

U.S. Public Health Service
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

June 16-17, 2004

Meeting held at the
Doubletree Hotel
Atlanta, Georgia

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National Task Force on Alcohol Fetal Syndrome and Fetal Alcohol Effect

Meeting Summary, June 16-17, 2004

A meeting of the National Task Force on Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) was held on June 16-17, 2004, in Atlanta, Georgia. Most of the Task Force members were new appointees. A matrix of the 2002 Task Force recommendations was presented, which highlighted progress made by CDC, NIAAA, and SAMHSA and others in responding to these recommendations.

Federal agency updates were provided. Dr. Louise Floyd detailed *CDC's work* in responding to the Task Force's previous recommendations, which included the development of diagnostic guidelines for FAS in partnership with the Task Force and other key experts in the field; establishment of a uniform surveillance case definition and methodology through the FAS Surveillance Network, and continued monitoring of alcohol use among women of childbearing age through the Behavioral Risk Factor Surveillance System (BRFSS). CDC activities focused on interventions with women, such as Project Choices, Project Balance, and Targeted Media Campaigns, were also described. Those efforts addressing the needs and characteristics of affected children include a research consortium that is examining the development of interventions for children and a longitudinal international cohort study.

One way translation of research into practice is being done is through the newly funded, state-based FAS prevention projects. These states are applying evidence-based prevention strategies and adapting/utilizing existing technologies to monitor prenatal alcohol use and track outcomes. Examples of CDC's educational efforts, the FAS Awareness and Education Projects and the FAS Regional Training Centers, were described. CDC also has several biomarker studies are ongoing as well.

Dr. Faye Calhoun, from *NIAAA*, expressed appreciation for the sustained interest of this National Task Force on FASD. Addressing FASD at the federal level is a challenge. "What cannot be seen cannot be counted," Dr. Calhoun said. The complexity and multiple unknowns about FAS and related conditions led NIAAA to accept the term of Fetal Alcohol Spectrum Disorders. The Interagency Coordinating Committee on FAS (ICCFAS) was formed to facilitate the needed interaction across federal agencies in the areas of research, professional training, pediatrics, reproductive health, juvenile justice, healthcare services, information dissemination, demonstration projects, and alcohol treatment. The challenge to progress, however, is iterative. Some member agencies cannot advance until other agencies involved provide the necessary knowledge. After research, the question then becomes how results might be tested. Also, many interventions (e.g., biofeedback, horseback riding, calligraphy, etc.), have been proposed to work, but there is no research evidence for any of them.

NIAAA currently has 104 grants funding FASD research and intervention programs, but work is only beginning on the translational research that will move the basic science up through increasingly complex animal models to human testing. NIH's fundamental, basic research includes: establishing the neurodevelopmental effects from FASD, developing a differential

diagnosis, and examining women's differing susceptibility to determine why one woman's body can handle alcohol without affecting the fetus while another's will not.

Research challenges include the difficulty of conducting cross-cultural assessments and brain imaging studies, improving behavioral tests and maternal interviews, and the use of new technologies in this area. NIH is working to build international teams of clinicians/researchers to facilitate data sharing between countries. Dr. Calhoun agreed with the opinion that the current "silo" mentality of agencies' work and research should give way to approaches used for other disorders; determining current research, how to address problems across multiple disorders, etc. A chart from a 1991 report presenting a model of perinatal alcohol and drug abuse prevention, intervention and treatment was distributed. It emphasized the intergenerational aspects of these problems, which may be helpful in developing recommendations of this Task Force.

Discussion: A model to look at organic contaminants (e.g., lead and mercury) is needed, as is more funding to support this work and collaboration among researchers. The ethical, legal and social implications of FASD also pertain to autism and other developmental defects, and could be addressed collectively. It may be preferable for school records to describe a child's deficits in the school system, rather than a "disability," but the IDEA legislation requires listed diagnosed conditions to ensure special education.

Ms. Callie Gass provided an update on activities from *SAMHSA's FASD Center for Excellence*. SAMHSA brings science and practice evidence into communities by building comprehensive systems. They use present state system capacity rather than creating new programs, and provide training and technical assistance. Their website is comprehensive and they have an extensive FASD resource database. The SAMHSA FAS Center for Excellence convenes the National Association for FAS State Coordinators (NAFSC) in bimonthly meetings to help states (and now some tribes) to develop their FAS-related plans. State planning is also facilitated by Center-convened town hall meetings. FAS activities in four states were described.

