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Centers for Disease Control and Prevention

National Center on Birth Defects and Developmental Disabilities

Records of the Meeting of the

**National Task Force on
Fetal Alcohol Syndrome and Fetal Alcohol Effect**

September 12-13, 2007

**Meeting held at the
Global Communications Center
Centers for Disease Control and Prevention
Atlanta, Georgia**

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**Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities
National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect**

**Minutes of the Meeting
September 12-13, 2007**

A meeting of the National Task Force on Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) was convened on September 12-13, 2007 in Atlanta, GA by the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD).

Wednesday, September 12, 2007

Call to Order

Jean A. Wright, MD, MBA, Chair, called the meeting to order at 9:00 a.m. and welcomed those present. She thanked everyone for attending the final face-to-face meeting of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (NTFFAS).

Introduction of Task Force Members, Liaisons, and Attendees:

Chair: Jean A. Wright, MD, MBA, Backus Children's Hospital, Savannah, GA
Acting Executive Secretary: R. Louise Floyd, DSN, RN, Fetal Alcohol Syndrome Prevention Team, DBDDD, NCBDDD, CDC
Designated Federal Official: Mary Kate Weber, MPH, Fetal Alcohol Syndrome Prevention Team, DBDDD, NCBDDD, CDC
Standing Member: Kenneth R. Warren, PhD, National Institute on Alcohol Abuse and Alcoholism (NIAAA), National Institutes of Health (NIH) Washington, DC

Task Force Members Present:

Kristen L. Barry, PhD, Department of Veterans Affairs and the University of Michigan, Ann Arbor, MI
James E. Berner, MD, Alaska Native Tribal Health Consortium, Anchorage, AK
Carole W. Brown, EdD, Catholic University of America, Washington, DC
Grace Chang, MD, MPH, Brigham and Women's Hospital, Boston, MA
Mary C. DeJoseph, DO, Philadelphia College of Osteopathic Medicine, Philadelphia, PA
Lisa A. Miller, MD, MSPH, Department of Public Health and Environment, Denver, CO
Colleen A. Morris, MD, University of Nevada School of Medicine, Las Vegas, NV
Mary J. O'Connor, PhD, ABPP, David Geffen School of Medicine at the University of California, Los Angeles (UCLA), Los Angeles, CA (*via phone*)
Melinda M. Ohlemiller, BA, MA, Saint Louis Arc and parent of a twelve-year-old with FAS, St. Louis, MO
Heather Carmichael Olson, PhD, University of Washington FAS Diagnostic Clinic, Washington State FAS Diagnostic and Prevention Network, Seattle, WA

Liaison Representatives Present:

American Academy of Pediatrics (AAP): George Brennenman, MD, FAAP

American College of Obstetrics and Gynecology (ACOG): Robert J. Sokol, MD, Department of Obstetrics and Gynecology, C.S. Mott Center for Human Growth and Development, School of Medicine, Wayne State University, Detroit, MI

March of Dimes (MOD): Karla Damus, PhD, Washington, DC

The Arc: Sharon Davis, PhD, Health Promotion and Disability Prevention Committee, Silver Springs, MD

Center for Science in the Public Interest (CSPI): George A. Hacker, JD, Alcohol Policy Project, Washington, DC

Liaison Representatives Absent:

National Organization on Fetal Alcohol Syndrome (NOFAS): Kathleen T. Mitchell, MHS, LCADC, Washington, DC

Other Attendees:

Kendall Anderson, MPH, Deputy Chief, Prevention Research Branch, DBDDD, NCBDDD, CDC

Jacquelyn Bertrand, PhD, Developmental Psychologist, FAS Prevention Team, PRB, DBDDD, NCBDDD, CDC

Coleen Boyle, PhD, Director, DBDDD, NCBDDD, CDC

Elizabeth Parra Dang, MPH, Behavioral Scientist, FAS Prevention Team, PRB, DBDDD, NCBDDD, CDC

Clark Denny, PhD, Epidemiologist, FAS Prevention Team, PRB, DBDDD, NCBDDD, CDC
Yvette Dominique, Battelle Contractor

Patricia P. Green, MSPH, Epidemiologist, FAS Prevention Team, PRBM DBDDD, NCBDDD, CDC

Melissa Hogan, Battelle Contractor

Catherine A. Hutsell, Health Education Specialist, FAS Prevention Team, PRB, DBDDD, NCBDDD, CDC

Treana Johnson-James, Battelle Contractor

Karen Howell, MD, Emory University School of Medicine

Eileen Miles, MPH, Battelle Contractor

Christine E. Prue, MSPH, PhD, Chief, Prevention Research Branch, DBDDD, NCBDDD, CDC

Esther Sumartojo, PhD, MSc, Associate Director for Science and Public Health, NCBDDD, CDC

James Tsai, MD, Epidemiologist, FAS Prevention Team, PRB, DBDDD, NCBDDD, CDC

Myra Tucker, Division of Adult and Community Health, NCCDPHP, CDC

Leslie O'Leary, PhD, Epidemiologist, Surveillance Team, Birth Defects Branch, DBDDD, NCBDDD, CDC

Jacqueline Vowell, Committee Management Specialist, FAS Prevention Team, PRB, DBDDD, NCBDDD, CDC

Stephanie Wallace, Writer-Editor

Opening Remarks

R. Louise Floyd, DSN, RN

Dr. Louise Floyd also thanked everyone for their presence at this final meeting. She expressed her gratitude to the members of the team who helped put together the meeting materials. She noted that the group would discuss two excellent documents during this meeting and stressed the importance of fully vetting both, given that the NTFFAS would have only one additional opportunity at the upcoming conference call in October to finalize these documents.

Overview of the Prevention Report

Mary Kate Weber, MPH

Ms. Weber indicated that she was asked to speak on behalf of the Prevention Working Group to present an overview of the draft report titled *Reducing Alcohol-Exposed Pregnancies*. She pointed out that that this report was the result of the effort of several Task Force members and consultants who are experts on many of the topics addressed within the report: Task Force members: Lisa Miller, MD, MSPH; Raul Caetano, MD, PhD, MPH; Mary O'Connor, PhD; Grace Chang, MD, MPH; Kristen Barry, PhD; and Mary DeJoseph, DO. Research Triangle Institute (RTI) International staff members: Frank DeStefano, MD, MPH; Suzanne Dolina, MPH; and Kimberly Leeks, PhD, MPH. CDC staff members: Louise Floyd, DSN, RN; and Mary Kate Weber, MPH. Ms. Weber expressed gratitude to the Task Force members and RTI staff for pulling this draft report together in a very short period of time.

With respect to the background of the report, Ms. Weber indicated that around 2004, a Task Force Working Group on Prevention was established. The main goal of the working group was to develop a report on evidence-based strategies for FASD prevention. Several subsequent Task Force meetings focused on prevention, highlighting both population-based and individual-level strategies. Additionally, the Task Force began to collaborate with CDC's *Community Guide* staff who works with the U.S. Community Preventive Services Task Force (USPSTF) to develop recommendations on prevention on a wide array of health topics, alcohol misuse being one of these. Thus, a collaboration was formed with the *Community Guide* through a contract with RTI International. The Task Force Working Group worked with RTI in the development of a report focused on community-based FASD interventions that was presented at the last Task Force meeting. The findings from the RTI report, along with information presented by Dr. Evelyn Whitlock on the recommendations of the USPSTF on behavioral counseling interventions for alcohol misuse, laid the groundwork for the report to be presented. Also, at the last Task Force meeting, a writing group was formed to help summarize and pull together the current evidence on FASD prevention strategies.

Ms. Weber indicated that Task Force members should have received a copy of the most recent version of the report in the packet they received upon arrival. A few minor changes were made to the alcohol dependence section and a draft executive summary was also added to the newest version. The main goals of the report are to: review evidence-based prevention strategies; develop recommendations based on the evidence; identify prevention research and practice gaps; and propose future research directions.

Essentially the report contains the following sections:

- Executive Summary
- Background & Epidemiological Overview
 - Scope of the problem
 - Commitment to FASD prevention
 - Examples of existing prevention guidelines and recommendations
- Alcohol Screening
- Current Evidence (the main section)
- Universal Prevention
- Selective & Indicated Prevention
 - Brief Interventions: General Population, Pregnant and Non-Pregnant Women
 - Indicated Interventions: Women with alcohol dependence
- Recommendations (follow each of the sub-sections within the Current Evidence section)
- Potential Strategies for Future Research
- Summary

As the data indicates, alcohol use during pregnancy continues to be a serious public health problem. One in eight pregnant women drink alcohol during pregnancy and 2% of them binge drink. Also, many pregnant women do not know they are pregnant until the second or third month, so they may continue to drink at risk levels and almost 50% of pregnancies in the United States are unplanned. With data from the Behavioral Risk Factor Surveillance System (BRFSS) survey's 2002 family planning module, CDC examined alcohol consumption patterns of women who might become pregnant. Fifty-four percent of these women reported any alcohol use (in the past 30 days). More striking is that 12.4% of these women report binge drinking, which makes them at particular risk for an alcohol-exposed pregnancy (AEP). Ms. Weber noted that these data only report on women reporting no contraception use. Women using ineffective birth control methods were not included, primarily because this would require more in-depth questioning on how woman use their birth control method. Hence, these data are most likely underestimating the true number of women at risk. Overall, these data indicate that reducing alcohol-exposed pregnancies is an important public health problem and emphasize the importance of developing effective strategies to address the diverse needs of women of childbearing age: those who are pregnant, who are trying to become pregnant or who might become pregnant.

While the data do not paint a good picture, there is some good news. FASDs are preventable. Progress has been made in the field of prevention over the past 30 years, effective strategies to prevent alcohol-exposed pregnancies exist, and it is time to spread the word about what works. More good news is that there has been a concerted effort to address prevention of FASDs at the federal level. There are a variety of federal prevention efforts that have been underway since 1973. Funding has mainly gone to NIAAA, CDC, and the Substance Abuse and Mental Health Services Administration (SAMHSA). These included the creation of the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS) in 1996, which brought various federal agencies together to collaborate and share ideas across agencies on FAS. Later, the National Task Force was created, which included representatives in the fields of FASD and alcohol from across disciplines and organizations, including professional organizations and

parent groups. In 2002, the Task Force released its first recommendations. Among these were specific recommendations on prevention and the Prevention Working Group also was created. In addition, in 2001, SAMHSA's FASD Center for Excellence was established which recently has been re-funded and will continue into the future.

Before getting into the evidence, the writing group felt that it was important to highlight some of the prevention recommendations and guidelines that are already in the field in terms of preventing AEPs. The 1996 Institute of Medicine (IOM) report looked at FAS comprehensively in terms of the epidemiology, diagnosis, prevention, and treatment aspects of the condition and includes recommendations specific to prevention. The CDC referral and diagnostic guidelines also devote a section to prevention, emphasizing the importance of screening and brief intervention. The American Academy of Pediatrics (AAP) and the American College of Obstetrics and Gynecology (ACOG) also have published guidelines related to alcohol use in pregnancy. ACOG also recently developed a toolkit providing guidelines to health professionals on how to screen and intervene with women of childbearing age, including both pregnant and non-pregnant women. Finally, the Surgeon General's Advisory, which this Task Force and its members were instrumental in moving forward, was released in 2005, providing guidance on preventing FASD to all women of childbearing age.

Also highlighted in the prevention report are a number of other broader-based recommendations and efforts focused on screening and brief intervention. Based on a systematic review of the literature, the United States Preventive Services Task Force (USPSTF) recommended that health providers screen all adult patients in primary care settings for alcohol misuse and provide counseling interventions for those identified as risky or harmful drinkers. This guide, developed in a collaborative effort between CDC and the National Business Group on Health, translates clinical guidelines and medical evidence to assist large employers with the information to help them select, define, and implement preventive medical benefits in over 40 different health areas. This purchaser's guide includes support for alcohol screening for adults and for women who are pregnant or planning a pregnancy. In addition, since January 2007, doctors have been able to bill Medicaid for alcohol and drug screening and brief intervention services using the new Center for Medicare and Medicaid billing codes. Also, SAMHSA currently funds 17 state-based screening, brief intervention, referral, and treatment programs (11 SBI cooperative agreements and 12 college-based SBI programs).

Another section of the prevention report focuses on alcohol screening. Before intervening with a woman at risk for an AEP, screening for alcohol use is essential. Screening with a valid tool is recommended. There are a variety of tools to choose from; however, they have not all been effective with female populations. Currently, the recommended screening instruments for identifying pregnant and non-pregnant risk drinkers include the T-ACE, TWEAK, and AUDIT-C for women. The CRAFFT is a tool used to assess substance use problems with adolescents. These tools, including the specific screening questions, are outlined in the report because the group felt that the reader should have the actual questions at their disposal right away.

In thinking about the issue of prevention, early on the Prevention Working Group agreed on the following assumptions: 1) strategies must be evidence-based or considered best practice; 2) consideration should be given to the full spectrum of prevention strategies; and 3) all women of childbearing age at risk for an AEP should be targeted. The effective prevention strategies

outlined in this report are categorized using the prevention framework previously adapted by the IOM Committee to Study Fetal Alcohol Syndrome in 1996. The following framework helped guide the writing group’s thinking in how they approached outlining the evidence:

Universal	Targeted to general public; focus on reductions in per capita alcohol consumption	Warning labels, taxation on alcohol, limited hours of sale
Selective	Directed at populations who may be at greater risk for an outcome because they are members of a group found to be at greater risk than the general population	Screening of women of childbearing age, targeted programs to women of childbearing age
Indicated	Targets the highest risk individuals	Women who have had a previous alcohol-exposed pregnancy, women drinking at high levels and pregnant; women who are already dependent and need specialized treatment

With respect to universal prevention, examples of population-based efforts include the *Community Guide*, which is coordinated by CDC. The Guide conducts systematic reviews of population-based programs. The Task Force on Community Preventive Services makes recommendations on the use of population-based public health programs and policies based on the reviews conducted by the Guide teams to identify what practices have worked to improve health, and to identify those that have not been researched adequately to help inform the public health agenda. The Task Force on Community Preventive Services recently selected “excessive alcohol use” as a priority topic area for systematic review. Although the reviews are not yet completed, proposed interventions to be evaluated include: enhanced enforcement of laws prohibiting illegal sale of alcohol to minors, retail outlet density and zoning restriction, limiting alcohol advertising exposure, and increased alcohol taxes. In 2003, the World Health Organization (WHO) Alcohol and Public Policy Group (APPG) conducted an extensive review of the literature that focused on 31 alcohol policy-relevant prevention strategies and interventions, many of which were population-based. These were further classified into seven categories: 1) regulating physical availability of alcohol, 2) pricing and taxation, 3) altering the drinking context, 4) education and persuasion, 5) regulating alcohol promotion, 6) drinking-driving countermeasures, and 7) treatment and early intervention.

The evidence on universal interventions in actually preventing FAS or FASD, however, is quite limited. A few examples of studies using a universal approach to prevent FASDs include the following:

- Bowerman (1997) assessed the use of an alcohol ban on alcohol possession in an Alaskan community. He found a significant decrease noted in first trimester alcohol abuse (-32%).
- Regarding labeling, Hankin (1993, 1996) looked at alcohol consumption rates by inner-city African American women attending a prenatal care clinic. After implementation of the label law, there was a significant decrease among non-risk drinkers; however, no

decrease in alcohol consumption was detected among heavier drinkers, which suggested that this may have a limited impact on women at greatest risk for having a child with an FASD.

- Glik (2001) published a study of a mass media (e.g., posters and tear-off cards) which found an overall increase in knowledge and awareness of the risks of alcohol use during pregnancy among African American and Latina adolescents.

Ms. Weber noted that while the recommendations were in draft form at this time, the group would spend more time during this meeting continuing to develop them, possibly adding others. She reviewed the recommendations, which are as follows:

1. Better measure the impact of universal prevention strategies and policies on women's alcohol use and pregnancy outcomes.
2. Development of better methods for evaluation of strategies not yet deemed effective due to lack of evidence (e.g. point of service, school-based) but play an integral part in efforts to prevent FASDs in terms of education and public awareness.

Selective and indicated prevention strategies are more targeted and intensive compared to universal strategies and fall along a continuum based on the severity of the problem. In reviewing the literature, the science basically led the group to brief alcohol interventions as the most promising approach to reducing alcohol use. The effectiveness of brief interventions has been demonstrated in multiple settings and with specific population groups. Those highlighted in the draft report include: The general population (e.g., primary care, emergency, and college settings); pregnant women; and preconceptional women. Seven systematic reviews of brief intervention (BI) are cited in the report. The most recent systematic review done in the area of BI in primary care settings was the 2004 U.S. Preventive Services Task Force (USPSTF) report on screening and behavioral counseling interventions for alcohol misuse. The author of this report presented at the last NTFFAS meeting. The review, which identified 12 studies that met the necessary criteria, found good evidence that screening can accurately identify patients at risk and brief interventions with follow-up produce small to moderate reductions in alcohol use that are sustained over 6-12 month periods or longer. The NTFFAS could not recommend screening for adolescents, given that the evidence at the time was limited.

Some of the key elements of the brief interventions identified in the USPSTF review, based on Dr. Whitlock's presentation during the last meeting, are that the studies in this review were typically brief, multi-contact interventions with repeat visits that extended over 2-12 months. Goal setting was often used as a tool within the interventions along with feedback, advice, and on-going assistance. The USPSTF review also stressed that additional staff or systems support were required for many of these studies. Staff training was provided ranging from 15 minutes to 2.5 hours. Research staff often conducted the assessments to identify at-risk alcohol users outside of the routine clinical encounter and also often summarizing assessment results and supplied intervention materials and follow up staffing. Additionally, the availability of referral sources for more seriously affected drinkers is an implicit need. The topic of "alcohol misuse" has been prioritized by the USPSTF for updating. The review for this will begin in late 2007 or early 2008.

Most of the interventions in emergency medical settings focus on patients presenting with injuries. The emergency medical setting essentially offers a window of opportunity when the individual may be more vulnerable and more open to seeing the connection between current consequences and his / her drinking behaviors and perhaps may be more motivated for change. A recent systematic review identified four studies that demonstrated positive outcomes for emergency department-based interventions. For those who received the interventions, there were reported reductions in alcohol use and heavy episodic drinking. Also, two of the studies showed that BIs in emergency rooms were effective at increasing referrals to treatment. Overall, studies also reported lower incidence in alcohol-related injuries, drinking and driving, and alcohol-related problems. BIs in emergency medical settings have been shown to be effective. This may be a potential area for further research in reaching women of childbearing age.

