). (Therefore, physicians are 4 times more likely to provide inaccurate information to their clients/patients compared with other professionals).
- ▶ Physicians are significantly more likely to agree that occasional alcohol consumption is safe during the second ( $p=0.003$ ) and third trimesters of pregnancy ( $p=0.001$ ). If the analysis includes only physicians who are responsible for educating, asking or interviewing, or screening clients/patients about their alcohol use, then this effect disappears.
- ▶ Midwives are 2.95 times more likely to agree that occasional alcohol consumption is safe during the third trimester of pregnancy ( $p=0.009$ ). (Therefore, midwives are 2.95 times more likely to provide inaccurate information to their clients/patients). Even after the analysis excluding midwives who are not responsible for educating, asking or interviewing, or screening clients/patients about their alcohol use, this effect persists ( $p=0.013$ ).
- ▶ While midwives are more likely to have a lenient attitude towards drinking during pregnancy, they are more likely to say that they are prepared to conduct alcohol risk screening ( $p=0.012$ ) and educate non-pregnant patients about the effects of alcohol on fetuses ( $p=0.034$ ).
- ▶ Nurses are significantly less likely to agree that occasional alcohol consumption is safe during the second trimester of pregnancy ( $p=0.04$ ).
- ▶ None of the people working in Indian Health Services answered that alcohol is safe during pregnancy regardless of any stage of pregnancy.
- ▶ Health care professionals/providers were asked about their roles in the following activities:

- Educating clients/patients regarding alcohol use:
  - Registered nurse (n=204)
  - OBGYN (n=199)
  - Nurse practitioner (n=182)
  - Midwife (n=165)
  - Family practitioner (n=157)
- Asking clients/patients about alcohol use during intake interview or via questionnaire:
  - Registered nurse (n=242)
  - OBGYN (n=188)
  - Nurse practitioner (n=172)
  - Midwife (n=161)
  - Family practitioner (n=151)
- Screening clients/patients for alcohol use during appointment:
  - Registered nurse (187)
  - OBGYN (n=187)
  - Nurse practitioner (n=159)
  - Midwife (n=155)
  - Family practitioner (n=136)
- ▶ 82% (n=252) of respondents answered that they were responsible for educating, asking or interviewing, or screening clients/patients about their alcohol use.
  - Proportions of responsible persons for each profession included:
    - 76% of physicians
    - 90% of nurse practitioners
    - 80% of registered nurses
    - 79% of therapists, counselors, and case managers
    - 100% of midwives
    - 58% of other professions

*Figure 2 (Appendix B) shows the percentages of health care professionals and providers who report they are responsible for educating, asking or interviewing, or screening clients/patients about their alcohol use grouped by professions.*

- ▶ Significant differences were identified across the different health care professions on whether they agreed or disagreed on several statements including:
  - FASDs occur at similar rates in all socioeconomic groups
  - FASDs occur at similar rates in all cultures and ethnic groups
  - Current research clearly describes the impact of alcohol on a fetus
  - The Affordable Care Act (ACA) provides resources for my work to screen patients for alcohol use

*Figure 3 (Appendix C) summarizes each profession's attitudes/knowledge toward FASDs. Each percentage represents persons who agreed with the stated attitude and knowledge.*

Several relationships did not result in significant findings, including:

- ▶ The types of employment site where people work (e.g., clinic, hospital, community-based center, etc.) were not associated with their perspectives on alcohol consumption
- ▶ The regions of the country where people work were not associated with their perspectives on alcohol consumption
- ▶ Whether their place of employment had a written policy or expectations about discussing alcohol use with pregnant and non-pregnant patients
- ▶ Whether a person is responsible for educating, asking or interviewing, or screening clients/patients about their alcohol use, is not associated with the person's perceived preparedness for dealing with alcohol related matters
- ▶ The size of community in which the health care professional/provider worked did not result in any significant differences regarding whether they thought any alcohol consumption was safe during pregnancy
- ▶ No significant trends were identified among any of the professions when comparing the length of time practicing and their dissemination of information concerning alcohol consumption during pregnancy

## Implications and Recommendations

It does appear many physicians and midwives could use more education to assure that the message of recommending no alcohol consumption during anytime in a pregnancy is consistently delivered. This was particularly true if the client/patient was in the third trimester.