Since the last Task Force meeting, the Center has provided training and technical assistance at 58 sites, to about 3,000 people. Since its website was upgraded significantly last winter, hits have quadrupled. An online FASD 101 slideset will be downloadable by field trainers and the website will soon be available in Spanish. A Certified Addiction Counselor (CAC) curriculum is currently being developed.

Liaison presentations were provided. Since the 1980s, *ACOG* has worked with the AAP, CDC, and NIAAA to develop and implement professional education on FASD and has conducted and reported studies. Now, OB/Gyns screen approximately 97% of pregnant women for alcohol use. However, only 25% of practitioners use standard screening tools, and only 20% of OB/Gyns surveyed knew that only abstinence can definitively avoid the effects of alcohol use in pregnancy.

In May 2004, the ACOG Committee on Ethics published an opinion on the ethical issues involved in OB/Gyn practice related to pregnant women's at-risk drinking and illicit drug use. The Ethics Committee noted that OB/Gyns have an ethical obligation to learn about and use protocols for universal screening questions, brief intervention, and referral to treatment. Dr. Robert Sokol will discuss next steps with ACOG regarding improved screening methods, improved brief

interventions; and the tracking/measurement of both. He will also talk with NCBDDD about doing another OB/Gyn survey to assess younger physicians' potential change of knowledge since the topic of FASD was added to medical school curricula. A NCBDDD/ACOG cooperative agreement is currently in place and could be the mechanism through which this could be done.

Discussion: Drs. Barry and Carmichael-Olson discussed the success of stepped interventions for women. The Department of Veterans Affairs is considering the addition of case management approaches to the behavioral interventions. Linking the intervention to the early mother-infant interaction, especially if the FAS prevention step taken is contraception rather than abstaining from drinking, was suggested. Reimbursement issues related to making screening for alcohol and drug abuse as a standard of care under CMS/Medicaid was also mentioned. ACOG's approach to FASD as an ethical matter was appreciated as potentially effective in lowering the medical community's concerns about stigmatizing women or raising the issue with no proven intervention. It was hoped that the combination of the Task Force's recommendations with published NIAAA and AHRQ recommendations, and the Dietary Guidelines for Americans, would produce a very powerful public health message.

Details of *NOFAS'* work in five priorities areas were provided: 1) FASD public awareness and education; 2) National FASD Information and Resource Clearinghouse; 3) public health intervention development and implementation; 4) collaboration; and 5) advocacy. Of particular interest in the third category was the development of a brain model, divided as alcohol-affected and -unaffected, to explain the resulting anomalies and behaviors to school children.

Discussion included a question on dissemination plans for these various educational materials (e.g. the brain model). The FASD Center for Excellence will facilitate dissemination through their national clearinghouse.

Dr. Damus presented on behalf of the **March of Dimes (MOD)**. The mission of the MOD is to improve infant health by preventing birth defects and infant mortality. As part of this mission, MOD is focusing efforts on preventing the problems associated with preterm birth. The two best predictors for preterm birth are having multiple births at one time and having a history of preterm delivery or prior low birth weight. More research is needed to better understand the many risk factors associated with preterm birth (e.g. alcohol use, smoking, drug use). The linkages between all of these risk factors need to be made clear, particularly the prevalence of poly-drug use.

Dr. Damus indicated that MOD has recently updated Peristats, which is available on their website. This data resource provides detailed, state by state information on various maternal and infant health indicators. A white paper is being prepared defining preterm birth as a common complex disorder, with a well-defined phenotype, high incidence, and genetic-based definitions. A MOD grantee published a paper identifying five potential genetic predispositions to preterm delivery. Other important risk factors include stress and susceptibility to environmental toxins. The MOD aims to amass the knowledge on basic science and mechanisms as well as on behavior and the environment in order to convince the obstetric field that there are ways to prevent preterm delivery. Finally, two MOD-supported bills to advance the prevention of preterm delivery are proceeding in Congress.

Discussion included comment that Alaska's low preterm and low birth weight rates (~6%) may be associated with Alaskan natives' higher dietary levels (2.5 to 5 times) of Omega 3 fatty acid. This might be an important intervention to consider.