Drinking among college students is a serious problem, especially in terms of binge drinking. College settings are another place where brief interventions have been shown to be effective at in the areas of both prevention and treatment. Some examples of successful programs include the Alcohol Skills Training Program (ASTP) and Brief Alcohol Screening and Intervention for College Students (BASICS). ASTP is a cognitive behavioral alcohol prevention program designed to teach students basic principles of moderate drinking and ways to cope with high-risk situations and excessive drinking. The ASTP program has shown a reduction in drinking rates and associated problems at both 1 and 2 year follow-ups. Also, the one session ASTP format has been found to be comparable to a 6-session format in reducing alcohol use. BASICS consists of an individualized assessment and feedback intervention in two 50-minute sessions. Several studies have shown the effectiveness of this program, with recent results indicating that participants who receive the program have significantly greater reductions in negative alcohol-related consequences and lower reported drinking quantities compared to the control group over a 4-year follow-up period. This is another area for future research that should be considered when intervening and treating college aged women who may be at risk for AEP.

One of the limitations when looking at studies across these settings is that analyses by gender or age is not often provided in the literature. The following recommendation was posed in response to this limitation:

3. Assure that intervention studies on alcohol misuse, abuse, and dependence include analyses of gender, age, and pregnancy outcomes, where possible.

A review of alcohol interventions in prenatal clinics concluded that brief interventions in prenatal clinics do produce positive results. Two-thirds of women stop drinking once they know they are pregnant. Despite awareness efforts some women continue to drink. Pregnant women are receptive to change in the prenatal period. Brief interventions have resulted in reductions in alcohol use, but most of the earlier studies were somewhat limited due to a lack of controls, small numbers of heavy drinkers, and the inability to assess the impact of treatment. Recent studies have advanced knowledge in this area, and have found that motivational interviewing (MI) with pregnant women is effective in increasing abstinence and decreasing alcohol use. Intervention effects can also be enhanced with partner participation, and pregnancy outcomes can improve. Studies discussed are as follows:

- Handmaker, et al (1999): Use of motivational interviewing within a brief intervention; Increase in abstinence in intervention group at 2 month follow-up.
- Chang, et al (2005): Prenatal alcohol use declined in both intervention and control groups; Most significant effects for women with highest use initially; effects of intervention significantly enhanced with partner participation.
- O'Connor & Whaley (2007): 10-15 minute session with nutritionist; women in intervention group 5 times more likely to report abstinence compared to assessment only group; newborns of mothers who were heavier drinkers and who received the intervention had higher birth weights, lengths and lower fetal mortality.

While it is very important to intervene with women who are already pregnant, from a prevention perspective, it is beneficial to intervene before a woman becomes pregnant. For this reason, there has been a focus on preventing alcohol-exposed pregnancy among preconceptional women. This includes women who are sexually active and drinking at risk levels who may be at risk for an AEP. In the late nineties, CDC funded a multi-site study known as Project CHOICES, which tested an intervention offering a dual approach to reducing the risk of AEPs by either reducing alcohol use, improving contraceptive use, or doing both. Project CHOICES provided a 4-session motivational intervention with 1 family planning visit to women at risk in various community settings. Follow-up was done at 3, 6, and 9 months. The total sample size was 593 at 9 months. The target population included women 18-44, 71% of whom were in study at 9-month follow-up. Both the intervention and control groups had reduced risk. More women in the intervention group changed both behaviors. The key finding was that the intervention group was 2 times more likely not to be at risk for an AEP compared to the control group. Project Balance, based on Project CHOICES, is a one-session program targeting college-aged women. The total sample size was 212 at one month. The target population included women 18-24. Follow-up was done at 1 and 3 months. There was a significant decrease in the risk of AEP in the intervention group, and that women were more likely to increase effective contraception versus reducing alcohol use.

Recommendations for selected and indicated prevention for women of childbearing age include the following:

4. Develop and implement alcohol screening and brief intervention programs among women of child-bearing age, especially pregnant women and women with co-occurring disorders, such as domestic violence and mental health issues.
5. Expand the education and training of health and social service professionals in the areas of screening and intervening with women at risk for alcohol-exposed pregnancies.
6. Intervene with high-risk adolescents to treat substance use problems prior to sexual initiation.

With respect to indicated interventions for women with alcohol dependence, women are more vulnerable to alcohol dependence than men. Brief interventions alone are not considered adequate treatment. Ensuring long-term abstinence requires intensive case management and aftercare. Effective treatment options include behavioral and pharmacological interventions. Project MATCH, a large scale, multi-site study, compared the effects of four 1-hour sessions of motivational enhancement therapy (MET) with 12 sessions of 12-step facilitation therapy and 12 sessions of cognitive-behavioral therapy in more than 1,500 male and female alcohol-dependent patients. Both 1 year and 3 years after the intervention, participants in all three groups reported

drinking less often and consuming fewer drinks per drinking day compared with their drinking behavior before treatment. The MET therapy of only 4 sessions appears to be more cost-effective compared to the others, given that it was lower in intensity but equally effective.

Another option for women with alcohol dependence is Alcoholics Anonymous (AA), which provides participants opportunities for support. The effectiveness of AA is unclear at this time. A recent Cochrane review found no conclusive evidence that AA or other 12-step programs demonstrate that participants achieve abstinence or reduce their alcohol intake when compared to other strategies.

Other studies have evaluated educational interventions among substance-abusing women before conception. One study focused on postpartum, substance-abusing mothers and their families and another focused on women with FASD, all of whom were enrolled in the same intensive, one-on-one intervention. The primary focus of the intervention was to assist the participants in obtaining drug and alcohol treatment, staying in recovery, and addressing other life challenges such as lack of housing, domestic violence, child custody, legal issues through intimate one-on-one education. The results were positive for participation, abstinence, use of reliable birth control, and decrease in subsequent pregnancies in target populations. Recent studies have also investigated the efficacy of pharmacological interventions such as naltrexone and acamprostate for alcohol dependence treatment in specialized and non-specialized settings, with or without behavioral interventions. Guidelines for the use of these drugs, as well as disulfiram (antabuse), in primary care or specialized care setting have been published by the NIAAA. These guidelines indicate that these three medications are approved for treating alcohol dependence. However none of these medications has been approved by the Food and Drug Administration (FDA) for use in pregnancy, but may be helpful for non-pregnant women.

Pertaining to indicated prevention for women with alcohol dependence, the recommendations include the following:

7. Assure adequate alcohol treatment access, including consideration of treatment barriers, for women of childbearing age and pregnant women.
8. Modify existing treatment matching system to include pregnant women and those with co-occurring disorders, such as special populations with unique treatment needs.
9. Implement case-management approaches for women at highest-risk of producing alcohol-affected children.
10. Conduct additional research on interventions for substance abusing or dependent women at risk for alcohol exposed pregnancies.
11. Conduct further research in the area of gender specific treatment needs for women.
12. Conduct ongoing research on the efficacy of AA as a community level intervention.

Based on requests from the last Task Force meeting, CDC asked RTI to conduct a review of existing reviews on intergenerational strategies, worksite programs, and computer-based interventions. These are summarized and included at the end of the report; however, the group was not certain whether these should be included. Having a section on future research directions is an important piece that the writing group did not have time to develop, but about which they were interested in hearing the full panel's thoughts and ideas.

In summary, Ms. Weber concluded that using effective, evidence-based prevention strategies is a critical step in preventing alcohol-exposed pregnancy. Population-based strategies on alcohol misuse are important and should be supported. The most promising strategy at this time is screening and brief intervention (SBI), although more research is needed on how SBIs work and what the essential elements are. An important challenge is to determine how to best implement and integrate SBIs into various systems of care. Indicated interventions for women with alcohol dependence are available, but more work must be done to address the complex needs of these women and their families.

Deliberations on the FASD Prevention Report

Mary Kate Weber, MPH

During this session, Ms. Weber invited the group to engage in a discussion about general feedback / concerns pertaining to the FASD Prevention Report, using the following questions as a framework:

- What is your overall feedback on report?
- Does the report include what we have discussed in previous meetings?
- Is anything missing that needs to be added?
- Are there topics included that should be omitted?
- Any thoughts on the future areas of research section? What should be highlighted here?

Discussion

- Dr. Warren said he thought this was an excellent report and he commended everyone who worked on it. With respect to the very high risk group (e.g., those who are alcohol dependent and / or have previously given birth to a child with FAS or an FASD), he knew of some studies that had targeted these populations. While he knew who the researchers were who were studying this, he has not been able to find the literature through Pub Med. He suggested they determine a way to make note of these studies, given that this is clearly the highest risk group. The leading risk factor for having a child with FAS is having already had a child with FAS. The Birth to 3 Project is targeted to these individuals.
- Dr. Olsen responded that in the new draft, the study that Grant did working with women who themselves are already affected is cited. To her knowledge, the only work that has been done targeting women who already have a child born with FAS is a pilot study she and her colleagues did with a very small group of individuals with motivational interviewing treatment. Beyond that, all there are is case studies of work that has been done with the PCAP programs. There is an abstract and information that can be made available so that this can be described as an option. Phil May's work in selected communities could also be cited. She agreed that this was a good idea that had not been pursued with the energy that it deserved. Perhaps the work belongs in the future research section rather than the section where published data are covered.
- Dr. Miller thought there was more on this topic included at one time (e.g., the studies with high risk mothers). Perhaps the Seattle studies could be reinserted. There was also more

lead-in previously about most FAS being the result of women who are alcohol-abusing / alcohol-dependent. She thought they needed to make this point.

- Dr. Olson added that a particular area that was missing was the entire literature on women-oriented chemical dependency treatment centers. There is a significant literature on the efficacy of these centers, and there have been some efforts to provide contraception along with chemical dependency treatment. That lays the groundwork for spending more energy on the indicated interventions, and is documentation that these women can be reached in an efficient, efficacious way. Perhaps all they need to do is add on to that an effort to educate about FASDs as well.
- Dr. Floyd added that in the late 1990s, CDC funded Susan Astley and Sterling Clarren to study those high risk women who present for evaluation of their children. They found sufficient numbers of biological mothers and looked back in time to determine whether they could find those who were not with their mothers. Basically, a small proportion of those women recovered and the vast majority did not. The investigators were able to provide referrals and a brief intervention. This study provides good information about the epidemiology on women who have had a child.
- With respect to NIAAA funding, Dr. Warren reported that a number of the recommendations made are actually currently being pursued. Because they are funded, they are public information. That is, there are abstracts available even though the papers have not yet been published. He can obtain this information and will forward it to the writing group. There are two major prevention studies: 1) a Phase III fetal alcohol prevention program in the Northern Plains targeted at all three levels (e.g., universal, selected, indicated); and 2) a South African study just now getting underway, which is a very large scale model in one of two intervention communities and three control communities. Phil May is the Principal Investigator on both of these studies. There is a need for future research, so they could state this in addition to noting that a number of studies have been implemented for which the results are not yet available. Nowhere has he seen a more intense universal prevention program than in South Africa. The program is very visible, with many activities that he has not even seen in the U.S. With respect to the epidemiology of what is going on in South Africa, the economy is improving and pregnant women are increasing the amounts they are drinking. That increase from the improvement in the economy is exceeding the reduction that is occurring because of universal prevention methods. He suggested including a statement that the effects, at least in the context of universal prevention, could be overshadowed by other events occurring within any particular community, including those that are socioeconomic.
- Dr. Floyd thought one issue that is sometimes difficult to understand when multi-level prevention programs are being carried out is that while some effects may be found on the outcomes being measured, the outcomes being measured may not be entirely clear. If they could obtain some of the evidence of the universal interventions to the robust level that brief interventions have received in terms of randomized controlled trials (e.g., clearly delineated activities, how they are measured, and the effects of those) it would be good to

point out the direction and contribution of the different intervention levels in these multi-level programs. There is certainly some very good information.

- Dr. Olsen indicated that she would gather what is available about the women identified in the Astley and Clarren effort, the information about the Bridges program, and some of the key references in the women-oriented chemical dependency literature.
- Dr. Sokol noted that the document itself did not seem as smoothly laid out as Ms. Weber's presentation. With respect to Dr. Warren's comments on economics, Dr. Sokol and Janet Hankin conducted the study that is cited in the document. What is not said in the document is that they did not find any substantial effect of labeling—there was none. It is not fair to say that the women who were not drinking drank less. It is true that somebody who had one drink a year did not have one drink a year. What they actually found to be the greatest determinant of whether women drank was how depressed the jobless rate was. This is very strongly correlated and the exact shaped curve can be tracked of the amount of drinking to the economic situation in Detroit. While he was delighted that the writing team cited them, he thought it was fair to say that the conclusion from that study was that there is no impact at all with respect to labeling. This is an important negative finding. With respect to Dr. Floyd's statement, he said he believes there is a lot of information on universal prevention that really is not relevant. Therefore, they are missing an opportunity. The real message should be that good evidence is needed on universal interventions because there is precious little, if any, to say they think maybe it will help. CDC hired somebody to find evidence, but they could find no evidence. However, this is not stated in the document. There is only one study cited on page 16, which is very weak. Also, on a separate issue, on page 21, line 811, in the O'Connor study, .06 is not significant in some of the higher birth weights. This needs to be cleared up because it does not meet the standard criteria for significance.
- Dr. O'Connor responded that originally they did not put the birth weight statistic as significant, but the reviewers said that because of the difference in the actual weight, it is clinically significant, so their recommendation was to include it.
- Dr. Sokol said he would just put "border line higher birth weights" and then a p-value if there is one for mortality. Also, with respect to the Handmaker study in the next paragraph, 44% versus 33% is nothing (lines 814 to 820). He thought it was embarrassingly weak to include in a review like this. Dr. Sokol also suggested moving everything in the beginning of the document that discusses the Task Force and what CDC is doing to an appendix. [Note: At this point, the group realized that his line numbers and pages were not the same as the latest version of the document, so the location will need to be clarified].
- Dr. Chang mentioned that Janet Hankin's work on preventing subsequent alcohol-exposed pregnancies had been published. She wondered if this would address some of the concerns being raised. She thought it was summarized in a review article that was published in *ACER* in 2002.
- Dr. Hacker agreed that the discussion of the Task Force and other activities in the beginning of the document would be better-suited in an appendix. He disagreed with Dr. Sokol about

the importance of including and highlighting to some degree the need for universal strategies related to all drinking, particularly related to under-aged drinking. There was a 2003 report by the National Academy of Sciences (NAS) that included a broad range of policy recommendations related to overall drinking. The importance of that is the correlation between early onset of drinking and the level and nature of problems associated with youth and adult drinking for those people who start early. Therefore, it is very important that despite the fact that there may not be an absolutely clear evidence base of universal policy and reduction in FASD, the fact that many of those same policies have been demonstrated to reduce consumption and problems across a wide range of other alcohol related issues is sufficient evidence to recommend that those policies be part of an overall approach. They should be strengthened in this report by including a reference to the NAS report, as well as to the Surgeon General's "Call to Action on Underage Drinking" released in late 2006.

- Dr. Sokol clarified that he did not say it was not important. He said they do not have evidence and should be asking for that evidence. While Dr. Sokol recognized that Dr. Hacker was interested in underage drinking, he said the fact was that this document is not about underage drinking—it is about FASD. The fact is, CDC hired somebody and they could find no evidence of any effect on FASD, which is what he thought they should say. He was also fine with saying that there is evidence that there are other things, in terms of alcohol intake awareness, that have been shown to be promising that need further evaluation.
- Dr. Hacker responded that underage drinking is related to all drinking. He thought that while promising areas needed to be evaluated, they should not ignore the potential effects of those kinds of policies on overall drinking and on the social norms of drinking in society that will affect drinking by women at risk.
- With respect to the *Community Guide*, Dr. Boyle noted that some of the recent work was relevant to this conversation. The *Community Guide* is undertaking reviews of four environmental policies, for example identification of alcohol facilities, taxation, etc. The reviews of at least two of these have been completed. The *Community Guide*, associated with Task Force similar to the NTFFAS, has come out with recommendations, which she hoped would be included in the NTFFAS report. The *Community Guide* highlighted the fact that drinking among underage women is on the increase. Obviously, from an environmental intervention standpoint, anything they can do to intervene with that is very important and powerful for public health. Even if the effect size is relatively small, this can have a remarkable impact in terms of FAS.
- Ms. Weber responded that the report does refer to some of the systematic reviews that are currently underway. Reviews have been completed on the enhanced enforcement of laws prohibiting illegal sale of alcohol to minors, alcohol taxation, and retail outlet density zoning restrictions. While these have not been published yet, she assured NTFFAS members that this information would be included.

- Dr. Sokol referenced the section “Evidence-Based Interventions for Alcohol Dependence” which states “the three medications currently used for alcoholism are not approved or are contraindicated in pregnancy.” It might be worthwhile to detail those in the same way as the various alcohol screens. With respect to the use of computer-based interventions, Steve Ondersma has several publications. Regarding the statement on page 27, to say that “. . . better evaluation measures should be developed to capture the impact of those strategies not yet deemed effective due to lack of evidence (e.g., professional training, school-based education, media campaigns, warning labels, and point of service signage). . . . These kinds of efforts have an important role to play in FASD prevention efforts in terms of education and public awareness . . .” Dr. Sokol said there is not any evidence for that statement, yet they are stating that these have an important role to play. This is hard to support. He suggested what they should say is that these may have an important role to play if they can document what these are doing.
- Regarding the section on future research, Dr. Damus said that because there is so much information coming out in terms of different types of genomic predispositions for alcoholism and other issues, it is very important to include this information. While there are no papers specifically related to this outcome, she still believed this information should be included in the report with a discussion of how, when these markers are identified, there would be various opportunities to target those individuals in whom they might want to invest more resources. There is a lot of information from NIAAA and others about this topic.
- Dr. Berner agreed. He thought the epi-genetic information that is beginning to accumulate on issues other than alcohol as having a transmittable, heritable effect on future generations from current use of either a drug or some accidental contaminant is too great to say that it should not be paid attention to in future funded research with respect to alcohol and transmittable, heritable defects that could be related to alcohol ingestion on the part of the mother or father. In addition, while they could not say statistically that labeling makes a difference, there is a very good case to be made for continuing this effort. To say that labeling does not make a difference is to ignore the fact that, for instance, if some commonly prescribed medications were found to be able to cause a teratogenic effect, they would be labeled in this manner. Even if they could not show that it decreased the amount of that side effect, they would be remiss in not labeling this. Industry may perceive this as there being no point in labeling alcohol as a risk during pregnancy because it cannot be shown that labeling reduces the risk. This should not be taken even inadvertently as their message. Dr. Berner also observed that there is very little in the current report that discusses the need to consider measures that deal with interventions in high risk family setting, as opposed to individual women to reduce the risk of children who use alcohol or who are abused by alcohol-using caretakers, as a risk factor for FASDs. At the very least this should be entertained as an addition to the “Research is needed” section.
- Dr. Brown said it seemed that the universal screening is weak in that they are not really following what the Surgeon General’s statement is. The tone of this report is that there is alcohol misuse. She did not know if there were studies about women’s behavior and their knowledge about being pregnant. A recommendation might be that there are a lot of

women who do not know they are pregnant yet, given that these women are not addressed specifically. The average woman does not know she is pregnant until 5.4 weeks into pregnancy. Women who have consumed alcohol do not know they are pregnant until 5.7 weeks of pregnancy.