As The Arc develops additional evaluation methods, we suggest that items such as questionnaires be briefer. In the current study, participants began to drop off at question #22 (page 5 of 14), this continued through the remainder of the questionnaire.

In developing the Phase II processes, the evaluators from Mason suggest an approach based on Rossi, Lipsey and Freeman's (2003) evaluation pyramid. This approach begins with a detailed needs assessment (as developed in Phase I), which leads into an evaluability assessment. This evaluability assessment shall serve as the foundation for future evaluative activities as it assures the development of an explicit program theory. Upon request from The Arc for services provided between January and August 2015 include the following tasks:

1. Reviewing HRSA/The Arc created milestones, and create metrics to measure and report progress toward achieving the milestones
2. Creating a process to evaluate the use of The Arc website on various materials and activities related to the FASDs Prevention Project
3. Building a process and related procedure to improve the capacity to improve follow-up of project participants
4. Identifying how to improve use of materials by physicians based on a trend analysis collected data
5. Creating a more effective procedure for mini-grant recipients (chapters of The Arc) to report their progress, implementation, and use of promising/best practices contained in the FASDs Prevention Project toolkit
6. Forwarding the identified most rigorous published FASDs evidence to The Arc to include in educational materials for health care professionals/providers

An initial review of the program logic model, submitted as part of the HRSA grant application, was reviewed. Our preliminary impressions are that this does serve as a sufficient beginning point; however, it can be further developed in the Phase II activities in order to reflect the contributions from a broader group of key stakeholders.

Representatives of The Arc stated several questions they will want addressed as they continue into the second and third year of the HRSA cooperative agreement. These questions centered around:

- ▶ How do the various health care professionals and providers find their information to inform their practice?
- ▶ How can The Arc influence the learning of these health care professionals and providers?
- ▶ How can The Arc influence change in health care professional and provider behavior?

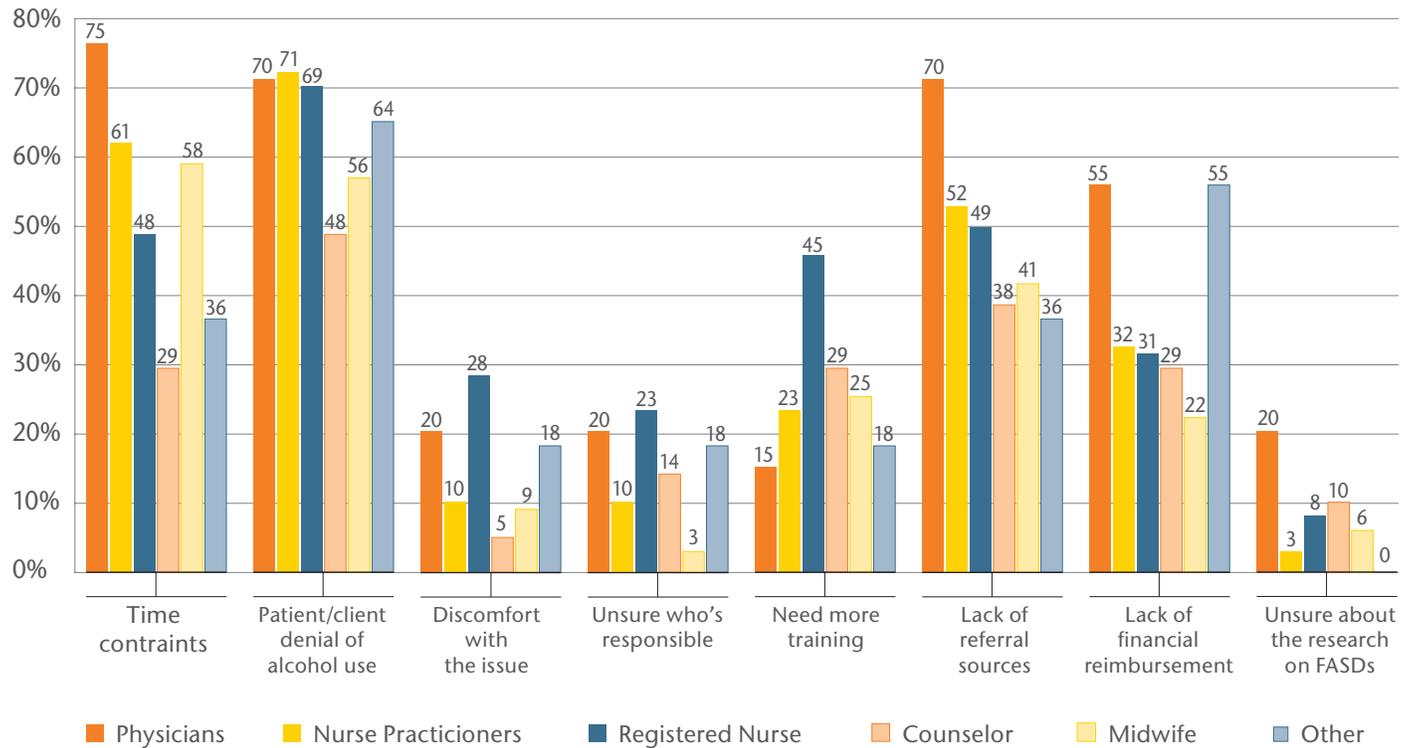
- ▶ How can the impact (long-term outcomes) of project efforts be measured more effectively?
- ▶ How can The Arc's FASDs Prevention Project website function more effectively, including:
  - How to drive people to the site?
  - Which products lead to behavior change?
  - Which resources are used?