Mr. George Hacker, Director of the *Center for Science in the Public Interest (CSPI)* Alcohol Policies Project, discussed CSPI's involvement in work to prevent underage drinking. This is one issue the Task Force may want to consider working on as well. A report by the National Academy of Sciences (NAS) provided science-based recommendations, which resulted in the development of the Interagency Coordinating Committee on the Prevention of Underage Drinking (ICCPUD) and the National Alliance to Prevent Underage Drinking (NAPUD). NAPUD works to ensure that the recommendations set forth in the NAS report are implemented. Priorities, as outlined in the NAS report, are to conduct a national media campaign aimed at adults, to improve federal coordination and leadership, and to increase resources for states and communities to prevent underage drinking. Bipartisan legislation is expected to be introduced soon. Mr. Hacker also described the CSPI media campaign that aims to remove alcohol advertising targeting youth from televised sports. CSPI is also pursuing an increase in alcohol excise taxes. In addition, CSPI is providing input into the next version of the dietary guidelines, which also includes guidelines for pregnant women.

Discussion included comment on the effectiveness of licensing requirement changes to reduce underage drinking, as well as suspension of driving privileges for 6-12 months for teens who have alcohol in a car.

The Arc of the U.S. develops and disseminates community education materials, high school curriculum and other FAS education and awareness materials. Ms. Sharon Davis provided a brief summary of the Arc's FAS activities. Primary prevention needs include ongoing education and awareness training. The Arc's FASTrack is a primary prevention project developed by the Arc Riverside (California). It trains high school juniors and seniors to give a one-lesson class on FAS to ninth- and tenth-grade health classes. Outreach to families is a secondary priority area. A CDC-supported curriculum is being piloted for alcohol-affected families and the professionals who support them. With help from seven Arc chapters, a curriculum was developed. This curriculum includes 3 modules: FAS basics, parenting skills, and obtaining support and services for children and families. Curriculum development and implementation focused on the need for early diagnosis to enable the child to receive the proper support – still a rare occurrence in many schools and other service systems.

Dr. Vinson, liaison to the *American Academy of Family Physicians (AAFP)* was unable to attend the meeting but a written statement was sent. AAFP supports enhanced physician awareness of FASD, how to prevent it, and how to refer to specialty care when needed. It is important to note too the complexities of family medicine. Since family physicians' encounters with FASD are infrequent, it may be more practical to look at the issue from the broader context of addressing alcohol problems. Recognizing FASD is therefore more likely to be indirect, through interventions with a mother with an alcohol problem followed up with an evaluation of the child (which would be very challenging) or through identification of a child's neurodevelopment problems with referral made to a specialist for further evaluation for prenatal alcohol exposure.

Open Discussion: Before convening into work groups to discuss primary prevention and diagnostic criteria and services for affected individuals and families, there was some general discussion about FASD prevention. The points discussed included:

- C Lack of detail on racial/ethnic disparities in research on FASD -- a possible Task Force statement could be that minority and special population issues should be addressed.
- C The Task Force should look at pursuing easy fixes such as adding a couple of questions about alcohol use during pregnancy to existing data collection tools (e.g., CSAT's assessment forms). Information also should be gathered about the birth mothers of all children identified as affected by FASD.
- C The focus, in terms of prevention strategies for women, should be to:
 - Determine needs and research gaps as identified by the experience of treatment centers for substance abusing women.
 - Provide child care and involve significant others in the woman's treatment. NIAAA has data on this.
 - SAMHSA program data, although not systematically gathered, indicate with relative scientific certainty that an intensive case management intervention approach is effective among women in their second high risk pregnancy. But since treating those women is seen as a medical and legal risk, many programs refuse to treat them for alcohol or drug abuse. The availability of treatment for pregnant women would be an interesting research area. Availability of treatment resources is critical to effective secondary and tertiary prevention.
- Some Task Force members suggested that CSAT do additional follow-up of pregnant women who received treatment in pregnancy. Certification of counselors could help to address the potential barrier of counselors who focus solely on the interests of the mother versus her child.
- Dr. Calhoun hoped that the Task Force would focus on the inter-generational aspect of FASD and stressed the importance of screening for all developmental disabilities, including FASD. Dr. Cordero called for recognition of developmental issues before 3-5 years of age (e.g., at 15, 18, or 24 months) to ensure the child is in an early intervention system by age three. A CDC pilot program and campaign on the signs of developmental delay (current focus on autism) is underway. Discussion of how to ensure that FASD is recognized as part of that entire spectrum of delays, and how the agencies can advance these efforts, was requested.