- Dr. Sokol said that from the OBGYN perspective, the term “peri-conceptual” is not used and should be. Also, when talking about 5 weeks of pregnancy, it is counted from the last period, so in terms of how long an embryo is there, it is actually three weeks. There has been a substantial amount of work that shows that before implantation, which is at least half of that, there is no effect. The rest of the evidence says that there is an increased risk of spontaneous abortion from very early exposure. This is the whole rationale for intervening before conception.
- Referring to line 387 that includes all of the proposed recommendations, Dr. Floyd suggested that perhaps they had attempted to cover too much territory. There are women at risk who are not pregnant but who are fertile, sexually active, not contracepting, and drinking at heavy levels. There is also the group of women who have previously had an affected child, and there are those who are drinking who have co-occurring conditions that put them at further jeopardy of having a poor outcome. Perhaps they should consider parsing this recommendation into more than one.
- Regard the recommendation at the end pertaining to measuring outcomes using standard monitoring and surveillance methods, Dr. Miller wondered whether this needed to be fleshed out further in future research or future plans. If they are going to discuss prevention, more time should be spent regarding measuring the outcomes of that prevention. Perhaps they need to expand this to include the Washington paper that addresses relating prevention to a decrease in FAS.
- Dr. Floyd said she was also thinking that one issue which was still very much like the “elephant in the room” was that they had an umbrella term that is a concept, with one diagnostic condition under that. If they are going to prevent under this umbrella, they should identify more conditions starting with alcohol-related neurodevelopmental disorder (ARND). She thought they needed to state that the work to establish the diagnostic criteria that can be used for initial clinical evaluation and surveillance should be furthered.
- Dr. Miller noted that in the introduction where this is discussed, it is discussed in a positive way as being something in which great strides have been made. She thought perhaps it could be phrased somewhat differently to indicate that more work needs to be done in this area.
- Referring to the proposed recommendations on page 387, Dr. Hacker thought those related to the universal prevention area were quite modest in that they only ask readers to study more. He suggested that it would be appropriate to provide a recommendation to “implement those prevention measures that are shown to reduce alcohol use among women of childbearing age or the target population, whether they are high risk or not,” with a specific reference to efforts like warnings in advertisements, the utility of warnings on the

containers, and other informational and educational strategies. He thought they should be on record as recommending some kind of action rather than just studying this to death. There is some evidence on taxes and other measures that have been demonstrated to reduce related harm caused by alcohol. The STD study is just one example that came out of CDC.

- Dr. Damus pointed out that it was assumed, based on recommendation 5 on the table on 387, that providers think this is a problem. This begins with screening and intervening, but she thought there needed to be a lot more in schools of training for all health care providers (e.g., nurses, doctors, pharmacists, et cetera) that alcohol is an important issue about which something can be done. There are studies to show that a large proportion of physicians tell women that it is okay to have a drink when they are pregnant. For both the public and providers, she suggested that they needed to study the knowledge, attitudes, and behaviors of those groups and acknowledge that they must convince people that this is a problem, and that it is modifiable.
- Dr. Sokol respectfully disagreed with Dr. Damus. CDC has sponsored surveys and ACOG recommended abstinence before the Surgeon General did. He was unaware of any evidence that a lot of obstetricians, or even family doctors, are telling women they should drink a lot during pregnancy. There certainly is some evidence that if a woman has a drink, it is reasonable to tell her to stop but not to worry about it. She does not have to have an abortion. Further, there is really very good evidence that he and Dr. Floyd published that the efforts made in the 1980s and 1990s to educate physicians were very effective. A very high proportion does screen, although not as well. ACOG is currently redoing the survey. He thought the wording on expanding the education and training recognized years of effort. Otherwise it would sound like nothing has been accomplished, although a lot has been accomplished. Recognition that alcohol is a problem is very high to almost universal in those trained after 1993.
- Dr. Damus indicated that MOD is analyzing a survey in Kentucky conducted in February and March 2007 of over 1,000 pregnant women in an initiative there. They continue to have women reporting that their provider told them it was okay to have a glass of wine and other drinks and that it was not a big problem. Other studies and surveys suggest that perhaps people know the importance of assessment and screening, but are not always giving the same messages to women. Nursing studies have shown that nurses do not think this is as much of a problem as they should. Therefore, Dr. Damus did not believe there was irrefutable evidence that all providers think this is a problem.
- Dr. Sokol said yes, in the clinical setting, they have to be able to tell women that there is no evidence that an occasional drink is harmful, no matter what anybody says. Anxiety is not good during pregnancy either. If a woman had a drink, a physician would likely tell her not to worry about it, but also to stop. That is good practice.
- Dr. Ohlemiller supported Dr. Damus because the Regional Training Centers, funded by CDC, have published a number of surveys out of that work that agree with Dr. Sokol that some providers know about the problem. However, there is still a long way to go. The word “expand” is probably appropriate in the recommendations because it does

acknowledge that there has been work done, but a lot of work still needs to be done with providers. In the Midwest, providers are still telling women all sorts of things beyond an occasional drink. They are hearing this everywhere, so she could not agree more that this must be addressed and may need to be strengthened in the recommendations.

Deliberations on Prevention Report Recommendations

Mary Kate Weber, MPH

During this session, Ms. Weber invited the group to engage in a discussion regarding their general feedback / concerns pertaining to the Prevention Report Recommendations, using the following questions as a framework:

- Any thoughts on existing recommendations? Deletions? Revisions?
- Does location of recommendations in the report makes sense?
- Should recommendations be in different categories (e.g., research, education and training, service delivery, policy)?
- Thoughts on other kinds of categories?
- Do members have other ideas for proposed recommendations?
- Should we limit the number of recommendations?

Discussion

- Dr. Miller noted that in a few places, some important recommendations are buried in the text in the report and should be separated out. For example, just before “Emergency Medical Settings,” there is a recommendation to address time, payment, and logistical barriers for brief interventions. On the next page, regarding screening and brief interventions, there is a statement that “the study of ED interventions focused on alcohol issues has proven to be effective and constitutes fertile ground for future research . . .” She suggested reading back through the entire report to separate out any other recommendations that are imbedded.
- Dr. Sokol thought the total number of recommendations was sufficient because usually, there is a very long list of recommendations and then nothing ever happens with them. He agreed with Dr. Miller that the imbedded recommendations needed to be highlighted, but suggested including them as sub-headings under the existing recommendations. For recommendation #2, he suggested replacing “development” with “develop” and adding “may” in front of “play.” With respect to recommendation #4, there is nothing on domestic violence and mental health issues in the body of the report. If they could support it in the body, then he thought it would be fine to include this recommendation. Regarding recommendation #6, he had no problem with recommending intervening with high risk adolescents, given that sexual initiation may come very early. However, there is nothing in this document to support that recommendation. If they plan to include the recommendation, then there must be a paragraph in the body of the report to say something about prevention efforts in adolescents. While he thought that all of the recommendations were really good, they must ensure that there is something in the text to support all of them.

- Dr. O'Connor offered some references on adolescent drinking; however, because she was breaking up on the phone call, she indicated that she would email these to Mary Kate Weber.
- With respect to the alcohol dependence section, Dr. Olson noted that the recommendations are important and clearly stated, but the information preceding the recommendations does not lead to recommendations 7-12. She thought they made some points during the previous discussion which would probably address this.
- Regarding the first section on "Universal Prevention," Dr. Hacker thought they needed to be more active rather than simply asking for more studies and better measurements. He thought they certainly could recommend the expansion of general public awareness campaigns to alert young women to the potential dangers of drinking during pregnancy. Recommending "general public awareness" campaigns would include a wide range of potential informational initiatives.
- Dr. Damus added terminology should be included such as "culturally sensitive" and "health literacy appropriate" because this is key. While it is implied, they should state this directly.
- Under "Potential Strategies for Future Research," Dr. Warren noted that the main two activities listed are "work-site" and "computer-based." While he had no problem with "work-site" he did not think they would find the highest risk women in that setting, nor did he think they would reach the highest risk women with a computer approach either. These are not the two he would think of for potential strategies. He suggested picking up some of the themes already discussed and emphasize the next steps, particularly in the context of interventions in the environments where women at high risk are found. That falls in both the "selective" and "indicated" categories. He noticed in the document that the two have been combined. Brief intervention is being targeted to the more selected audience than the highest risk audience. He realized that there had to be an overlap at some point, but at what point does a selective intervention become a targeted one? It depends upon the degree of risk in the individual. NIAAA is involved in terms of FAS prevention and work-site is not the major thrust.
- Ms. Weber clarified that "work-site" and "computer-based" were included because it was suggested during the last Task Force meeting that CDC look at reviews of these. Therefore, CDC had RTI conduct a review of the reviews and summarize them. These were included in the document originally, but the working group did not believe they fit very well. While these two do not have to be included, they do need to identify what goes in that section.
- Dr. Warren suggested changing the heading to "Potential Lessons from Other Alcohol-Related Problem Areas."
- From the audience it was suggested that correctional facilities be included, given that this is where many high risk women are located. Dr. Olson responded that there is literature on

chemical dependency treatment in correctional facilities and family planning, which could be referenced. Dr. Floyd added alcohol / drug treatment centers.

- In response to Dr. Warren’s comments, Dr. Brown thought “work-site” and “computer-based” were simply examples, so perhaps they should be included in the body of the report as they relate to the topics.
- Dr. Olson noted that often when they talk about community-level FASD prevention, they are really talking about multi-level interventions (e.g., universal educational approaches happening concurrently with selected interventions for women at risk, coupled with intensive treatments for the highest risk women, coupled with health education for adolescents). The sum is really what is accomplishing prevention; however, that is never really mentioned or documented in the report. Perhaps a separate section should be included that addresses being able to monitor the community level using long-term surveillance, and perhaps having a methodology for documenting what is happening at the community level the way Phil Mays tried to do in certain communities. The future of the research will lie in looking at the sum total of what is being done and being able to document this using some kind of epidemiologic indicator that they are having an effect on the outcome of interest. The more global view does not seem to be embraced in the report. The Astley paper is a cutting-edge attempt to do this, which could be mentioned here.
- Dr. Prue noted that this is what the tobacco world did 15 years ago when they mobilized communities to map out what was happening at all levels. That is, tobacco took an ecological approach, which this report should do as well. All systems must be engaged to move the dial on this important issue.
- Dr. Olson agreed, stressing that they have one example of an effort to do that. She thought their mission in this document was to step-up to say what really should be happening. That would tie the document up nicely—they could have a finish that discusses the multi-level interventions that accomplish prevention in the long-run.
- Dr. Wright said she thought this was what Dr. Warren was talking about earlier with regard to what Phil May attempted to do in South Africa. There are other methodologies that could be used, such as GIS mapping of outlets, which is part of the community approach to determining how many alcohol facilities there are, and doing environmental scans in terms of policies in certain communities. They backed themselves into a corner in a sense in talking about some of the unproven strategies by calling the report an “evidence-based” approach. Ecological studies are really what people are looking at for the future. It is difficult to know how to say it exactly, and in the end knowing exactly what was done that made a difference may be hard. If someone cannot afford the whole package, this could be problematic. She suggested citing the studies that are being done that may provide more evidence about a comprehensive approach at all levels.
- Dr. Olson suggested that perhaps they needed to make the argument that research is needed to define the full spectrum of the disability and that long-term surveillance methodology is needed. They could then point to work that has been done or is being done, and add the

point that the recommendations in the rest of the document should continue. The way it is written now with potential future directions, the notion of looking at different cultural groups, suiting indicated interventions to different cultural groups, and translating research into community settings—all of that feels as though it is not endorsed as a future direction, which ties in with what Dr. Warren said.

- Dr. Floyd agreed that this is relevant. The fact is that they have laid out all of the things that could be done, but if talking about X, Y, Z communities that have high prevalence rates, they need to address how to package the interventions that are evidence-based and add some ecological information as well in terms of tailoring interventions to specific groups.
- Dr. Caetano noted that two themes were being discussed: 1) whether to describe in more detail, and even recommend, that the intervention approaches should be done at multiple levels; and 2) whether specific pieces of research are being missed that deal with ecological indicators or are focused at the ecological level in communities. The framework for prevention is easy to insert if it is missing. There is an initial paragraph that discusses universals, selective, and indicated interventions. This could be expanded to include a more specific discussion of the multiple levels of intervention that need to be implemented in the community at the same time, or integrated. In other words, none of these approaches is a “magic bullet.” Therefore, interventions are needed at several levels. Because of that, the interventions must also be monitored with epidemiological indicators.
- Dr. Floyd responded that in terms of the ecological model, they would be including all levels of prevention, including policy (e.g., interventions at the individual, community, universal, etc.) that are intended to provide baseline information about what the problem is and what kind of policy activities need to be undertaken.
- Dr. Caetano did not think they had explicitly, in one paragraph, described the model and identified the model as the basic theoretical framework that the Task Force utilized to develop the report. Somewhere on page 8, lines 180 to 223, the framework that they used in approaching FASD prevention should be explicit.
- Dr. O’Connor agreed that they needed to include information about the multi-level approach, and they probably need to dismantle some of these studies. She said she was impressed with Project MATCH in that regard. No matter what was done, it had a positive effect. However, it was specific to certain populations. She thought they needed to match the different components of the interventions to different groups depending upon whether they are pregnant or not, socioeconomic background, etc. More research is needed regarding what the most specific and effective interventions are that take the least amount of time, so that they can be incorporated in the community.
- Related to what Dr. Caetano said, Ms. Weber agreed that they should expand and flesh out more of what they think the framework should be. That framework is what they used, but perhaps they should specifically recommend that a multi-faceted approach must occur in order for these to get into the community.

- Dr. Miller thought that made sense from a practical point of view. This is what they are trying to do in Colorado on a very small scale. They have not been able to do this yet on a large, community scale, but they have a model of brief interventions that go all the way from a media campaign to an indicated case-management prevention model and are conducting surveillance simultaneously. While there are still a lot of gaps, this resonates with what they are trying to do.
- Ms. Weber noted that CDC is adapting Project CHOICES interventions by working with state health departments. In terms of other recommendations, it seems like they have evidence-based approaches that work, but they have not addressed what needs to be in place at the community level for those to be received. If it is not on providers' "radar screens" they will not refer women to the intervention. Women often do not even understand what risk drinking is. There are many other activities that must serve as the foundation for introducing interventions to women. While she was not exactly clear how they should articulate this, it seemed like something they should consider in terms of implementation.
- Dr. Floyd suggested something like research into development of community assessment tools that could be used to indicate directions in terms of tailoring interventions that are science-based to a particular community.
- Dr. Miller thought they were a ways from implementing the multi-level community approach, let alone how to tailor it.
- Dr. O'Connor suggested making this a recommendation for a next step.
- Dr. Prue said that important to her is that this document declares what is known about evidence-based interventions. The translation leap, which a lot of other states are wrangling with, is that there are communities that may or may not be aware of evidence-based strategies, may or may not be prepared to implement them, and may or may not have the infrastructure to use any one of them or any constellation of them. She did not believe anyone had the answer on *how* to get these known things into systems.
- Dr. O'Connor suggested that, with respect to multi-level interventions, they could add a new recommendation regarding the use of the Internet for screening and brief interventions. This is being done in the obesity community and is in the obesity literature. This is an ideal setting where someone could work on the Internet anonymously to receive help. While this will not address all communities and individuals, given the way the Internet is so pervasive, it is important to mention it.
- Dr. DeJoseph suggested a pop-up message on My Space.
- Dr. Damus added that along those lines, the March of Dimes is creating a pre-conceptual short that will appear on You Tube. Some of their biggest responses have been for piloting

some educational clips on You Tube. Many groups are doing this and it seems like a very good strategy.

- Dr. Floyd said this sounded like they might be ready to entertain a recommendation to endorse multi-level interventions as evidence-based, or that the research should move in the direction of multi-level interventions.
- Dr. Sokol suggested tying that to Dr. Warren’s comment and include something that discusses this as a recommendation for research in order to develop some evidence, and state “including, but not limited to” in order to capture some of the suggestions that have been mentioned: Internet, workplace, et cetera.
- Dr. Floyd suggested they craft a potential recommendation.
- Dr. Warren suggested working on a recommendation pertaining to multi-level approaches during lunch.
- Dr. Prue proposed that the subject be referred to as “comprehensive, multi-faceted interventions” and then go on to “include.” That encompasses the concept of the various levels—the multi-level approaches as well as the important concept of multiple strategies, such as policy, environmental, and education.
- Cathy Hutsell suggested that the Task Force use the phrase “comprehensive, multi-level approaches, including but not limited to....” and then be explicit on the activities. This is similar to how her group described health promotion in Healthy People 2010.
- Dr. Caetano added that if they planned to use the terminology “comprehensive, multi-faceted interventions,” this should be defined.
- Dr. O’Connor said they still need to dismantle studies. In her own study she kept wondering what it was that made the difference and if there are easier and quicker ways to do this so that it will be more accepted in the community.
- Dr. Miller was not clear whether they were ready to formulate a recommendation at this point. Were they saying that more research is needed or that the recommendation was more about translating research to practice? They might still be at the translational stage.
- Dr. Floyd responded that she considered multi-level is what Phil May is doing. It is universal, selective, and indicated. He is implementing those levels as he is defining them. That is the only science-based program available at this time that is multi-level. It seems that he is having some success. She wondered if they were ready to say that this may be a promising approach for the future that should be considered a future research direction.
- Dr. Olson said to include the fact that there are multiple pieces that have to be put in place for that to happen (e.g., surveillance, methodology, education, documentation of what is happening in the community). The recommendation is that they are suggesting that people

move forward in that direction, including developing the technology to be able to implement it.

- A recurring thought that Ms. Hutsell was having as they discussed the importance of evidence-based interventions, as well as promising practices, is that it is very important to emphasize those. Particularly with respect to community health promotion strategies, it is also important not to lose site of the opportunity to encourage the innovation that can take place at various levels.
- Referencing to the graph on page 47, Dr. Wright said to her it begged the question or call to action that the curve of the graph had not really changed. With that in mind, she wondered if there should be a recommendation that not only should there be surveillance, but also some re-appraisal of where the nation stands on this within a certain timeframe. Perhaps many of the recommendations are still new and there have not been that many tools in the community to move the bar nationally, but perhaps this is the place to call for that just like those who called for the original Congressional language that resulted in the establishment of the NTFFAS.
- Dr. Brown agreed. This paper is the last opportunity for the NTFFAS to speak. There is enough evidence in the paper to make strong statements about what can happen in terms of aggressive work around prevention. With respect to the multi-level work specifically, they should be able to say that interventions have been shown to be effective in certain communities. It is good practice and common sense for communities to begin thinking about the community as a whole systematically.
- Dr. Floyd added that it sounded sensible that the same strategies would not be in every community. Strategies would vary according to community profile and needs. She wondered if the group wanted to include a recommendation that addresses multi-level interventions and more research into multi-level interventions, employing strategies that are tailored to the community's needs.
- Dr. Caetano thought they could do two things: 1) expand the description of the framework as he suggested earlier, including the multi-level approach; and 2) to be in accordance with that, they could recommend that one type of intervention only is not going to deal with a problem as complex as FASD, that according to the framework used by the Task Force, communities need to think about implementing different levels of intervention. If doing that, the best thing to do is to try to obtain some evidence on whether those multi-level interventions are being effective. There are some examples.
- Dr. Floyd responded that in terms of retrofitting a model, that was not where the writing team started. They began by reviewing the evidence, and they have a report of the evidence. There are some potentially promising reports with respect to Phil May's multi-level approach. If the science, or evidence at hand, did not lead them to multi-level strategies, then they should simply state that they reviewed the evidence and state what that included. However, for future research this may be a promising approach.