The primary limitation in this analysis was that the sample was not randomized; however, given that mailing lists from professional organizations were used, it likely was reasonable representative.

## Appendix A:

### Reported Obstacles for Discussing Alcohol Use with Clients/Patients by Health Care Professionals/Providers

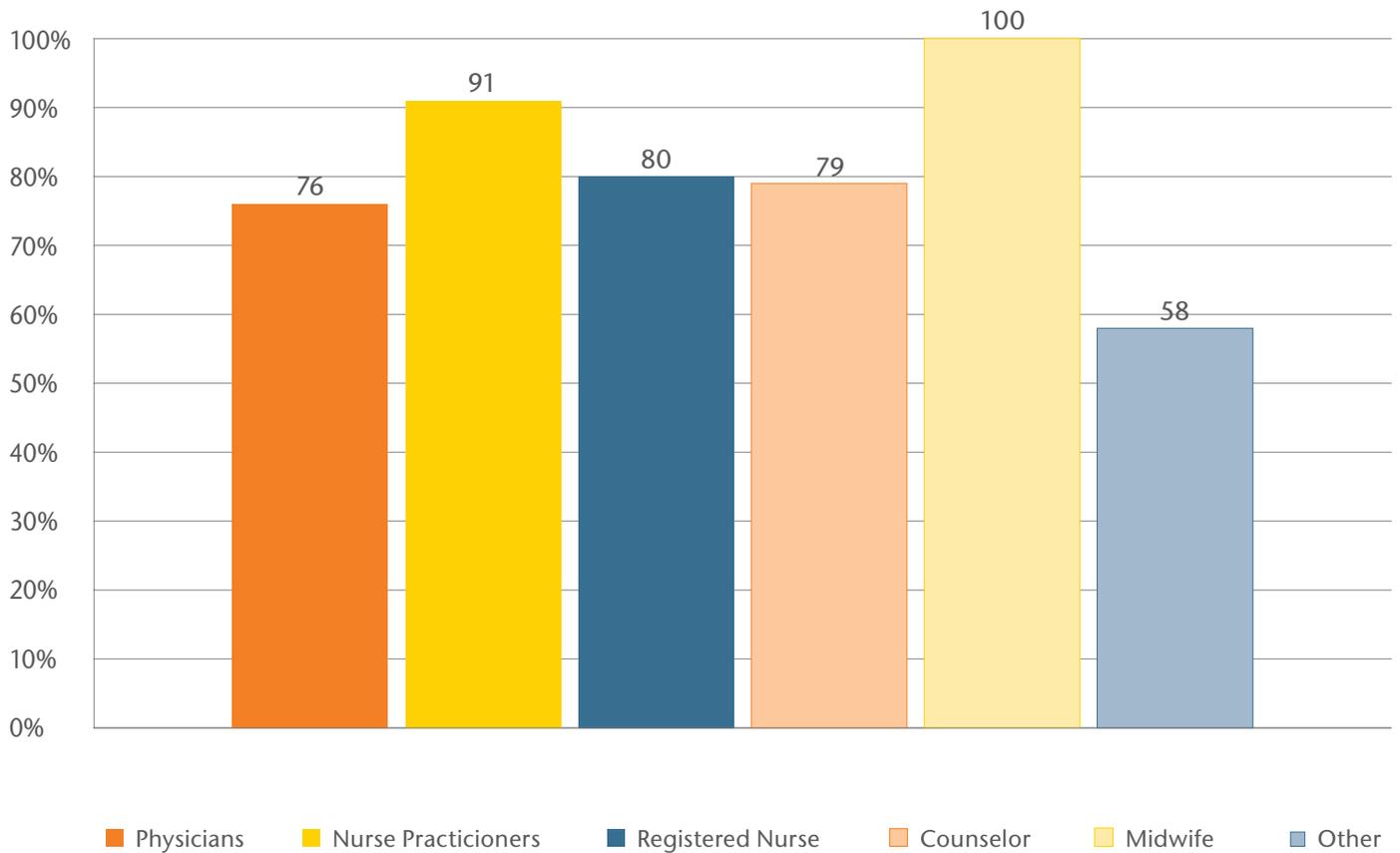
Figure 1: Reported obstacles for discussing alcohol use with client/patient by health care professionals/providers