Two work groups convened: one to address primary prevention, the other to address essential services for individuals with FASD and their families. The charge of the work groups was to define the over-arching goal for the work group and to develop a process to achieve its goals, including resources needed, roles and responsibilities, and a timeline for completion of work group tasks.

On June 17th, **work group reports** were provided. Drs. Cohen and Carmichael-Olson outlined the discussions of the newly-named ***Post-Exposure Work Group***. They first noted the need to be sensitive to persons with disabilities in language and documentation. Ms. Ohlemiller agreed to provide a brief presentation on this issue to the Task Force at the next meeting. The work group focused on continued work on diagnostic criteria for conditions other than FAS, the essential services system, and best practices. From work in these areas, a goal statement would emerge.

Topics of discussion:

- C The group will not only determine best practices, but will also consider replicability and sustainability of programs after federal funding ends.
- C FASD certification for teachers, how to convey the importance of having teachers certified to the Department of Education, and how this process would be carried out by the states.
- C Early intervention needs to involve inter-generational issues. Early identification and tracking is needed of women who are exposed themselves and their children from birth.
- C FAS needs to be part of the DSM-V. Discussion of how to approach APA for inclusion of FAS in the DSM-V is needed.
- C The Task Force should work with the ICCFAS on issues of service eligibility criteria to ensure life-long support for adults with FAS, particularly in housing and ongoing psychological and behavioral needs.

The work group will continue to communicate (with new members invited) to produce: 1) research agenda recommendations that include moving the diagnostic criteria discussions forward, but also examining best practices, research gaps, and determining if a particular service is appropriate for children with FAS; 2) draft a letter of inquiry from the Task Force to the APA regarding inclusion of FAS in the DSM-V, and follow up as needed; and 3) develop a statement or document focused on best practices and service delivery for the entire life span. The draft document will incorporate descriptive data from the field as well as the literature, and focus on key concerns to be addressed by the research agenda.

Discussion included the following:

- Work with state addiction programs to identify children of pregnant women early.
- A recommendation was put forth to invite a representative from CMS/Medicaid to describe the Early Periodic Screening Diagnosis and Testing (EPSDT) program.
- The importance of linking best practices research to the realities of living with FAS was discussed. Clinical and experiential data are needed to support a best practices document.
- The work group will focus on the life span issues of FASD. The Task Force should consider inviting a representative from Housing and Urban Development (HUD) to discuss their program since this is a major issue for adults living with FASD.
- Issues related to the judicial system were also discussed by the work group and will be explored further. Ms. Myers indicated that guidelines are needed for judges and the state bars. Her organization, the National Indian Justice Center, has a model that has been used for tribal court judges. Contact with the Arc of New Hampshire's Developmental Defects Offenders Program also was suggested. Their education and advocacy guidelines include persons with FAS in the criminal justice system. NCBDDD will help to connect this work group with the ICCFAS, which has a Juvenile Justice Work Group with similar goals.

The **Primary Prevention Work Group** discussed several frameworks in which to work: 1) focus on the essential steps to effective public health action which include research, education and training, policy development, tracking/monitoring, and access to services; 2) focus on the seriousness of the problem, identify key target groups, develop specific approaches (selective, indicated, or universal) to meet target group needs, and assess risk factors; and 3) develop an agenda for the work group to respond to (a "straw man") – topic areas to be developed would

include epidemiology, studies of effective interventions, and population-based prevention approaches. Through discussion, two prevention approaches were emerging: one focusing on high-risk populations and the other on population-based approaches. It will be difficult to assess impact on FAS/FASD rates; however, substitute measures could be determined (e.g., assessing policies or systems to give some insight on impact). The conclusion was that a comprehensive approach is needed for this complex problem, with different interventions used in response to the level of risk. A prioritization exercise would define areas where work on FASD might produce the greatest impact. Also discussed was using a harms reduction approach (e.g., as done with needle distribution for AIDS prevention) in order to pragmatically intervene in the problem without necessarily first going to its root causes.