- Dr. Caetano did not agree because he thought they had evidence from interventions at different levels, which show that they work. They may not have looked at any particular piece of research that implemented interventions at different levels in one particular research project. But when they craft the report, they went from universal interventions to all of the others, so the group took a comprehensive, multi-level, multi-stage approach.
- Dr. Warren said he looked at the NIH public database and quoted the following abstract from one of Phil May's grants, "The prevention program utilizes a combination of control and pre / post measures designed to assess indicated, selective, and universal prevention techniques applied by four Plains Indian communities, two controls and one urban research site. Utilizing specific techniques of research and prevention developed previously in American Indian communities, this study further assesses the effectiveness of comprehensive, community-wide prevention of FAS, its extent, and which specific techniques are most viable. The program will continue to measure and define the epidemiologic characteristics of FAS . . ." Basically, the specific aims are to "continue the well-established multi-site, multi-system, comprehensive approach proposed by the Institute of Medicine . . ." Clearly, this is an on-going program and there is another study underway as well in South Africa that basically has taken lessons learned from this study. Dr. Warren thought they had to acknowledge that this is a research direction which is being invested in and pursued, which is appropriate to be pursued, and the outcome is forthcoming. The best prevention approaches can then be refined based upon findings that come forward.
- Dr. Berner said his observations certainly resonated with what Dr. Warren said about American Indian communities. He thought it was more about telling those communities that they *can* do it rather than telling them *how* to do it, and providing the information to let that community develop a prevention program that fits their cultural history, language, and spiritual understanding.
- Dr. Warren also noted another abstract, which basically outlined the types of interventions being undertaken (e.g., community reinforcement, motivational enhancement, principles for drinking control and birth control, et cetera). It addresses the issues of cultural sensitivity as a function of the communities. The intent of the project is to develop recommendations that are applicable to American Indian, Alaskan Native, National, and International communities. In other words, there are lessons to be learned for all groups.
- Dr. Olson indicated that she did a literature search to determine whether she could find an article published on the outcomes, but could not find anything. She wondered if Dr. Warren had a reference.
- Dr. Warren responded that he did not. He could not find a reference on outcomes, but even without it, because this is a report which is recommending future research directions, he thought it was appropriate to acknowledge that there is an investment in research currently underway. Therefore, it is not only a recommendation that the research should be undertaken, but also it is to acknowledge that it is currently on-going. He suggested

telephoning Phil May to find out if there are any papers. He has presented findings at various research conferences.

- Dr. Floyd indicated that they renamed a section in the paper as “Potential Lessons Learned,” which would be an appropriate place to include Phil May’s information.
- Dr. Miller wondered whether they were missing some basic issues because they were assuming there were already recommendations and / or that some recommendations were already being followed. For example, there did not appear to be a recommendation about screening.
- Ms. Weber responded that Recommendation #4 addressed screening.
- Dr. Miller thought perhaps they needed a single, separate recommendation that focuses on implementation of screening. It seemed to get lost in Recommendation #4.
- Ms. Weber agreed that it would be worthwhile separating it out into a clear recommendation about screening.
- Dr. Sokol noted that data show while women are being asked about alcohol use, it is not necessarily by a formal screening tool.
- Dr. Brown pointed out that in spite of efforts discussed in this report; the trends are not that favorable. Therefore, it seemed that a more aggressive, multi-faceted approach should be undertaken toward prevention. This builds on what Dr. Wright said earlier.
- Dr. Wright suggested adding something in the text that describes what is going on in the tables, and which drives through to recommendations.
- Ms. Weber noted that Dr. Hacker had mentioned exploring existing data systems that are looking at alcohol use more broadly to determine whether there is a way to tease out our specific target population (e.g., injury, drinking / driving, emergency department data). That might be more along the lines of the general population recommendations. There is work done with CDC’s alcohol research group, but there are other systems that are not CDC’s.
- Dr. Olson said she was discussing this with Dr. Hacker as well. He was suggesting that there are archival databases where alcohol policies or other policies that could impact on women of childbearing age could be teased out of archival data that already exist. She thought Dr. Caetano had done some of this as well.
- Dr. Warren indicated that NIAAA has a policy database that is web-accessible, which includes policies and legislation at the state level across the country. This is known as the Alcohol Policy Information System (APIS). APIS does not have data per se. It has policies, so it is a catalog of various laws and regulations that have been implemented.

There are FAS-specific laws included in this database, pertaining to bottle labeling and drinking during pregnancy.

- Dr. Floyd was not clear what the purpose of this would be, in that there is quite a good literature in the emergency department setting that it is worth identifying and intervening with women in that setting. Unless it was to add to the epidemiological data of characterizing and profiling where these individuals come into contact with healthcare systems—opportunistic intervention. She also wondered if the APIS database could be used in mapping or characterizing communities or states with respect to their policies on alcohol.
- Dr. Caetano responded that they could go from a description of the policies in various states that potentially could have an impact on FAS. It would be interesting to see the difference between states in terms of those types of policies. Once that was done, they could begin to think about states that have more or fewer policies and use those that have fewer policies as controls and those who have more as experimental conditions to begin to conduct a natural experiment, a quasi-experimental design, to see if any of these policies have an impact on incidence / prevalence of FAS. He thought this was a little farfetched for their purposes.
- It was noted that it would also depend upon the capacity of the individual states to make the FAS diagnosis.
- Ms. Weber asked how the group felt about the placement of the recommendations in the document. In the Executive Summary, these are all listed up front. Based on the conversations earlier in the morning, it appeared that they needed to possibly separate out some of these, as well as incorporate some new recommendations in the next draft. She requested that anyone who made suggestions email the details to her. She knew they would be contacting some of the people on the writing group because specific people wrote specific sections, so she wanted to give them the opportunity to give their feedback.
- Dr. Floyd suggested that perhaps it would be beneficial to have a smaller group who would review the edits / revisions.
- Ms. Ohlemiller wondered if there were thoughts on where to place the cross-reference to the “Call to Action.” It looked like either up front on pages 14 and 15, in the discussion about what the effects of alcohol are and the long-term consequences would be a good place to make a quick nod to the other paper and refer the reader to more information. Lines 445 and 446 talk about lifelong effects / indications, which might be a good place.
- Dr. Olson suggested right after line 410 referring to the “Call to Action” by whatever its title is going to be, and then on page 15, briefly mention that “this guide focuses on prevention, but essential services are also important.”
- With respect to the expansion of communication venues, Dr. Damus wrote something that could perhaps go under universal prevention regarding the idea of “Develop, pilot,

evaluate, and disseminate appropriate prevention / educational messages targeted to susceptible populations through more innovative venues of communication, such as the Internet (e.g., You Tube, My Space), interactive computer-based programs, Ipod casts, blogs, cell phones, and novel signage” in order to take into account all of the new communication vehicles that some of the most at risk populations might better respond and react to.

- Dr. Wright noted that NOFAS has a video on You Tube.
- Dr. Floyd suggested including a couple of statements in the text referring to newer evidence of documenting changes in the way information is accessed, citing some articles and venues that could serve in expanding their reach. She heard that all presidential candidates are cultivating these venues for communications, with the expectation that this is going to play a large role in determining who will become the next president.
- Dr. Prue indicated that CDC is using more pod casts and other creative ways of reaching audiences.
- Dr. Damus noted that this raised the issue of surveys and representative samples when many young people have no land lines, so they cannot be sampled well. For some of the traditional surveys that have been depended upon, there is no framework that allows for obtaining a representative sample from all of the wonderful methodologies that have been created over time.
- Regarding Recommendation #5, Dr. Olsen suggested adding the words “early intervention and social service professionals” because many women with young children can be found in these settings (e.g., Head Start, developmental centers, therapeutic child care facilities that serve children who have been maltreated, etc). This is also a perfect place to capture women who may be ready to have another child because these are all women with young children. She wrote an article, which she will provide to Ms. Weber, although it is primarily expert consensus. She stressed that if they could not document it, they should not include it.
- In terms of the document length, Ms. Weber requested feedback. She reminded them that they spoke earlier about a couple of places where they could summarize further or totally eliminate. One area was the section summarizing the Task Force activities, although she was not clear if that would include the outline of prevention guidelines and recommendations section—some of the recommendations made on broad-based alcohol screening and brief intervention efforts. Perhaps some items could be moved into a chart and placed in an appendix.
- Dr. Caetano suggested drastically reducing the text beginning on page 14 of the background and epidemiological overview, and perhaps placing what is on page 16 in an appendix. A lot of the text on pages 14-18 could be reduced.

- Acknowledging that the writing group agonized over this, Ms. Ohlemiller suggested one way to shorten the document would be to append all of the screening tools. They do need to be in the document.
- Given some of the discussion in the group, Dr. DeJoseph suggested rather than putting the screening tools in the end in an appendix, perhaps they could keep it in the body but put it in a table and then include something more expanded in the appendix about how to score them, etc. She noted that in primary care, all anybody ever remembers is the CAGE screen. Reinforcing the importance of these questions in the body of the document is important.
- Dr. Floyd agreed with Dr. DeJoseph's point about primary care settings. Surveys have shown that if physicians do use evidenced-based screening, they use the CAGE. She thought it was in the best interest to move the field into accepting and using evidence-based screening instruments for child bearing aged women.
- Dr. Sokol thought they had stated in the document that CAGE does not work.
- Dr. Floyd said they do say it, but it does not make a difference.
- Dr. Olson noted that the CAGE statement was on line 652. She suggested naming a table "Evidence-Based Instruments for Women at Risk," so that the name of the table tells them what it is and gives them the exact questions and a little footnote with the data.
- Dr. Barry noted that even the Veterans Administration (VA), which serves a lot more men than women, now recommends and generally uses the AUDIT and AUDIT-C. That is the national recommendation from the VA, which is a change in thinking about screening instruments and recognizing that the CAGE did not work well for everyone.
- Dr. Floyd indicated that they would include brief information about why certain instruments are more useful and appropriate than others. They could cut out some of the information about the research that has been done on the groups for which these different instruments have been shown to work better, although it does support what they are saying about using the recommended instruments. She wondered if they could telescope page 22, prevention strategies, somewhat.
- Dr. Brown commented that the document reads somewhat like a textbook. It is written with a lot of explanation and not just the research that is known. The document discusses using research that works and formulating new research, so there are two aspects. She thought they should make that more clear, thinking about the audience.
- Ms. Weber reminded them when they were originally discussing what this product would look like, they were thinking along the lines of the "FAS Guidelines" document. If thinking about the product being a journal article or *MMWR* report, it is lengthy.

- Dr. Caetano said there is some unevenness in that in some parts of the document they had taken somewhat of a textbook approach. There is possibly too much explanation in some parts.
- Ms. Ohlemiller noted that the p-value seemed out of place, given that this is not a research paper.
- Regarding pages 32-33 (worksite and computer-based interventions), Ms. Weber reminded the group of the earlier discussion when Dr. Warren noted that it was not clear why these were included, and of Dr. Damus' suggestion later that they be subsumed into a list of various innovative technologies.
- Dr. Warren said the more he looked at this section, the more out of place it seemed. It simply does not connect back to the rest of the document.
- Ms. Weber noted that if they incorporated some of the references suggested by Dr. Damus somewhere in the body of the document, they could remove the workplace and computer-based section, and keep the innovative technologies in Dr. Damus' recommendation. She also noted that there is an alcohol dependency section, which includes intergenerational strategies as a peripheral piece (page 31, line 1191). She wondered what others thought about this section.
- Dr. Sokol responded that he found this to be interesting and is of increasing importance, given that some of the children who were diagnosed long ago are coming to the fore. This goes with the business about being potentially at major risk. He thought this was good and that it should be included.
- Dr. Olson agreed, but pointed out that it did not translate into a recommendation in that section. Potentially it could go into a different location that discusses teenagers, or a recommendation could be created related directly to the intergenerational issues.
- Dr. Damus noted that it seemed like the end section did not belong because it discusses children of alcoholics and then complementary and alternative medical programs for pregnant women. Then medications are discussed, which have already been discussed elsewhere. Something seems to be cut and pasted in the wrong place and merely needs to be moved.
- Referring to the next page in the box on evidence-based interventions, Dr. Berner wondered if that specifically went with the intergenerational strategy section or if it was related to something else.
- Ms. Weber replied that it was related to the previous section.
- Dr. Olsen indicated that she made a list of various articles that she plans to send to Ms. Weber, which will pertain to different sections. Her specific comment was that the whole alcohol dependence section needs to be revised to lay the groundwork for recommendations

7 through 10. She plans to send information that will help to do this. She also pointed out that medications are discussed, but there is never a recommendation except for the generic one about conducting additional research on interventions. Perhaps they should add “including medications.”

- Dr. Warren is also sending information for this section as well.
- With regard to this same section, Dr. Floyd clarified that the group agreed in the beginning that they did not want to get into this fully, but they did not want to ignore it either. What it includes now is that there are guidelines for use of these pharmacological approaches in NIAAA’s guidance for clinicians. She thought they were better off endorsing NIAAA’s recommendations versus crafting their own recommendation.
- Dr. Olson thought the text should be clarified further to reflect this.
- Dr. DeJoseph suggested that rather than making this a section for alcohol dependence; they could make it a section for women who are at highest risk (e.g., those who are alcohol dependent, those who have a previously affected child, women in corrections, etc). Then they could tie medications in. This would still include Project MATCH, medications, and complementary and alternative therapies. However, complementary and alternative therapies are not strongly evidence-based. Anecdotally there is a huge amount of support, but this can be deleted if there is not strong evidence. She and Dr. Miller offered to re-write this section.
- Dr. Floyd did not think they should make a recommendation about treating alcohol-dependent women in this document. Stating that the guidelines exist should be sufficient. Perhaps their recommendation should be something related to expanding dissemination and acceptability of those guidelines to health care providers.
- Dr. Warren indicated that NIAAA’s “Clinical Guide” was developed to aid primary care physicians and other health care professionals with the appropriate management of alcohol use disorders, specifically alcohol dependence. The intent is to provide general information to all clinicians. Various versions of the guide are likely to be developed in the future that are likely to be more relevant to some practices than to others. The “Clinical Guide” is an extremely important document for clinicians, but there is not any recommendation in it that one should use medications with women who are pregnant. That obviously would be an exclusion criterion because the drugs are not approved for use in pregnancy. The bulk of the guidelines has to do with screening and includes an appendix which has prescribing information. The latest edition has information on various medications as well. The guidelines are on the NIAAA website. He said he was having difficulty understanding what the problem was with the paragraph in the Task Force document, although he understood the point that it got into a discussion of drugs, but did not address behavior. Rather than take the drugs out (because this is not just pregnant women, it is also includes women of child-bearing age), they could state in the Task Force document that the NIAAA guidelines include behavior-oriented patient management as well. They could state that “pharmacological and non-pharmacological” strategies can be found in the NIAAA guide.

NIAAA's main mission is to address alcohol dependence, which will continue until there are no more alcohol disorders.

- Dr. Olsen said that would tie into Recommendation #10, which says “conduct additional research on interventions.

Report from the NTFFAS Post Exposure-Working Group

Heather Carmichael Olsen, PhD

The writing group members for this report included: Carole Brown, EdD; Karla Damus, RN, PhD; Mary O'Connor, PhD; Melinda Ohlemiller, MA; and Heather Carmichael Olsen, PhD. CDC staff members included: Louise Floyd, DSN, RN; Mary Kate Weber, MPH; and Jacquelyn Bertrand, PhD.

With respect to the history of the “Call to Action” document, Dr. Olson reminded everyone that it was a follow-up on a motion made at an earlier meeting. The original idea was to write a letter calling for action and sustained momentum, which dovetailed with the realization that the Task Force would be ending within a year and with the possible end of the Center for Excellence. When a motion is made at the Task Force, they are required to act on it, which is what they have been working on for the past year. As the idea was discussed, the notion of a letter being something that would prompt action slowly evolved into a document that could be thought of as a “Brief Research & Policy Report.” This came from several discussions the writing group had with CDC and the realization of the parameters under which the Task Force operates, which are to provide technical assistance as opposed to putting forth statements that suggest exactly what should be funded or letters sent to bodies that may or may not actually be able to act on them as advocates. What evolved was the idea of writing a list of recommendations with a very short introduction and pertinent background information, which initially came before the recommendations, but which has since been moved to be background information that follows the recommendations. The important thing to realize is that this document was meant to carry out part of the Task Force's original mission of recommending “essential services for affected persons and their families / caregivers.”

Dr. Olson requested that the members keep in mind the purpose for this document and the fact that it could be looked at as complementary to the “Prevention Guide.” What the document is not and cannot be is what the “Prevention Guide” is aiming to be. Therefore, the “Call to Action” was not meant to be an evidence-based review because the areas that it covers (e.g., all of the essential services for affected persons and their caregivers) are far too broad because they include diagnosis, a full continuum of services, intergenerational strategies, etc). Thus, writing an evidence-based review would be an impossibly long document and, in fact, those kinds of reviews are slowly being developed as the research accumulates in other venues that are better suited to doing that. Therefore, the writing group kept their sights on what the document was, a “Brief Research & Policy Report” and did not aim to either do an evidence-based review or to make specific recommendations to specific agencies to do specific pieces of action. This is a very delicate balance. One of the questions before the full Task Force was whether this had or had not been accomplished because at its heart, this should be a useful and functional document. If it is, it should go forward and if it is not, it should not go forward. During lunch, Dr. Damus raised the idea that perhaps they needed to change the title to ensure that it is clear that this

document is not focused on prevention, but is focused on essential services for affected persons and their caregivers.