## Appendix B:

### Percentage of Health Care Professionals/Providers Responsible for Clients/Patients Education

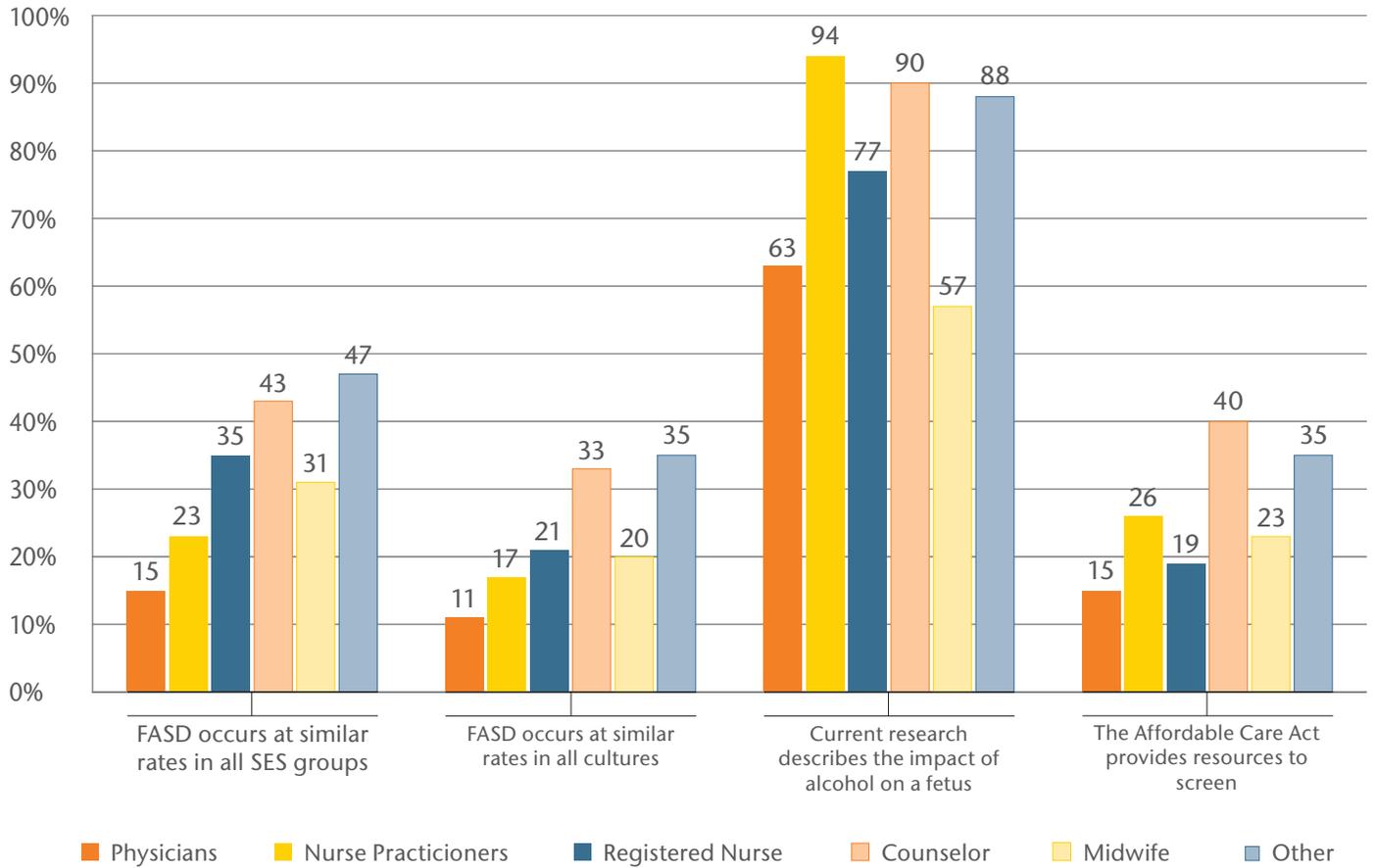
Figure 2: Percentage of health care professionals/providers responsible for educating, asking or interviewing, or screening clients/patients about their alcohol use