Discussion included:

- C A good model for FASD is CDC's folic acid campaign which raised physician awareness and changed their clinical practices.
- C This work group should be renamed the Prevention Work Group, since it addresses primary, secondary and tertiary prevention. The full range of FASD will require expanded strategies to address a number of different issues.
- C Option #2 was favored by Dr. Cordero, who related FASD work to the national measles eradication program, as well as the folic acid campaign's reduction of neural tube defects through fortification of foods. However, the differences noted were the absence of a vaccine for FASD, or an effective biomarker such as there is for folate.
- C On the other hand, reducing binge drinking is likely to bring a good effect. Risk groups need to be determined to relate specific impacts to effect sizes, which will range across the spectrum of those at risk. It was also mentioned again that addiction treatment centers were the primary route to those at highest risk of an alcohol-affected pregnancy. Convincing this high risk population of the need to use contraception is necessary, and could measurably reduce incidence.
- C The Task Force discussed requesting that SAMHSA review and potentially revise their intake data collected forms and evaluation process to better collect information helpful to identify exposures in their clients and their children. **The Task Force recommended unanimously that a CSAT representative attend the next Task Force meeting to discuss both the processes and data collection forms used at addiction treatment centers.**

Business items reviewed by the Task Force included endorsement of the NOFAS FASD definition. **The Task Force voted unanimously to endorse the definition of FASD.** An MOD suggestion was well taken that effective promotion of this definition must include the contribution of alcohol on other perinatal outcomes, such as low birth weight and preterm delivery. However, it was also said that focusing on FAS-related birth and developmental defects is seen as a good place to start, in view of the scarcity of conclusive epidemiologic data on alcohol-attributable risk associated with spontaneous abortions, preterm delivery, low birth weight, etc.

A Task Force request that the Surgeon General reissue the advisory on alcohol use in pregnancy has reached his office and a response is still pending. Efforts were made to have FAS included in the IDEA's reauthorization list of covered conditions, but IDEA was already well on its way to approval when the Task Force motion to explore this was put forth. The Task Force was urged by

the Arc and NOFAS to continue to work on this with the Department of Education, particularly the new staffer to lead the Office of Special Education and Rehabilitation.

Progress toward a FASD certification for teachers is being pursued by Task Force member, Dr. Charles Schad. Dr. Schad has gained support to develop a state model in his home state of South Dakota. NIAAA will provide a contact to pursue federal Department of Education endorsement, and South Dakotan senators have supported the initiative. Dr. Schad hoped to complete the South Dakota portion of this campaign by the end of summer.

CDC's Futures Initiative was briefly outlined. CDC is undergoing organizational changes to increase its ability to better respond to public health challenges and to improve health impact. This strategic planning process has a special emphasis on life stages, meaning that in planning public health strategies we need to recognize that people are moving in and out of particular age-related stages which present unique health concerns and risks. CDC's reorganization has resulted in merging various operating Centers, Institutes, and Offices within Coordinating Centers. NCBDDD is part of the Coordinating Center for Health Promotion. The Coordinating and Operating Centers' roles and responsibilities should be clearer by the next Task Force meeting.

Public comment was solicited twice during the meeting, to no response. The next meeting will be scheduled between December 1-15, with the final date to be coordinated by NCBDDD.

Appendix A outlines motions voted on during this Task Force meeting and provides a list action items and possible future Task Force agenda items.

**U.S. Public Health Service
Centers for Disease Control and Prevention
National Center for Birth Defects and Developmental Disorders
National Task Force on Alcohol Fetal Syndrome and Fetal Alcohol Effect**

**Minutes of the Meeting
June 16-17, 2004**

JUNE 16, 2004

A meeting of the National Task Force on Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) was convened on June 16-17, 2004, in Atlanta, Georgia, by the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD). Most of the Task Force is now comprised of new members. The meeting was convened at 9:09 a.m. by Acting Chair Dr. Raul Caetano. Chair Dr. Jean A. Wright, was unable to attend.