With respect to the aims of the document, the writing group wanted it to be a brief “call to action” and for it to make some strong statements, but they did want the statements to be based on evidence and to stay within the parameters of what is and is not known in the field. They thought of this as a document with a limited lifespan of approximately three years. Therefore, if it is a document with a brief lifespan because it is calling for action and for particular kinds of action, a rapid dissemination plan is required. The writing group also wanted the document to be useful as a credible summary. Dr. Floyd stressed to the writing group that if references existed, they should always be from peer-reviewed journals. Almost every reference is. This is very difficult when at the cutting-edge of a field and what exist are abstracts or expert consensus documents. However, the writing group tried to limit the use of those as materials they were referencing. What they wanted the document to do in a clear and user-friendly fashion, because they imagined that it would be used by groups who were promoting action, was highlight what had been done and the fact that a great deal still needs to be done. They wanted to make strong statements that some things are known, momentum should be sustained, and it should not be continually studied without action. At the same time, it needs to be clear that a great deal remains to be done. Dr. Olson expressed her gratitude to Drs. Warren and Sokol for reading the document carefully and making comments that highlighted the need to stay within the parameters of what is known and not to recommend actions that are not yet fully understood. They also wanted the document to stimulate interest in action and research.

Regarding the structure of the document, there is a two-page introduction, which is meant to be reproduced front and back and is concise and easy to read. They also wanted to have two to four pages of comprehensive recommendations, which is difficult when faced with a short introduction and a long list of recommendations. Currently, the recommendations are grouped into two categories at two different priority levels, although she did not think that the writing group agreed with themselves about this. If they simply include the first set of recommendations, this is another front and back section. If all of the recommendations are included, it is three pages. But then there is important background information for talking points, which they believe is current and well-cited, that is appended to the document—a good reference section that is not too long, but which is available for people who want more detail on particular recommendations. They also appended short (most two pages) lists of accomplishments and future directions for the federal agencies, the Interagency Coordinating Council, and the Task Force that are really carrying a lot of the momentum for FASD. As noted earlier, the idea was raised that they might want to cross-reference this with the “Prevention Guide,” so that they could really perhaps reduce information on prevention in this document and make its aim more clear. That would mean revising the initial introduction.

Given that the Task Force is sunsetting, Dr. Olson said that what the writing group was hoping for was to determine whether this document should go forth. If so, the plan is to complete the document before the Task Force sunsets. Therefore, during this Task Force meeting, they hoped the full Task Force would consider approval, non-approval, or an extension of time for comments. However, the only extension possible would be until the conference call in October, which would mean that another draft would be circulated for the full Task Force to consider.

Depending on approval outcome, the other issue they want the full Task Force to consider was a dissemination plan. The writing group has given dissemination some thought. Dr. Olson said her personal request to those representing liaison groups would be consideration for their particular liaison agencies whether and how this document could be used. She pointed out that the reason they were sitting at this table was because they were so important, and the hope was that this document would at least travel through those liaison agencies if useful and approved. Others they thought might be able to utilize this document include:

- FASD State Coordinators
- SAMHSA / CDC / NIAAA websites
- Focused dissemination opportunities, such as the FASD Leadership Institute in October in Atlanta for which there has been a request that at least materials from this report be presented for those thinking about future research in FASDs
- Family advocacy and other groups

Discussion

- Ms. Ohlemiller thanked Dr. Olson for shepherding this document, stressing that while she was very modest about it, she was the one who moved, shaken, and wrangled everyone together to make it happen. She requested that during the discussion, the group keep in mind the target audience. As opposed to thinking specifically about the research community, although the research community is included, this is more a community-based document. It is designed to be about as broad as it can be in terms of its reach, yet focused in terms of its intent.
- Dr. Sokol thought the document was substantially improved. Prioritizing the recommendations was helpful, and it gave him an additional thought. It seemed to him the business end of the argument of this document is that they have years of experience and 20,000 papers saying that FASD is a terrible problem. Many children are living with this problem and there some things that would be really good to have done. Having said that, he suggested putting the priorities in a slightly different order. He thought the first action needed to be that many people should push for recognition of a diagnosis. People cannot get these services if they are not paid for, and they are not paid for if there is no diagnosis. Whatever the diagnosis, this needs to be dealt with. This is a top priority. The second priority is that there is limited information about what can be done effectively, by way of secondary prevention, to improve the lives of these children and their families. Therefore, the second thing that needs to be done is get better information, which makes this document of interest to the research community. There is not a lot of work and it is only in the last few years that there has been any science about this. Third, he thought diagnostic access and so on would be appropriate.
- Dr. Boyle agreed with respect to the second level of priorities. All of these are important, which is why they are included. However, as a clinician, she stressed the importance of a recognized ICD-9 code in terms of obtaining services.

- Dr. Brown clarified that the first recommendation on page 3 does discuss diagnostic capacity. She wondered if his suggestion was that perhaps they roll together category recognitions with that.
- Dr. Sokol responded that he would modify categorical funding and diagnostic classification systems to be a top priority because he did not believe anything else will happen until this was done. Once it is a disease, it will appear in textbooks, curricula, etc. This will move forward what can be done for people.
- Dr. Brown agreed, but she thought the heading “Second Level Priority” was not necessary.
- Dr. Ohlemiller clarified that the tiers came from the original round of feedback. Another problem with doing so is that they risk alienating groups who feel like they are second tier who may not be so sensitized if it is just an ordering with no tiers. She was thinking particularly about the recommendation for adult services, given that there is a growing groundswell about what to do with adults with FASD, who may not take kindly to being in a second tier.
- Dr. Olson agreed. It was simply a suggestion. The writing group ranked the recommendations and Dr. Olson did a simple compilation rating them and then ordering them in the order the group consensus generated. These were originally in an order that was more logically derived, beginning with education and working up to the national forum. She likes the way this is done in the “Prevention Guide” with the recommendations highlighted in boxes and the evidence preceding them, but that is not what this document is about. She requested input about how to rank these in a way the Task Force felt comfortable with.
- Dr. O’Connor suggested eliminating some of the list or combining some of the items because the list is very long. A large laundry list may not be as effective.
- Dr. Olson recognized that it was difficult to know how to proceed. The last recommendation is at a different level of conceptualization. It does not fit because it is more specific, so that one could be eliminated without losing a lot of content, even though it is important. The preceding recommendation is the one for the national forum.
- Dr. Sokol said parent groups are mentioned repeatedly, so many times, it sounded defensive. He suggested taking a few of those out.
- Dr. Olson said there is a specific recommendation included and she felt strongly that it was one she would have ranked higher.
- Dr. Sokol clarified that he meant in the body of the document.
- Dr. Warren said he thought the document was vastly improved and that they should go forward with it. Referring to page 10, he said that while he wished it was a true statement

that “In some communities, sustained, multifaceted community action can result in measurable reduction in prevalence of FAS,” he was not sure it was true.

- Dr. Olson agreed that this sentence probably does need to be altered. The article cited (Astley, 2004) was sent to the Task Force a couple of years ago, but she thought it was reasonable to frame that sentence in a more speculative fashion. She said what she was attempting to do there was marshal evidence for the fact that there really is momentum to go forward, although she did not want to marshal evidence that is not sufficiently strong. The only other reference would be Phil May’s 1995 paper and Janet Hankin’s article.
- Dr. Warren said he was familiar with the literature and the works cited in the sentence before represent real evidence, while the Astley one is not. He suggested that deleting this would not harm the document.
- Dr. Olson responded that the concept was the same that they were discussing earlier in the morning, that they want multi-level intervention. Multi-level intervention could be introduced elsewhere. She agreed that the citations should be very defensible.
- Dr. Sokol suggested taking out the Astley sentence and stating, “It is reasonable to suggest that assessing different preventive approaches . . .” It will come out the same. If 1 in 100 or 1 in 200 births in the country are alcohol-affected, it is defensible without citing anything. There is plenty of documentation of many problems. These are some reasonable things that could be done to help.
- In response to an inquiry regarding why some segments of the document were highlighted, Dr. Olson responded that the document was circulated and commented on with some close editing by a couple of people. She considered that very carefully and then simply highlighted the portions that changed from the previous draft.
- Referring to page 10, an inquiry was posed regarding whether it was “prevalence” or “incidence” of FAS.
- Dr. Warren responded that this is “prevalence” because FASD is a lifelong disorder. New cases are incidence.
- Dr. Miller suggested removing the word “prevalence” because they are talking about exposure to fetuses.
- Dr. Floyd’s recollection of this study is that it was looking at children who presented to the clinic system in Seattle, Washington so they would have been of various ages. They would not have been newborns, so it really was a prevalence of the children who appeared there and were diagnosed with FAS at a point in time.
- Dr. Warren said he re-read the sentence and because it is new cases, it should be “incidence.”

- Regarding the idea of having two tiers, Dr. Wright wondered if any thought had been given to separating the research recommendations.
- Dr. O'Connor agreed, noting that the list is long.
- Dr. Wright also noted that this may also relate to the question of whether the document should have a different title. If the title is "Policy Recommendations," then research is a part of it. But starting out with "research" as an opening word, but then research does not appear until several pages in is problematic.
- Dr. Olson agreed that the "Call to Action" component of the title seemed appropriate, but she was unclear about the remainder.
- Dr. Damus said she thought they really had to make it clear that this document was targeting affected families and their caregivers. Although they are always looking for prevention of recurrence and occurrence, especially for the children who can become parents and have a range of issues, the document is supposed to be looking to services and support. However, this is not clear. She did not believe just changing the title would make this clear, although some of the suggestions made thus far in the discussion would make this more clear. The document has a very important mission and very important user base, and integrating the discussion would move it toward that direction. She thought this was a very necessary document, which would be a nice complement to the report from the Task Force.
- Dr. Sokol suggested "Fetal Alcohol Spectrum Disorders (FASD) Services and Support: A Call to Helpful Actions."
- Dr. Wright wondered where the thought was reflected in the document that the statistics have not changed. One of the reasons they have a call to action is that despite knowledge about specific interventions, the statistics have not changed.
- Ms. Ohlemiller suggested that this could be the introductory one-sentence cross-reference to the prevention document.
- Dr. Miller did not think they could categorically state that the prevalence has not changed. One recommendation is that they do not have good, on-going surveillance and that this is why they rely on the maternal alcohol exposure information so much. That can be referenced; however, while it continues to be a problem, she did not believe they could say anything about what the trends in prevalence are.
- With respect to the title, Dr. Brown suggested "Call to Action: Ensuring Essential and Evidence-Based Services for Persons with FASDs and their Caregivers." Rather than the research topics being separate recommendations, she suggested that they be included under each topic.

- Ms. Ohlemiller said the problem with “evidence-based” being in the title is that they had not walked people through an evidence-based journey like the “Prevention” document does. If they did that, it would be an incredibly short document. She suggested “Call to Action: Ensuring Research and Essential Services for Persons with FASDs and their Caregivers.” The first thing the writing group did was research the Task Force mandate so they would know what they were supposed to have accomplished with this Task Force. Some of the document is derived directly from that language.
- Dr. Floyd said she did not see anything in the document to build a science or evidence-based interventions for children affected.
- Dr. Boyle noted that in a lot of the recommendations, the mention is made of education of providers and of research. If two of the recommendations were more fleshed out in terms of one being for education of providers, which is in there, they could remove it from all of the other recommendations. Similarly with research, if they beefed up the recommendation about the research, they could remove that from all of the other recommendations.
- The final title suggested was “Call to Action: Building Essential Services and an Evidence Base for Identifying and Treating Persons with FASDs and their Caregivers.”
- Dr. Floyd thought they could end at “Building Essential Services” because part of the recommendations being made will address evidence-base. As the evidence builds, it would be incorporated into essential services. Otherwise, the title may be too long and lose impact.
- Dr. Olson concluded that the title should be something along the lines that clarifies that this document is about building essential services, which is part of the Task Force’s mission.
- Ms. Weber read the mission of the Task Force, “To foster coordination among all governmental agencies, academic bodies, and community groups that conduct or support FAS research, programs, and surveillance.”
- Dr. Berner disagreed with removing the last two recommendations, given that not everyone will read both documents. Dr. Olson removed this from the list of suggestions.
- Dr. Floyd noted that under the recommendation “Modify categorical funding and diagnostic classifications,” they have not made a statement as clearly as would be helpful about the need to delineate the FASD condition. The case definition seems somewhat different from the rest of this recommendation. She suggested removing the case definition out of that to give it its own bullet, and addressing the issue of the importance of arriving at consensus definitions of the criteria for the conditions that are part of FASD.

Dr. Olson recapped that the following suggestions would be incorporated in the final document:

- Craft the title differently.
- More clearly focus the first two pages on essential services.
- Remove the second level.
- Flesh out recommendations that are described.
- Change “Recommended Policy Response” to “Recommendations”.
- Categorize the recommendations according to some sort of system wherein the Task Force members all have a chance to provide their rankings, along with categorizing them (via email).
- Create subheadings for recommendations (e.g., #1, #2, et cetera) so people can pick out easily.
- Clarify delineating ARND: Pull that out in a separate recommendation and augment it in text.
- Move “Modify categorical funding and diagnostic classification systems” further up in the list.
- Dr. O’Connor has a minor change to a specific recommendation [which she will email given that she was breaking up on the phone].

Motion

Ms. Ohlemiller motioned to approve the finalization and dissemination of the document produced by the Post Exposure Working Group. Dr. Brown seconded the motion, which carried unanimously.

“Call to Action” Dissemination Discussion

- Ms. Ohlemiller wondered whether there was already a plan in place for the “Prevention” document, and if they could link the dissemination of both documents. She thought perhaps they could combine the dissemination discussion for both.
- Ms. Weber responded that the “Prevention” group had engaged in some dissemination discussions.
- Given that the “Prevention” document was not completed, a joint dissemination discussion could be complicated. Dr. Warren proposed that the “Call to Action” be sent to the following:
 - ICCFAS, because that does not end, with the recommendation that it be incorporated into all of the recommendations that come forward from the ICCFAS because it is a policy statement
 - Any other advisory committees that are continuing to go forward
 - NIAAA (request that it be incorporated into NIAAA’s strategic plan)
 - CDC to an equivalent location
 - Look at the Charter of the Task Force to determine where else it should go, such as HHS and the Surgeon General [Ms. Weber noted that there is a communication protocol at CDC with respect to FACA. The CDC Committee Management

Office sends it forward to HHS to be vetted, after which CDC can disseminate to whoever they wish)

→ Director of CDC or at least the Director of the Division

- Dr. Ohlemiller inquired about the timeline and whether CDC would shepherd this along, given that the Task Force is ending.
- Ms. Weber responded that it would need to be a group effort. She can deal with the FACA-required processes. Because this is a Task Force product, it will be included on the Task Force page on the CDC's website. In terms of any other dissemination, in their office, this will require further consideration.
- Dr. Olson inquired about publishing the document.
- Ms. Weber stressed that the document would not be disseminated by October 24, 2007, but the product must have final approval by then, at which time it can be forwarded to Committee Management, which will submit it to HHS, where it will remain for 30 days to be vetted. After that time, they could disseminate the product. Discussion about dissemination can continue after the sunset. The document can be disseminated to liaison groups and that other groups could disseminate it after the sunset (e.g., through NOFAS).
- Dr. Olson thanked the Task Force for supporting this document, stressing that the Working Group would work diligently to get it where it needed to go. She concluded that it had been a pleasure working with all of them.

Recognition of Task Force Liaison Members

Dr. Coleen Boyle

Dr. Boyle thanked everyone for their dedication, hard work, service, and for the products developed by the Task Force. She thought the products would have important impact for individuals and families affected by FASD. To acknowledge the contribution of the Task Force members, she presented each with a certificate in recognition of their service.

Dr. Boyle also acknowledged the excellent guidance and work of the Fetal Alcohol Prevention Team at CDC. She noted that Dr. Louise Floyd had been an expert in guiding this process, which involved a lot of work. Mary Kate Weber has served as a wonderful Designated Federal Official to the Task Force and has really helped to move the wonderful products forward. Jackie Vowell has provided guidance and administrative of this Task Force since its inception. Dr. Boyle asked that everyone give them a round of applause as well.

Dissemination of Task Force Products

Mary Kate Weber, MPH

During this session, Ms. Weber requested that the group further deliberate on dissemination ideas for either document.

Discussion

- Dr. Damus said that while putting these documents on the web is very important, not everyone will find them. There must be multiple locations in order to have the greatest

impact. The March of Dimes gets a lot of hits and they are continually adding information to their site which discusses issues around alcohol and the risks in the pre-conceptional and pregnancy periods. Academic Edge created a very good DVD that Dr. Sokol linked them up with, and they are happy to share any documents through the March of Dimes website. She thought a CD-ROM that included the “Prevention” report and “Call to Action” document, as well as some abbreviated slide sets would provide tools to help clinicians and policy makers talk about these documents with their audiences. They would also be willing to include the ACOG Tool Kit. CD-ROMs are cheap and easy to do, so having a central place to disseminate materials should be beneficial, in addition to the linkages to all of the websites they discussed earlier. She also thought when they released something like the Task Force products; they also should get it out in newsletters of professional organizations, not just nationally but in their local sections or districts. Every state has Association of Women’s Health, Obstetric, and Neonatal Nurses (AWHONN) representatives. There is also family medicine, health departments, the Association of Maternal and Child Health Programs (AMCHP), etc.

- Dr. Wright wondered if there were ways to introduce the Task Force products into ACOG and AAP journals. Ms. Weber responded that that was the approach used with the guidelines. After publication of the full report, they could also summarize the work in shorter pieces in these journals.
- Dr. Berner said he would certainly like to get the products into the hands of the AAP Committee on Substance Abuse as soon as possible, even if it was only a draft. They are currently working on a revision of the FAS policy for AAP.
- Ms. Ohlemiller noted that now that the Center for Excellence has been extended, they will be a key partner because they have a mailing list of liaisons in all 50 states. They also keep track of which states have task forces and coalitions, many of which are also made up of state health departments, faculty from universities, opinion leading physicians, etc. They should be encouraged to disseminate widely through their state systems, which would have a pretty deep reach.
- Dr. Davis said the Arc was always available to help disseminate. The products could go on the Arc website, listserv, to the chapters, to their public policy staff, et cetera. She could facilitate getting the documents to the national office.
- Dr. Brown wondered if the Arc disseminated to the Council for Exceptional Children, parents, special education networks, etc. Dr. Davis responded that they do not unless there are representatives of those groups on the listserv.
- Ms. Ohlemiller indicated that the Arc does have a policy division, works with United Cerebral Palsy, and does some work on the Hill, so it would be useful to get the document into their hands.
- Dr. Olson suggested the American Academy of Family Physicians.

- Ms. Weber indicated that they would connect with Mark Mengel from St. Louis. It was also noted that Susan Rich with the American Psychiatric Association was working to get FAS in the new version of the DSM and is interested in the work of the Task Force. Ms. Weber requested that all other ideas be emailed to her
- Dr. Wright inquired as to whether the group believed they were ready to make a motion about the “Prevention” report. The consensus was that, given the significant number of revisions required, the document was not ready to be voted upon.
- Dr. Warren inquired as to whether approval could be voted upon via email. Ms. Vowell said that this may be a possibility, but indicated that there are rules for FACA-Chartered committees and that she would have to check with CDC’s Committee Management Office.

Public Comment / Adjourn

With no public comments offered or further business posed, Dr. Wright formally adjourned the first day of the Task Force meeting at 4:00 p.m.