## Appendix C:

### Health Care Professional/Provider Attitudes/Knowledge towards FASDs

Figure 3: Percentage of health care professionals/providers who agreed with the statement regarding attitudes/knowledge toward FASDs



## Appendix D:

### Rigorous Research Studies

Floyd, R. L., Weber, M. K., Denny, C., & O'Connor, M. J. (2009). Prevention of fetal alcohol spectrum disorders. *Developmental Disabilities Research Reviews, 15*, 193-199.

This article reviews evidence-based alcohol screening and brief intervention that are in place to reduce problem drinking and an alcohol-exposed pregnancy (AEP). The article also highlights a report of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect that introduces effective intervention efforts to reduce AEPs. The authors suggest the use of evidence-based alcohol screening tools and brief counseling for women at risk for an AFP, as well as other effective population-based strategies to help achieve future alcohol free pregnancies.

Riley, E. P., & McGee, C. L. (2005). Fetal alcohol spectrum disorders: An overview with emphasis on Changes in brain and behavior. *Experimental Biology and Medicine, 230*, 357-365.

The authors introduce a wide range of neurological deficits and behavioral problems found in children prenatally exposed to alcohol. They argue that intervention needs to go beyond the affected individual to prevent future cases and that prevention efforts need to be aimed at high-risk groups, which should be a high priority in terms of public health.

Stade, B.C., Bailey, C., Dzenoletas, D., Sgro, M., Dowswell, T., & Bennett, D. (2009). Psychological and/or educational interventions for reducing alcohol consumption in pregnant women and women planning pregnancy. *Cochrane Database of Systematic Reviews*, issue 2.

doi: 10.1002/14651858.CD004228.pub2.

Stade and colleagues review four randomized controlled studies examining the effectiveness of psychological and educational interventions for reducing consumption of alcohol among pregnant women, or women planning for pregnancy. Results from individual studies suggest that interventions may encourage women to abstain from alcohol on pregnancy. However, results were not consistent, and due to the paucity of studies, the number of total participants, the high risk of bias of some of the studies, and the complexity of interventions, they could not determine the type of intervention which would be most effective in increasing abstinence from, or reducing the consumption of, alcohol among pregnant women.

Sokol, R. J., Delaney-Black, V., & Nordstrom, B. (2003). Fetal alcohol spectrum disorder. *JAMA, 290*, 2996-2999. doi: 10.1001/jama.290.22.2996

Sokol and colleagues summarize what have been reported with respect to fetal alcohol terminology, identification, effects, prevalence, and prevention of exposure. They argue that maternal alcohol use is the leading preventable cause of birth defects and developmental disorders. They also emphasize how fetal alcohol exposure is routinely under-identified.

Zoorob, R., Aliyu, M.H., & Hayes, C. (2010). Fetal alcohol syndrome: Knowledge and Attitudes of family medicine clerkship and residency directors. *Alcohol, 44*, 379-385.

This study examine knowledge and attitudes of family medicine clerkship and residency directors by conducting a self-administered anonymous survey (N=571). Although both groups of residency and clerkship directors show high level of knowledge of FASDs and of alcohol counseling practices for pregnant women, the study found a gap in curriculum for teaching FASDs between pre-doctoral and graduate levels of medical education.

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