Thursday, September 13, 2007

Call to Order / Review of Previous Day’s Discussion

Jean A. Wright, MD, Chair, NTFFAS

Dr. Wright called the meeting to order at 9:00 a.m. With respect to the previous day’s discussions, Ms. Weber indicated that she would review all of the comments that were made. While she may be able to act on some of the suggestions without follow-up, she may need to seek additional feedback from some members who made specific suggestions, particularly those who had information / resources they thought should be incorporated. For example, Dr. Warren had information on multi-level intervention projects and Dr. Olsen volunteered to write two paragraphs within the alcohol dependence section, highlighting some of the work done with substance abusing women and families of women with FASD. Ms. Weber will work with RTI and the working group members to make the proposed modifications. As soon as the modifications are complete, she will disseminate the revisions to members for review. She expressed her hope that the document would have received enough review by the October 24, 2007 conference call to receive approval of what has been outlined. Upon her return to the office, she planned to develop and send a timeline to members.

FEDERAL UPDATES:

Interagency Coordinating Committee on Fetal Alcohol Syndrome

Kenneth R. Warren, PhD

Dr. Warren indicated that the purpose of the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS) is to improve communication, cooperation, and collaboration among disciplines and federal agencies that address issues related to prenatal alcohol exposure. ICCFAS was first established as directed in an appropriations bill in 1996. Unlike the NTFFAS, because the membership is all federal agencies, ICCFAS does not expire, does not operate with a charter, and is not a FACA committee. Virtually every agency is represented on the ICCFAS, with the exception of the FDA. Given that there are no drugs approved for use in pregnancy related to alcohol, the FDA does not currently have a role. The following link <http://www.niaaa.nih.gov/AboutNIAAA/Interagency> leads to the ICCFAS organizational chart.

The themes around which the ICCFAS bases the foundation of its work include prevention of drinking during pregnancy; intervening with children and families affected by prenatal alcohol exposure; improving methods for diagnosis and case identification; increasing research on etiology and pathogenesis; and increasing information dissemination. In addition to the ICCFAS Executive Committee, they currently have three special Work Groups to implement high priority goals and special projects: Women, Drinking, and Pregnancy Work Group; Juvenile Justice Work Group; and Education Work Group. Work Group Members include agency representatives, researchers, educators, parents, medical professionals, and legal professionals.

On May 9, 2007, closed meetings of the three ICCFAS Work Groups were convened. For the Education Work Group, this was a planning session for their July 2007 Symposium. The Juvenile Justice Work Group reviewed progress toward 2001-2006 recommendations and the agencies' projects on justice issues. In addition, they prioritized efforts for next year. The Women, Drinking, and Pregnancy Work Group reviewed their priorities, began initial development of their vision and mission statements, and began planning for a 2008 workshop, symposium, or conference.

On May 10, 2007, an ICCFAS Public Meeting was convened. This meeting included a Plenary Session that pertained to evidence-based, best, and promising practices. Presentations included the following:

- Evidence-Based Practice and the Evidence-based Practice Centers
Charlotte Mullican, MPH, AHRQ
- SAMHSA FASD Center for Excellence Environmental Scan of Best Practices for FASD Prevention and Care of Persons with FASD
Callie Gass, NG, SAMHSA
- Indian Health Service Environmental Scan of Promising Practices in Native American Communities and Health Systems
Judith Thierry, OD, MPH, HIS

The ICCFAS Research to Practice Meeting, which was a public meeting convened on July 12 – 13, 2007 included the following attendees: 11 FASD experts from the Biomedical Community; 5 representatives from FASD advocacy groups; 7 parents of persons with FASD; 5 other FASD Experts; 6 directors of school programs relevant to FASD; 6 U.S. Department of Education-funded researchers, demonstration project leaders, directors of technical assistance programs; 9 school teachers; 5 other school staff; and 12 staff from ICCFAS agencies. The idea of the meeting was to bring together the FASD research community and the relevant members of the education community and have them engage in a dialog about FASD and education. Leaders of information dissemination in the education field attended. They provide information to schools and teachers about the Individuals with Disabilities Education Act (IDEA), No Child Left Behind, and other federal programs. Representatives from the federal center that dispenses information on training for the education community were there as well.

The emphasis at this meeting regarded what the U.S. Department of Education could do to improve education outcomes for students with FASD. The July meeting focused on how the U.S. Department of Education could stimulate activity at state and community levels. The overall purpose of the meeting was to: 1) exchange evidence-based information about the impact of prenatal alcohol exposure on the intellectual, social-emotional, and behavioral functioning of school-aged children; 2) explore the implications of prenatal alcohol exposure on teaching and learning for affected students; 3) share information on state and local education agency initiatives to address the needs of students affected by prenatal alcohol exposure; and 4) increase the understanding of how to support the capacity of state and local education agencies in their efforts to improve educational outcomes for students affected by prenatal alcohol exposure.

Meeting activities included an FASD overview by the biomedical experts, an introduction to the 2007 education landscape, three examples of effective FASD programs, and progress reports from in-progress projects. Group discussions included the implications of FASD for teaching (common/shared understanding; utility of a diagnosis in the educational setting; focus on individualized instruction; focus on systems coordination and capacity-building). The examples were shared, each one different in size, scope, and funding source: Davis Livingstone School in Manitoba; State of Alaska Program; and a new program in Minneapolis Public Schools. A summary and proceedings are being prepared and will be posted online.

Dr. Warren said he went to this meeting with a major question in mind: Does etiology matter? That is, if someone has a particular deficit, is it important to know the cause of that deficit in order to address it in an educational and/or clinical setting? The very strong answer from a number of authorities who were there was that etiology does matter very much. This knowledge is extremely important and valuable, and emphasizes the need not only to identify individuals who have a particular deficit (e.g., reading, education, difficulty interacting with peers), but also the need to have some information about the etiology (and whether alcohol is the cause of the etiology).

Dr. Warren then highlighted the activities of other members of the ICCFAS. With regard to the Department of Education, Office of Special Education & Rehabilitative Services, each year the National Association of State Directors of Special Education (NASDSE) Project Forum and the U.S. Department of Education Office of Special Education Programs issue several reports on special issues of importance in education. In January 2007, NASDSE published a report describing FASD initiatives in several states. Of the 27 states responding to the NASDSE survey, only Alaska, North Dakota, Florida, and Maryland said they had special FASD programs. The Department of Education is currently reviewing and evaluating service delivery for students with FASDs across a range of educational service models, and is exploring the relationship between students with FASDs and IDEA 2004 provisions regarding response to intervention, early intervention services, and progress monitoring.

In the summer of 2007, the Department of Justice, Office of Juvenile Justice & Delinquency Prevention (OJJDP) announced several different generic RFPs for Field-Initiated Research, Demonstration, and Evaluation projects. FASD experts were encouraged to submit FASD-relevant proposals in response to these solicitations. In FY2007, OJJDP also funded a project to

survey how well health care needs are met for persons in state juvenile justice facilities. One of the health issues included on the survey list is FASD.

For the Agency for Healthcare Research and Quality (AHRQ), the highest priority for unsolicited applications to AHRQ in FY2007 was research on systems and organizational interventions for improving healthcare quality for low-income people in under-resourced settings and communities. FASD experts were encouraged to submit applications.

In FY2007, the Health Resources & Services Administration (HRSA) worked with Children's Research Triangle Park and NOFAS on screening for alcohol use, knowledge about FASDs, and patient education at five HRSA Community Health Centers (CHC) and three Maternal and Child Health Sites. In FY2008, this project will be extended to additional sites. Patients at the 97 HRSA Healthy Start sites are screened for alcohol use, counseled, and referred, as appropriate. This fall, HRSA will be conducting a new training session on FASD for Healthy Start staff. The training session will be available via videocast for future use. HRSA has also funded a contract to assess the effectiveness of risk assessment tools that combine identifying domestic violence, depression, substance abuse, and alcohol use. The goal is to define best practices.

Indian Health Service (IHS) surpassed its 2007 Government Performance and Results Act (GPRA) goal of screening 28% of 15-44 year old females for alcohol use. Thus far in 2007, 41% of women of childbearing age have been screened at IHS sites and reporting tribal facilities. The DHHS-Health Canada Memorandum of Understanding FASD Workgroup has completed its 5-year work plan. The focus has expanded with a new emphasis on Maternal and Child Health. An earlier developed memorandum of understanding was to meet regularly and share information and ideas between Health Canada, IHS, and Native Americans in Canada and a U.S. Working Group on FASD was formed in 2004 and consists of 9 Canadian members and 12 U.S. members. These groups continue to meet regularly and share data and information and ideas on health services and data collection.

FASD-related research is found throughout the research portfolio of the National Institute of Child Health and Human Development (NICHD) including projects supported through the Child Development and Behavior Branch, the Perinatology Branch, and the Mental Retardation and Developmental Disabilities Branch. Projects include basic and applied research and support for scientific meetings with sessions on relevant topics. FY2006 funding for projects with direct relevance to FASD totaled \$4 million. Additional millions of dollars fund projects studying basic research on maternal health in general, overall childhood development and well-being, with numerous projects on cognition and behavior. Funds are allotted for basic research on normal development as well as developmental disabilities. Several large centers are supported, which provide resources for studies on child development. The Prenatal Alcohol in SIDS and Stillbirth (PASS) project is a collaborative effort of NICHD and NIAAA on prenatal alcohol exposure, FASD, SIDS, and stillbirth and has been funded for a Phase II to determine critical factors in high-risk babies. Recruitment of subjects of Phase II has begun at clinical sites. Just this week, the first of 12,000 children to be included in the study was born in Cape Town, South Africa.

Substance Abuse and Mental Health Services Administration (SAMHSA) has awarded a second five-year contract for an FASD Center for Excellence to Northrop Grumman. The new contract

began on August 1, 2007. Tasks and activities will reflect a shift in focus from raising awareness about FASDs to disseminating information about what works and fostering effective interventions. A smooth “transition” is underway, as is an Expert Panel selection process. The Center will issue new RFPs for subcontracts in late September, and staff is currently updating the website. RFPs will address: decreasing the incidence of FASD through evidence-based programs to decrease alcohol consumption among pregnant women; and improving functioning and quality of life of people with FASD and their families. The targeted applicants are state agencies, juvenile courts, and public and private non-profit organizations. The RFPs are to be posted on www.fasdcenter.com.

All public ICCFAS meetings are announced on the website, and the website also contains information about the ICCFAS membership and has electronic links to websites of member agencies and their programs.

National Institute on Alcohol Abuse and Alcoholism

Kenneth R. Warren, PhD

Dr. Warren reported that the NIAAA budget had been a little over \$25 million for the past three years. NIH has had a flat budget for the last few years, which is also reflected in the NIAAA budget. In the context of FY2006, the funding portfolio for research on fetal alcohol spectrum disorders totaled \$26.3 million, which was broken down as follows: diagnosis 11%, etiology 60%, interventions 6%, and prevention of drinking during pregnancy 23%. The 2007 figures are expected to be at least as high.

With respect to major NIAAA FASD-related activities, FY2007 included a review of the NIAAA-FASD extramural research portfolio by the NIAAA Extramural Advisory Board in February 2007; approval of EAB recommendations by the NIAAA National Advisory Council in May 2007; and review and renewal of the CIFASD projects. The recommendations of the NIAAA Extramural Advisory Board regarding how NIAAA should be pursuing its research on FASD included the following:

- *Define the full range of FASD phenotypes and endophenotypes across the life-span using advanced methods, technologies and applications from integrative biology / systems biology and database approaches.*
- *Produce data-driven consensus criteria for diagnoses of the full spectrum of prenatal alcohol-derived disorders.*
- *Improve prenatal and develop early postnatal identification of individuals who have been exposed and are at risk.*
- *Explore and expand domains for early identification of affected children including: dysmorphology, neurobehavioral assessment, brain morphology and function, sensory systems, circadian regulation, immune and other systems.*
- *Develop and validate biomarkers to assess the exposure and insult to the mother and fetus.*
- *Evaluate tiered screening starting with commonly ascertained, less specific biomarkers and moving to more targeted markers (e.g., FAEE, ethyl glucuronide, micro and macronutrients, pre- and post-natal ultrasound...genetic polymorphisms).*

- *Correlate markers of exposure with improved methods for ascertaining drinking history (quantity, frequency, timing, maximum) before and during pregnancy, and correlate both with outcomes.*
- *Conduct analyses of pre- and postnatal nutritional, genetic, epigenetic and environmental factors to determine risk or protective factors and co-morbidities (e.g., tobacco, other drugs) that may alter susceptibility and natural history of FASD. Partner with other ongoing studies to achieve this end.*
- *Encourage studies of early interventions in high risk and affected children, and develop interventions for problems later in life.*
- *Assess the safety and efficacy of interventions (e.g., nutritional, pharmacological, neurobehavioral, and environmental) during peri-conceptual, pregnancy, and lactation periods.*
- *Elucidate biological mechanisms that contribute to ethanol teratogenesis in a range of experimental models and in humans, including mechanistic links to biomarkers and treatment.*
- *Pursue mechanistically-driven design and testing of therapies that antagonize or mitigate the effects of prenatal ethanol exposure.*

In all of these activities, the Extramural Advisory Board encouraged NIAAA to:

- Explore ways to partner with other NIH institutes, government agencies (VA, SAMHSA, CDC), other countries (e.g., Canada), and healthcare systems (HMOs, Kaiser) to accomplish these aims.
- Engage a range of disciplines from molecular genetics to social psychology that address neurodevelopmental problems of children.
- Support the routine collection and banking of biomaterials, such as hair, meconium, serum, cells, and DNA for future analysis.

Major NIAAA FASD-related activities during FY2007 included an RFA for competitive renewal of cooperative agreements under the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD). Funding will be awarded for five more years of support for eight existing projects and funding of two new projects and principal investigators to join the CIFASD program. The overarching CIFASD theme is to utilize clinical and basic science projects to facilitate and enhance the diagnosis and treatment of both FAS and FASD, particularly ARND. These questions are approached best through a collaborative international effort. CIFASD involves six countries on three continents. The CIFASD Network has three core support facilities, three basic research projects, and four clinical research projects. The key CIFASD research goals are to:

- Use state-of-the-art psychometric instruments to refine and improve the parameters on the neurobehavioral phenotype(s) for FASD.
- Develop innovative technologies for case recognition, including advances in 2-D and 3-D imaging technologies to reliably distinguish facial features of individuals with a clinical diagnosis of FAS from controls (across lifespan). An interesting paper related to 3-D imaging will appear in *Alcoholism: Clinical and Experimental Research* in October.

- Address, through non-invasive imaging and neurobehavioral assessment, the relationship of brain structural abnormalities to specific neurobehavioral profiles (humans, mice, and sheep).
- Address, through non-invasive imaging and 3-D facial analysis, the relationship of facial dysmorphism to brain structure (human, mice, sheep).
- Explore prenatal ultrasound as a diagnostic approach for FAS and FASD case recognition.
- Apply gains in knowledge from these findings to improved FASD diagnosis and intervention.
- Explore nutritional risk factors and modifiers associated with outcomes in offspring (prospective study).
- Apply gains in knowledge on nutrition (e.g., choline?) and other modifiers for prevention and intervention.

Discussion

- Dr. Damus inquired as to why the National Institute of Nursing Research and the Office of Minority Health were not involved in the ICCFAS.
- Dr. Warren responded that they were originally. Although they originally had a staff person involved, currently they have chosen not to send an individual. He thought it was worth pursuing and indicated that he would tell Sally Anderson, the Executive Secretary for the ICCFAS, to follow up on this. They had had very active participation until a few years ago from the Nursing Institute; however, when the key staff person left to take another position, no one filled in behind her. The Office of Minority of Health has always been involved in this activity, although they have had some personnel turnover, which is why there has not been a representative in attendance. The Office of Research on Women's Health is another logical office to be involved. He agreed that it was time to make an effort to get these particular entities attending the meetings and doing whatever they can. Even if they cannot contribute funding, contribution of their intellectual insights would be very valuable.
- Dr. Damus said she would also expect the Healthy Start Initiatives to be very much involved. This is a very important vehicle to make a difference, especially once these wonderful products are available. She also thought FDA should be involved because they are now very much into the notion of life course perspective and pre-conceptional and inter-conceptional health. As more things become available, they really do need to reach out to the FDA.
- Dr. Warren responded that HRSA is involved. The Bureau of Maternal Health is an active member and they do attend, and a number of people from HRSA attend every meeting. He also agreed that FDA should be involved as well.
- For the record, Dr. Brown noted that the meeting in July was very helpful for the people from the special education perspective. The nine teachers were her Masters students, and there were a number of seasoned technical assistance people in special education for whom it was a huge shift in terms of their understanding of FASD. If only four states have

anything to respond to in a survey, that is a seriously low number. She said she thought the National Association of State Directors of Special Education is a prime target for receiving the products of the NTFFAS and any future products.

- With regard to workforce development, Dr. Prue wondered where training the workforce about screening and practices fit.
- Dr. Brown responded that it had been “left in the dust.”
- Dr. Morris indicated that in her state, the Perinatal Substance Abuse Prevention Committee met with the State Department of Education, which told them that the State Department of Education was only there to make sure that federal guidelines were followed, and since FASD was not mentioned in IDEA and other areas, FASD was therefore not going to be dealt with at the state level, although the districts could do whatever they pleased.
- Dr. Prue wondered whether this should be part of these documents the NTFFAS was preparing.
- Dr. Ohlemiller said they made an attempt to address these issues with the new IDEA regulations, but it did not go anywhere. Their intent is to keep that alive somehow, someday. It is a huge problem in her district. Most states would have to physically add FAS to their state policy regulations, and most states are not going to do that. They are not looking for new things to fund.
- Dr. Olsen indicated that they have it included explicitly and tied to IDEA in the current “Call to Action.” It is a pervasive, serious problem. That was one of the problems with ranking the recommendations because they thought that was the number one recommendation, yet there are so many things that have to be done, it was further down on the list. Perhaps they could draw it out and make it higher priority in the newer version.
- Dr. Warren asked whether any state had implemented anything. He thought Alaska would have, given that they tend to lead the way.
- Dr. Berner responded that the state developed its own guidelines years ago. It is now enshrined and no one seriously questions it. The arguments every year are related to the percentage of funding that these particular programs receive, but they are always considered non-political and are funded equally well or equally poorly, depending on the state’s fortunes, by whichever party is controlling the administration.
- Dr. Olson indicated that in Washington, it is not named and it is very difficult to get funded based on any sort of alcohol-related diagnosis. It has to be qualified as “other health impaired.” Typically, ADHD is the way people choose to qualify a child.

Centers for Disease Control and Prevention

R. Louise Floyd, DSN, RN

Dr. Floyd reported that CDC's focus had been very much on the two Task Force reports, and will continue to be. In addition, at the annual meeting of the Research Society on Alcoholism in July 2007, CDC presented a symposium on Project CHOICES interventions and adaptations of the CHOICES model by CDC and other federal agencies, including SAMHSA's Center for Excellence and two projects funded by NIAAA looking at determinants of change in interventions with pre-conceptional, high-risk women. Also, CDC just awarded TKC Communications a three-year contract to translate, market, and disseminate the CHOICES intervention model to targeted populations of women at risk for an alcohol-exposed pregnancy. Deliverables will include preparation of a training curriculum, a user's manual, and a participant workbook and materials. They will be testing these materials through train-the-trainer workshops. In addition, Dr. Bertrand presented on the interventions and results of their five "Intervening with Children with FAS / ARND" Phase 1 projects at the joint meeting of the ICCFAS Education Working Group and the Department of Education in D.C. in July 2007. Those projects are now in Phase 2 of implementation.

CDC continues its work in surveying health provider groups about knowledge, attitudes, and practice behaviors regarding FASD prevention. In addition to their work with ACOG mentioned earlier by Dr. Sokol, they are planning a survey of family practice physicians in 2008. They are also finalizing the Regional Training Centers Training Curriculum on FASD for production and release in the next three to six months. The Regional Training Centers are now in the third year of their second round of funding. Later this year, CDC will be releasing a core curriculum developed by the Regional Training Centers, CDC, and NOFAS that covers the seven core competencies.

A contract was awarded to NOFAS through TKC Communications for dissemination and evaluation of the K-12 curriculum developed last year through funding from CDC. They are also preparing an FY2008 Funding Opportunity Announcement to address intervening with women with multiple behavioral risk factors that co-occur with alcohol misuse. There is continued support of the CDC Preconception Care Initiative through work with the Select Panel on Preconception Care and assistance for the upcoming summit meeting in October in Oakland, California. CDC has a presentation on health disparities and multiple risk women, which includes alcohol misuse, and input into a number of the sessions that will be presented at this summit.

Discussion

- Dr. Damus asked how large the sample was of the survey of provider groups.
- Dr. Bertrand responded that this was a sample of over 600 psychiatrists drawn from a listing that Battelle keeps of medical professionals that are very representative. It is broken down into two groups: 1) those who focus on women (primary prevention types of issues with questions similar to the ACOG survey); and 2) those working with children (with questions similar to the pediatrician's survey about recognizing children with FASD). Those are not mutually exclusive groups. The hope is to get it on their radar screens. What is coming back are the usual things they hear, such as they are not thinking of FAS or

alcohol exposure. CDC sees psychiatrists as a really important group who should be thinking about these issues. The practitioners are saying the same things (e.g., they did not receive adequate training; they would like some CME training, etc). With regard to the 2007 ICCFAS/Department of Education meeting Dr. Warren discussed, Dr. Bertrand indicated that four out of the five intervening projects were presented there. In the fifth, the children were too young. She continues to receive very positive, enthusiastic feedback from the presentation. Those four sites have all been contacted by different states and people wanting to obtain and implement their interventions. They have been trying to work with the Department of Education for years, and that meeting really cracked it wide open. It was a great meeting and people are thrilled.

- Mr. Ohlemiller inquired as to how the information from Phase 1 will be distributed beyond that symposium. She wondered if papers were being written about Phase 1 or if they were waiting for Phase 2.
- Dr. Bertrand responded that she was thrilled to report that they have a full draft of an overview paper out to all five sites for review. CDC is discussing where to publish it, and she requested ideas about others who should receive it. Beyond that, they likely will engage in other dissemination efforts, such as letters to editors. Dr. O'Connor has published her individual Peer Friendship Development Project in *Clinical Psychology* and the Marcus Institute's project was in *ACER* this summer. Along with the overview paper, each of the sites will be publishing their results.
- Dr. Ohlemiller inquired as to whether there had been any thought of offering trainings around the key concepts of these grants. This is really a first and there is a lot of anticipation to know the outcomes of these projects. She suggested that if there are discretionary dollars, some sort of trainings should be offered so that State Departments of Education, as well as individual providers, could readily access this information right out of the hands of the people who were developing the projects.
- Dr. Bertrand replied that it was a great idea to organize a "traveling road show" of some sort, especially since Phase 2 moves the projects into community settings. This has been shown to be efficacious in university settings with graduate student free labor and many extras, but how it will function stripped down and in the real world of limited staff, turnover, etc. remains to be known. This is a great group to be doing this because they have firsthand knowledge now of what it takes to do this in a more realistic setting.
- Dr. Ohlemiller pointed out that it would also raise credibility and awareness.
- Dr. Brown noted that the National Association of State Directors of Special Education has an annual meeting, which is sometimes timed with the Office of Special Education Special Projects meeting.
- Dr. Berner suggested sending this information to the IHS providers as well. This is a perfect topic for providers and the IHS will put it out to every tribal health program in the U.S. People forget that even though things are distributed in the professional communities

involved in education, this would be good to provide to IHS Tribal providers because they work with Tribal school systems. They do have a newsletter that publishes papers, not as an independent journal, but of topics that have been synthesized that are of special interest, which this would be.

- Dr. Bertrand noted that the project in Oklahoma, which is younger children, is working with several Indian Nations. Clearly, the meeting in July and these projects dispelled the myth, “Let’s not diagnose it because there is nothing that can be done.” That is a pretty big accomplishment.

SAMHSA FASD Center for Excellence Update

Provided by: Mary Kate Weber, MPH

Ms. Weber presented the update for SAMHSA, reporting that the first iteration of the FASD Center for Excellence ended on July 31, 2007. SAMHSA awarded a new contract for the FASD Center to Northrop Grumman that began August 1, 2007. The Center’s focus has shifted from raising awareness about FASD to disseminating information about promising practices and to incubating new effective and evidence-based interventions. The challenge is to build on what have been learned. The second iteration of the FASD Center will continue many of the same activities, with some new enhancements or modifications that reflect the shift in focus. With respect to oversight, a 15-member Expert Panel will replace the 30-member Steering Committee. The panel’s purpose will change from providing guidance on the overall direction of the Center to more focused advice on specific Center products and activities.

Providing technical assistance/consultation and training to the Center’s target audiences will remain a cornerstone of the FASD Center’s activities. Going forward, the Center will focus more of its training and technical assistance on implementation of evidence-based practices. The audiences include the new subcontractors and their partners, states, communities, health and social services providers, faith-based organizations, Tribes and Tribal organizations, and community-based providers who work with FASD. In the second iteration, the Center will also provide trainings for SAMHSA’s Centers for Applied Prevention Technology (CAPT) and Addiction Technology Transfer Center (ATTC) Network. Curriculum development will focus on the development or modification of two curricula targeted at priority audiences or on priority topics. Staff will also develop two web-based tutorials on FASD.

In terms of FASD prevention and treatment subcontracts, the Center will release a new RFP in late September. Applications will be accepted from states, local communities (including Tribal governments), and juvenile justice systems. The process will be a full and open competition. The new RFP reflects an enhanced focus on services for adults and incorporates lessons learned from the first FASD Center subcontract. Those lessons include:

- Funding organizations that reach or serve high risk populations
- Funding those organizations that have the authority to change service delivery policies and procedures
- Specifying the evidence-based practices to be implemented
- Providing technical support from the developers of the evidence-based practices
- Specifying and supporting data collection/reporting for evaluation

The Center's promising practices activities will aim to increase the number of FASD programs eligible for the National Registry of Effective Prevention Programs (NREPP) and provide technical assistances to selected programs that want to apply the NREPP. Activities will include a new "Science to Service" project. The goal is to increase the number of evidence-based FASD programs by awarding funds to programs to evaluate their interventions and use that outcome data to assess the programs for inclusion in NREPP.

With respect to developing comprehensive systems of care, the Building FASD State Systems (BFSS) meetings will resume next spring. Through the Center, SAMHSA will continue to support the National Association of FASD State Coordinators (NAFSC) as it continues to expand its membership and focus. In addition to enhanced support to develop the NOFAS Birth Mothers Network, this second iteration of the Center will pursue an active outreach effort to engage other agencies and organizations with an interest or potential interest in FASD.

Information dissemination was and is the Center's most visible activity, and includes the following:

- The Center's website will be enhanced to include podcasts and RSS feeds. While no major revamping is anticipated in the near term, plans call for the inclusion of a more science-driven content focus on promising practices, a new focus on capacity-building activities, and more audience-specific pages.
- The FASD Call Center will continue and will embark on a marketing effort to double or triple the current volume of calls.
- The FASD Viewing Library will continue to be housed in the FASD Center office in Rockville, Maryland.

In terms of data collection and analysis, the Center will continue to identify trends and gaps by conducting an environmental scan of the current state of the field of FASD and by continuing to develop the searchable FASD database.

LIAISON UPDATES:

American College of Obstetricians and Gynecologists

Robert J. Sokol, MD

[Note: This update was actually presented during the first day of the meeting; however, it was included here with the other Liaison Updates for ease in reading].

Dr. Sokol reported that the American College of Obstetricians and Gynecologists (ACOG) had continued along the lines he described during the last Task Force meeting. Over 15,000 of the Tool Kit CD-ROM and brochures have been distributed. It is unknown how many of those have accessed it on the ACOG public website, but 15,000 is a large number and they are sent out generally on request. It is frequently being utilized in conjunction with face-to-face training programs at regional and statewide meetings. Tool Kit order forms were included in the meeting bags for the 6,000 participants of the ACOG annual clinical meeting in San Diego in May and the Tool Kit was featured in the clinical meeting's daily newspaper. The Indian Health Service (IHS) has promoted the Tool Kit to its providers, both in meetings and in publications, resulting in a large number of orders from individual IHS clinics. The Tool Kit has been promoted via newsletter in Canada and Australia, and both hard and electronic copies have been distributed.

The Tool Kits will continue to be distributed to individuals ordering it. In addition, it will be further promoted within smoking cessation and state women's health programs. This effort has been very successful.

ACOG, in conjunction with CDC, will administer a survey that is a follow-up to a survey conducted in 1999 or 2000. The questions are very similar, so they should be able to assess ACOG Fellows' knowledge, attitudes, and practice regarding FASD prevention, as well as recognition and use of the Drinking and Reproductive Health Tool Kit in order to determine whether clinicians' behaviors have been modified over time. Dr. Sokol believes it will be beneficial to conduct another of these in a few years to gauge the outcome of the Tool Kit. The survey is due to be released in September, although it will take a while to receive back and analyze.

At the ACOG Annual Clinical Meeting in May, a Fun Run to benefit NOFAS was held, which was sponsored by a pharmaceutical company. About 100 Fellows and their family members paid the registration/donation fee and braved the early morning hour and chill to help eradicate FAS/FASD.

Dr. Sokol shared a commentary he wrote titled, "Preventing FASD: A Word to the Wise," which the President of ACOG requested he write. This is a commentary that will be out in a few months. It will be published in a publication that goes out with the *Green Journal*, which goes to every member of ACOG. It is one of the largest and highest impact clinical OBGYN journals in the world. He included it because it is short and provides one perspective, his own, regarding what professionals can and should be doing for primary prevention of FASD. He expressed his hope to use this as a final opportunity to state that ACOG has been working closely with the Institute and CDC for many years, and that he hopes this will continue until there is evidence that the prevalence of FASD has been reduced. Although this was difficult to write, Dr. Sokol said the reason he agreed to do so was because there was an article in the journal about five years ago regarding cesarean section on demand, which had very high impact.

**American Academy of Pediatrics
George Brenneman, MD, FAAP**

Dr. Brenneman said that while he had hoped that there would at least be a draft of the new American Academy of Pediatrics (AAP) FAS policy statement that has needed revisions for quite some time, it was not yet available. It does keep the door open for him to give drafts of the two Task Force documents to the Committee on Substance Abuse in the AAP, who could review the contents. He thought this would be of great value to them as they revised the AAP FAS policy. He thought the "Post Exposure" document especially would be of value to the AAP policy, particularly with respect to the concept that the AAP has about the medical home, which is an important concept for children with special needs.

Dr. Brenneman gave an update on the AAP National Conference and Exhibition which will convene in San Francisco this year. In reviewing the content for FAS-related presentations, he identified the following:

- A two-hour seminar, which will be held twice, titled “Substance Abuse from A to Z: Early Prevention or Dreadful Consequences?”
- A two-hour seminar, which will be held once, titled “Prenatal Exposure to Drugs and Medications: What Does the Evidence Tell Us?”
- At least one presentation as a plenary session has to do with adolescents, “Adolescence: The Critical Focus on Substance Abuse.”

This shows that there is some interest on the part of the AAP and its members to deal with some of these relevant issues.

The Arc

Sharon Davis, PhD

Dr. Davis reminded everyone that the Arc advocates for people with intellectual disabilities and their families, and is also actively concerned about the prevention of intellectual disabilities. With respect to FASD, the action takes place with their 900 chapters that are advocating or providing services. Ms. Ohlemiller, for example, is supporting families and people with disabilities as well as advocating and working toward prevention of FASD. At the national level, one of the most important things they do is their public policy effort. They have a highly respected public policy staff, which is why this would be a good venue for dissemination of the Task Force products. The public policy staff is very active with the Consortium for Citizens with Disabilities. In addition, they hold an annual convention, for which she was asked to assist. In doing so, she made certain to include a session for the chapters to present what they are doing related to prevention, including FASD. One of their very active volunteers established a fund called the Godfrey Oakley Prevention Fund, which offers small grants to chapters for prevention activities every year. There are always some proposals that come in related to preventing FASD. These are announced during the convention.

Center for Science in the Public Interest

George A. Hacker, JD

Dr. Hacker thanked CDC staff, the Task Force members, and the liaison organizations for all he had learned working with this Task Force over the last several years. He expressed his hope that they would continue to work together in some way on issues of mutual concern.

He reminded everyone that the Center for Science in the Public Interest (CSPI) is more involved in the universal/environmental prevention policy area. CSPI has been engaged in a number of activities recently, upon which Dr. Hacker reported. During the last meeting, he reported that he CSPI had worked on legislation to provide new funding with a focus on underage drinking prevention, The Sobering Truth on Preventing Underage Drinking Act, which passed last December. It was authorized at \$18 million dollars, which was somewhat whittled down, and now includes some helpful information for the alcoholic beverage industry that was included as an effort to garner their support. Unfortunately in the appropriations process, that authorization has been whittled down even more, coming out of the House with an appropriation of \$7 million that would fund some community-based coalition enhancement grants, \$1 million for the Intergovernmental Coordinating Committee on the Prevention of Underage Drinking (ICCPUD), and \$1 million to continue a national public service campaign in broadcast media. In the Senate, where the appropriations bill has just come out of the Appropriations Committee, the

appropriation offered \$4 million—\$1 million for the National Adult Oriented Media Campaign, a public service (PSA) campaign run by the Ad Council; and \$3 million for grants to community coalitions. If an appropriations bill ever comes out of Congress this year, CSPI expects to receive approximately \$4 to \$7 million, which is not a lot of funding for an important new program on underage drinking.

Dr. Hacker also reported somewhat disappointing news on the universal prevention policy front related to alcohol excise taxes. There is a great deal of effort this year to increase the budget for the State Child Health Insurance Program (S-CHIP). Many of the people in Congress have been seeking ways to fund \$50 billion in the House and \$35 billion in the Senate. Ultimately, the decision was made to look to tobacco tax increases to fund the increases in funding for that program, which faces a Presidential veto. CSPI tried diligently by organizing the same groups that supported the tobacco tax increase, by going to CSPI's basic coalitions, and by meeting with virtually everyone on the Finance, Ways and Means, and Health Committees in Congress to get people interested in raising alcohol excise taxes, which have not been increased since 1991. There is very little interest in raising alcohol excise taxes. There is incredible fear of the National Beer Wholesalers Association and other alcoholic beverage industry lobbies; nobody in Congress is willing to take on that battle at this time, despite the perfectly logical rational argument and essentially the same support among groups for an increase in alcohol excise taxes.

In 2003, CSPI together with approximately 60 groups, petitioned the Alcohol and Tobacco Tax and Trade Bureau of the U.S. Department of the Treasury (TTB) for improvements in the labeling of alcoholic beverages to include ingredients, calories, serving sizes, number of servings per container, a mandatory alcohol content disclosure, and the definition of low-risk drinking out of the U.S. dietary guidelines. TTB finally came out with a proposal, for which comments are due at the end of October, that is, in part, responsive to that petition, but that is primarily responsive to efforts by certain distillers to provide nutrition information under the guise of serving facts on alcoholic beverages. On the one hand, the proposal would require a mandatory label, so it is not permissive, which is a plus. Alcohol content would be required to be disclosed on all alcoholic beverages, which it is not currently. Beer is not required to disclose alcohol content. However, the alcohol content may be disclosed any place on the label or the container, not necessarily on the brand label where it now appears on liquor and wine. Another plus is that calorie content would be disclosed. In addition, the proposed serving facts label would not be required to have alcohol content on it. It would essentially be a nutrition label with some extraneous information related to proteins and fat, which do not occur in very many alcoholic beverages. Dr. Hacker saw a billboard in Atlanta for Bud Select, which is a low calorie beer, that said, "99 calories; Zero grams fat," obviously intended to promote beer as a diet drink. Also, the serving sizes are essentially reference amounts. They have nothing to do with the alcohol content. They are a reference amount for the nutritional information in those beverages. For an agency that is supposed to be regulating alcohol labeling and alcohol issues, TTP is going in the wrong direction. Also, TTB rejected CSPI's efforts to get a statement of the U.S. dietary guidelines definition of moderate to low-risk drinking on the container. In terms of the labeling of alcohol content, CSPI is equally concerned that TTP seems to be deferring to an international trade agreement, which raises larger issues of how international trade agreements might preempt public health mandates in this country. Thus, CSPI will be developing comments in the next two to three weeks opposing much of what TTP has proposed.

CSPI's immediate plans related to FASD are to reissue guidance for those at the state level to promote measures that would require point-of-sale warnings about drinking during pregnancy. Only 22 states thus far have that requirement. No state has incorporated that requirement in the last five years, so this effort appears to have stalled. CSPI will attempt to jump-start those efforts. Another avenue of generalized public awareness related to drinking during pregnancy which CSPI is pursuing is the content and targeting of women by alcohol producers in women's magazines, as well as the editorial content related to women in those magazines. The plan is to review the magazines with the top 10 circulations and use the findings to promote reintroduction of a bill in Congress that would require warnings in advertising. They are not clear yet whether those labels would be solely related to drinking during pregnancy, or whether they would be a series of warnings, including one that relates to drinking during pregnancy. Many years ago there was such a bill known as the Sensible Advertising and Family Education (SAFE) Act, which would have required a series of rotating warnings in advertisements. CSPI's hope is that with the new Congress in a year or so, they will have more success in at least getting some public attention for that issue.

Discussion

- Dr. Caetano inquired as to what process would be followed once the time period for public comments came to a close.
- Dr. Hacker responded that at the close of the time period, he expected that TTB would review the comments and issue a final rule. He has heard that there may be a request for an extension of time from at least one sector of the alcoholic beverage industry, which may not be so bad. Perhaps it would be beneficial to stretch this issue out in order to have it considered in a new administration.
- Dr. Caetano wondered what the inclination was to shy away from clearly showing the alcohol content in the label (e.g., is it internal to TTB or is it pressure from the industry?).
- Dr. Hacker said he thought two things were occurring. The liquor industry in particular, and specifically Diageo, the largest liquor marketer, have been pushing to be permitted to provide information related to the absolute alcohol content in fluid ounces in a drink. Actually, they want to define a standard drink to drum home the message that "a drink is a drink is a drink" whether it is beer, wine, or liquor. That is why, if a label shows the fluid ounces, but the fluid ounces are included on the label (ethanol), a percentage of alcohol by volume disclosure would have to be included in the serving facts label. That is one of the standard operating procedures (SOPs) that TTB has given Diageo and the liquor industry. On the other hand, TTB has provided the brewers (not now required to list alcohol content) an option to place alcohol content anywhere on the label. His guess is that although that disclosure no longer has to be on the brand label, as it is on liquor and wine currently, it may still appear there because it has to be a single field of vision with other supposedly important elements of information like the type of wine and brand. So, it will probably continue to be on that label. Allowing the alcohol content anywhere on the label is also a SOP for the beer industry to give them something out of this as well.

- Dr. Warren noted that alcohol is highly caloric. It is somewhere between a carbohydrate and a fat. It is the shortest fat—it is only two carbons and it is the smallest carbohydrate. It is not classified as either. It is 7 kilocalories per gram compared to carbohydrates, which is 5 kilocalories, and fat, which is 9 kilocalories. The information is accurate on the sample label Dr. Hacker shared—it states that there are 90 calories for this content of beer. But to an individual who does not have a background in nutrition or biochemistry, which is probably most of the population, a sense of this being great—it is low in carbohydrates and low in fat. It is actually in between a carbohydrate and a fat, and it really is a carbohydrate and a fat. It is intriguing.
- Dr. Hacker noted that CSPI originally proposed a different form of label, which isolated calories in order to make them much more prominent on the label. Proteins, fats, and carbohydrates were not even included on the originally proposed label.
- Dr. Prue pointed out that the labeling really did capitalize on the nutrition illiteracy in this nation. Commercials now are touting zero trans fats, which makes people believe it is healthy when it is still saturated fat, which is the bad fat. She wondered if any market testing was being conducted with audiences to determine how they are determining these labels and how that might affect choices.
- Dr. Hacker responded that he did not believe TTB had done any consumer testing, either of this or of their argument in rejecting CSPI's request for listing the definition of moderate or low-risk drinking. That is one of the weaknesses of this regulatory proposal.
- Dr. Prue thought that seemed like an action they could all at least comment on (e.g., the need for consumer research in interpretation of this).
- Dr. Hacker concurred, pointing out that it was certainly one reason to request some delay in implementation. Historically, with respect to the NLEA nutrition labeling requirements, FDA did a tremendous amount of consumer research on those issues.
- Dr. Warren wondered if the TTB was the agency that had labeling per se that the BATF used to have.
- Dr. Hacker responded that TTB is the old BATF. The BATF was split up in the Homeland Security Act. Firearms went to Justice, while Alcohol and Tobacco stayed in the Treasury Department.
- With respect to the calories, Dr. Wright wondered if the calories were divided between two servings.
- Dr. Hacker responded that one of the problems is the way serving size is calculated. For instance, one of the examples given in the proposal is that a 12 ounce beer, with an alcohol content of as much as 10% alcohol by volume, is considered to be one serving. 10% is more than double the amount of alcohol in probably 97% to 98% of all of the beer consumed in the US. 90% of them are probably less than 4.5% or 5%. So, it is odd how they are determining

serving sizes and it is without reference to the alcohol really. The serving is not in reference to the alcohol, but rather to the FDA standard, which is ordinary consumption amount.

March of Dimes

Karla Damus, RN, PhD

Dr. Damus said she always felt honored and privileged to represent the March of Dimes, and expressed the March of Dimes' sadness about the sunseting of this important Task Force.

She reported that the March of Dimes has had a lot of changes and will soon be changing their name officially from the March of Dimes Birth Defects Foundation to just March of Dimes in that they are doing all perinatal outcomes now. They are seeing, as most agencies are now, that perinatal health is a good predictor of health throughout life and in order to do something about perinatal outcomes and women's health, they must start very early involving men, women, boys, girls, and whole families. It is really about good health promotion throughout life, starting before pregnancy and certainly targeting pregnancy, because a lot of this like any outcome is based on the ability to understand biologic predispositions and the interactions with the environment. The environment includes behaviors, cultures, and other issues which must be understood in order to help people modify these very difficult issues. They really are getting a lot of exciting science as well.

The March of Dimes' major focus currently, of all of the adverse outcomes of pregnancy (and they are all related) is to try to do something about the leading problem in this country, which is preterm birth. The rates are going up so that now, more than a half a million babies are born too soon in this country (e.g., at less than 37 completed weeks of gestation). If they look at this outcome as they do many health outcomes, there are very serious disparities by racial/ethnic group, socioeconomic factors, region, etc. and also environment and stress. When people are stressed, they try to do something to make themselves feel better, and these things are often socially marketed through advertisements and other messaging. For some people it is chocolate, for some it is cookies, and for others it is substances. They are learning from all of the research on genomic, proteomic, and metabolomic predisposition that, indeed, that people are self-medicating when they smoke cigarettes, drink alcohol, etc.

One issue is the high rates for a number of perinatal outcomes that continue into adulthood. There are high rates of hypertensive disorders and cardiac disease in African American and non-Hispanic Black families. There are high rates of preterm births in the Hispanic population. California has over 540,000 live births a year and Texas has over a third of a million. More than 55% of their births are Hispanic. The demographics in this country are changing and some of the outcomes will worsen instead of getting better unless they do something about it now. The impact is lifelong, is a very serious problem, and is extremely costly. Since the last Task Force meeting, the final Institute of Medicine Report (IOM) came out, which was so important, and the March of Dimes had a lot to do with that. The report is entitled, "Preterm Birth: Causes, Consequences, and Prevention." In that report, it is reported that the national bill, for not only infant hospitalization, but also for some of the costs in the first several years of life to the family for the babies affected, is over \$26 billion. While it is not clear from the data exactly what contributes to that, and there is a lot of overlap, but it is known that average first year costs are at least 10 times higher and the average length of hospital stay is 9 times higher for preterm babies

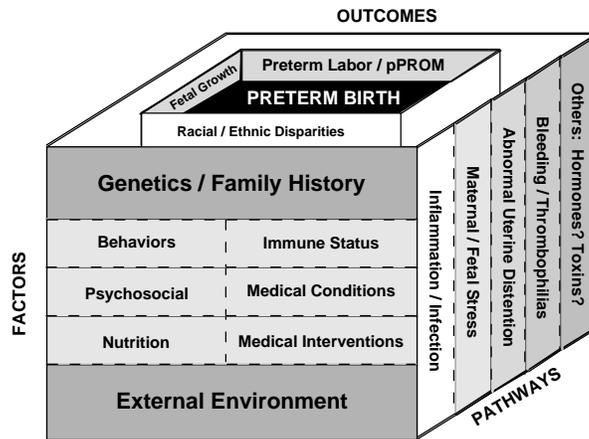
compared to term babies. More analyses are being done on the costs to employers. A very large study was conducted that shows a 20-fold increase in the cost to the average employer. Dr. Damus is co-author on a paper that was recently published in *Pediatrics* looking at a very detailed breakdown of costs related to hospitalizations in the first year of life for preterm births.

The March of Dimes has made a very important statement in their Campaign Goal I by embracing the Healthy People 2010 goal that the rate of preterm birth should be reduced from 12.1% in 2002 to 7.6% in 2010, although the country is going in the wrong direction with the rates continuing to increase. The March of Dimes Campaign Goal II is to raise awareness of the problems of prematurity, but like everything else, people must believe that it is a problem to be concerned about, just like this Task Force is trying to make people believe that prenatal alcohol exposure is a major issue. Some good news is that since the March of Dimes campaign began in 2003, there has been some increase in awareness, particularly in women of reproductive age, although women can and do get pregnant much earlier and now are having babies into their fifties.

The six areas of focus in the March of Dimes campaign have not changed: Raise public awareness; educate women of childbearing age; support affected families; assist practitioners to reduce risks; support new research on etiology; and advocate for health care access. Based on these, it is clear to see why the March of Dimes is so excited to be a part of the activities discussed in the Task Force. Dr. Damus said she thought the March of Dimes research agenda was one of the most directed at prematurity mechanistic research of any agency in the United States because they take that as their primary investment now. Out of their portfolio of about \$35 million a year, a lot goes into other types of adverse outcomes in pregnancy, and certainly a big amount of it does not go into just preterm in genomics, but into all adverse outcomes, birth defects, and the issues since the human genome has been mapped. They really want to understand the etiology better and all the contributors, especially how important it becomes if someone has a risk factor like exposure to alcohol and how that can be modified if there are some biologic predominants that cannot be controlled.

The pathways to preterm birth represent a very complicated issue. They are beginning to understand them, including the stress, abnormal clotting, abnormal uterine distension, multi-fetal gestation, and other pathways. They are getting better biomarkers to better predict which women might be at highest risk. A lot of work is being funded to focus on certain metabolic issues. For example, if someone has certain genetic polymorphisms in CYP1A1 and GSTT1 and smokes cigarettes or is in a working environment with secondhand smoke, their likelihood of having a low birth weight, preterm baby increases dramatically. These data are not there yet with respect to ethanol, but it is just a matter of time.

The article in *American Journal of Obstetrics and Gynecology* regarding the March of Dimes' policy paper for their Scientific Advisory Committee tried to take those pathways and deal with more modifiable factors in terms of medical interventions, nutrition, psychosocial behaviors, etc. These interactions result in adverse outcomes and the disparities they are seeing as well, because in here they address the environment, political issues, and other environmental factors. Family history is very important as well.



The March of Dimes is focusing on six key research areas: 1) population studies to identify common risk factors among women; 2) the role of genes, and the interaction with lifestyle factors such as smoking; 3) studies to determine why African Americans and other groups have higher rates of preterm births; 4) the role of infections and how the body responds to infection; 5) the role that stress may play in early deliveries; and 6) clinical trials of new potential treatments.

The more information they get, the more important it becomes to understand how to translate things that can represent breakthroughs or opportunities to contribute even more to the practice and knowledge base of those who are seeing families on a daily basis. There is increasing discussion about this and these are major challenges. The March of Dimes also realizes the importance of involving not only professional providers, but also in this situation they are working with funding from CDC to develop programs targeting minority families in the pilot sites in California, Florida, Illinois, Pennsylvania, South Carolina, and Texas through faith-based communities to get messaging out and to help them. This is a great intersection with the incidence of substance abuse that has not quite been expanded upon. This is an opportunity to do more.

Dr. Damus indicated that she would leave this meeting to travel to Minnesota, Rhode Island, and then Kentucky. She is the Program Director of an initiative called “Healthy Babies are Worth the Wait,” which is a high priority of the March of Dimes for the next three years. This is a partnership with Johnson & Johnson Pediatric Institute and the Kentucky Department for Public Health. There are three sites in Western, Eastern, and Central Kentucky as comparison groups. The intervention sites are the University of Kentucky, King’s Daughters Medical Center, and Trover Clinic. This is an ecological design where they are trying to show whether they can do something to bring down the rates of preterm births, particularly targeting singletons, given that there is not a lot that can be done about multi-fetal gestation. While these areas are mainly non-Hispanic White, there are very high rates of preterm births. The average is about 15%, while the nation is 12.7%. The goal is a reduction to 12.8% by 2009. They also realize that a lot of efforts have to be made in the Kentucky program, one of which has to do with provider continuing education and modifiable risk factors in the community such as substance abuse.

The March of Dimes wants people to keep thinking about prematurity as a major issue. Rates are much higher with substance use and alcohol use, so for the March of Dimes, the month of

November is Prematurity Awareness Month. November 13th, 2007 is designated as Prematurity Awareness Day. Major structures like the Empire State Building and Niagara Falls will be lit up in pink and blue to raise awareness. This is an opportunity to take modifiable risk factors such as alcohol, smoking, and other things to really empower communities to know where resources are and to maybe make a difference. The March of Dimes will be doing a lot of these things. The notion, even before a woman is pregnant, is to think about wanting to go full term unless there is a medical reason for the mom and/or the baby not to do so. The March of Dimes is using many well known role models to get this message out and to have people thinking about such questions as: What can you do about substance abuse before you even get pregnant? What about inter-pregnancy intervals? What if I have chronic conditions? What if premature birth runs in my family? This is a great opportunity for agencies to work with the March of Dimes to do more.

They are also targeting businesses, and there too they could be offering a lot more programs to families all over the spectrum. Of course, the March of Dimes really believes in doing continuing education for nurses, physicians, and all other providers of perinatal services. The March of Dimes has been fortunate to be supported by Johnson & Johnson in this effort and have reached over 30,000 providers in four years. There are also families who do have an adverse outcome. By 2007, every state in the nation will have a NICU Family Support Program. One of the goals is to get to those families in order to try to prevent preventable recurrence. There is a great deal of concern about S-CHIP reauthorization. The March of Dimes has the Office of Governmental Affairs in Washington, DC which is always on the Hill lobbying for these concerns. That is why the March of Dimes is so happy that the last legislation passed in 2006 was the PREEMIE Bill. She thanked many of the agencies at the Task Force meeting because everyone got together on this. The March of Dimes worked very hard and does have the ability to lobby, which they take very seriously. Although this bill took a while, it was unanimously passed by the Senate in August 2006, the House passed it on December 9th, and it was signed into law on December 22nd.

The purpose of PREEMIE is to reduce the rates; have support for a more evidence-based standard of care; and to reduce infant mortality and disabilities. Of course, that means that great agencies like CDC need to be funded to expand and intensify their overall research portfolio; and to link PRAMS data with maternal-infant clinical and biomedical information. With respect to education, PREEMIE authorizes grants for demonstration projects to test and evaluate educational outreach and materials; improve treatments and outcomes; and respond to informational and emotional needs of families. There is an Interagency Coordinating Council on Prematurity and Low Birthweight through which they want to advance collaboration across HHS; which will provide an annual report to the Secretary and Congress; and which will oversee the coordination of the implementation. The March of Dimes is very excited that there is supposed to be a Surgeon General's Conference on Preterm Birth, most likely in late 2007 or early 2008 to put a focus on this and all of the things that can make a difference.

In conclusion, Dr. Damus reported that the new Medical Director for the March of Dimes is Alan R. Fleischman, MD, who is also the Ethicist on the National Children's Study. Currently, he is at NICHD, but will join the March of Dimes on October 1st. He is a neonatologist who is well known for his work in bioethics. He has also been the Senior Vice President of the New York Academy of Medicine. He is also the Senior Vice President of the March of Dimes, which is a

level that no previous Medical Director has been, so there is a lot of opportunity here. She expressed her hope that the group would see him as someone to involve in important issues.

Based on marketing research, also changing is that the March of Dimes' major annual event known as "Walk America" will now be known as "March for Babies." They are also changing their logo which will go to lower case and will possibly be purple or green.

Discussion

- Dr. Wright requested clarity on the S-CHIP graph shown by Dr. Damus.
- Dr. Damus replied that the graph reflected the percentage of uninsured, low-income children in the U.S. from 1997 to 2005. The percentage has been decreasing. On the March of Dimes website, in the free interactive data system, one can choose their state to determine how they compare with the national rate of uninsured, low-income children (see <http://www.marchofdimes.com/peristats/>). The S-CHIP law, like many other legislative initiatives, has made some difference in the ability to deliver services to the neediest families. Therefore, reauthorization is important so that the rates will not go back up to where they were. It is sad that the rates are this high anyway, and in many areas, they are much higher than the national rate. There are many issues and the March of Dimes has many materials to help everyone advocate for reauthorization and to make sure that parts of this are not cut that allow for services for women as well.
- If S-CHIP is not reauthorized, Dr. Warren wondered when it would expire.
- Dr. Damus responded that it would expire September 30th.

National Organization on Fetal Alcohol Syndrome

Kathleen Mitchell, LHS, LCADC

Dr. Mitchell was unable to attend the Task Force meeting. A handout of NOFAS updates was shared with Task Force members.

Next Steps

Potential Collaborative Activities after the Task Force Sunset

Final Task Force Conference Call: October 2007

Ms. Weber asked the Task Force members to consider ways the group could continue the types of dialogues they have been having, given that they have been very productive, multi-disciplinary exchanges. Suggestions included the following:

- Continuation of the Task Force Listserv
- Community of Practice Concept to distribute information (Dr. Brown's suggestion)
- Conference calls (which the March of Dimes offered to help support on a quarterly basis)
- ICCFAS (which is not sunseting and could perhaps add a Working Group)
- At least one follow-up call with the liaison members to follow-up on dissemination of the two products, given that they will be the momentum in getting these to advocacy outlets

The final Task Force conference call will be convened on October 24, 2007 from 12:00 a.m. to 2:00 p.m. EST. At least eight voting Task Force members (a quorum) must be present on the call in order to take a vote on any Task Force decisions. Therefore, Task Force members were asked to notify Ms. Weber immediately if they could not attend.

Closing Remarks

Jean A. Wright, MD, Chair, NTFFAS

R. Louise Floyd, DNS, RN

Mary Kate Weber, MPH

In closing, Dr. Wright expressed the Task Force's gratitude to Dr. Floyd, Ms. Weber, Dr. Boyle and all of the other CDC staff they have grown to know and love, and whose work and commitment to the field are greatly appreciated. She also expressed gratitude for the Task Force members' willingness to continue to be of assistance after the sunset.

Dr. Floyd said she had been reflecting on the number of people who had gone through the cycle of serving on the Task Force since its inception. She said it had been a great honor to work with everyone who had been a part of the Task Force. The expertise has been "cream of the crop" in all of their efforts. She said she felt enhanced personally and professionally, and that she would always remember the Task Force.

Ms. Weber expressed her gratitude as well, stressing how much she always learned from and enjoyed the interactions and exchanges at various meetings and is honored to have served in this capacity for the last couple of years.

Dr. Prue said that while this was only her second Task Force meeting, the two observations she had was that it is a very pleasant, insightful group. They have agreed to disagree and all put their ideas on the table. Having been in other venues that were not so pleasant, this was wonderful to watch. In addition, the group has been very productive. The list of all of the accomplishments of this Task Force is quite extraordinary, even in the last six months, for which she commended everyone.

Public Comment / Adjourn

With no public comments offered or further business posed, Dr. Wright officially adjourned the Task Force meeting at 12:30 p.m.

Minutes approved on 01/22/2008
by Jean A. Wright, MD, MPH
Chair, National Task for on FAS/FAE