Task Force Members, Liaisons, and Attendees

The following people were in attendance:

Executive Secretary: José Cordero, MD, MPH, Director, NCBDDD, CDC
Designated Federal Official: Louise R. Floyd, DSN, RN, Team Leader, CDC FAS Prevention Team

Task Force Members present were:

Acting Task Force Chair: Raul Caetano, MD, PhD, MPH, University of Texas School of Public Health, Dallas, TX

Kristen L. Barry, PhD, Department of Veterans Affairs, Ann Arbor, MI
James E. Berner, MD, Alaska Native Tribal Health Consortium
Deborah E. Cohen, PhD, New Jersey Department of Human Services, Trenton, NJ
Lisa A. Miller, MD, Colorado Department of Public Health and Environment
Raquelle Myers, JD, National Indian Justice Center, Santa Rosa, CA
Melinda Ohlemiller, St. Louis Arc, St. Louis, MO
Heather Carmichael Olson, Washington State FAS Diagnostic and Prevention Network
Charles M. Schad, EdD, retired academician, Spearfish, SD

Standing Member: Faye B. Calhoun, DPA, MS, National Institute for Alcohol Abuse and Alcoholism (NIAAA), National Institutes of Health (NIH)

Absent:

Mark B. Mengel, MD, MPH, Saint Louis University School of Medicine, St. Louis, MO
Colleen A. Morris, MD, University of Nevada School of Medicine, Las Vegas, NV
Jean A. Wright, MD, Backus Children's Hospital, Savannah, GA

Liaison Members present were:

March of Dimes: Karla Damus, RN, PhD, Senior Research Associate

Center for Science in the Public Interest: George A. Hacker, JD, Director, Alcohol Policies Project

National Organization on Fetal Alcohol Syndrome, Kathleen T. Mitchell, Program Director and National Spokesperson

American College of Obstetrics and Gynecology: Robert J. Sokol, MD

Absent:

Daniel C. Vinson, MD, MSPH, Professor, University of Missouri-Columbia (American Academy of Family Practitioners)

Christopher Cunniff, MD (American Academy of Pediatrics)

Federal agency staff present were:

CDC: Martha Alexander, Jacquelyn Bertrand, Elizabeth Parra Dang, Patricia Price-Green, Maggie Kelly, Cathie Ramadie, René Ross, Jacqueline Vowell, Mary Kate Weber

SAMHSA: Callie Gass, Project Director, FASD Center for Excellence

Others in attendance included:

Marie Murray, Meeting Reporter, Atlanta, GA

Opening Comments

Dr. Floyd outlined the contents of the meeting packet, which included the Task Force charter; minutes of the last meeting; a matrix developed on the federal agencies' progress in addressing the 2002 Task Force recommendations; and several publications relevant to FAS and Fetal Alcohol Spectrum Disorders (FASD). A Federal Advisory Committee Act (FACA) training on the rules and procedures Task Force members must follow was provided during lunch for new members who had not yet received the training.

Background on the Task Force's congressional mandate, mission, and goals was provided by NCBDDD Director, Dr. José Cordero. From these goals, 15 recommendations were developed by the previous Task Force members, which were published in CDC's *Morbidity and Mortality Weekly Report (MMWR)*. The previously-mentioned matrix will be used to track those recommendations and the federal agencies' responses. Updates on the latter are provided below.

Agency Updates

CDC. Dr. Louise Floyd highlighted some of the NCBDDD activities underway that respond to the Task Force's 2002 recommendations. She asked the Task Force members, in their own review of the matrix, to consider what gaps may still exist and need to be addressed.

1. *Develop a uniform clinical case definition for FAS and other prenatal alcohol-related conditions.* Diagnostic criteria for FAS were developed in a collaborative partnership, and approved by the Task Force in May 2004. The diagnostic guidelines document is now in clearance at CDC. It is expected to be presented at the NCBDDD national conference in Washington D.C. on July 28.

Remaining work will be to identify additional conditions, based on the science, now that it

is agreed that there is a spectrum of conditions, at one end of which lies FAS. The establishment of diagnostic criteria for the other related disorders (i.e., ARND) is needed. Related work currently underway at CDC includes the following:

- a. A research consortium (Principal Investigator, Dr. Jacquelyn Bertrand, NCBDDD) is examining the development of interventions for children diagnosed with FAS/ARND and is collecting data on characteristics of the alcohol-exposed children in the project. A common database is expected to further describe the neurodevelopmental characteristics of these children. Consortium members include University of Washington, Marcus Institute (Atlanta, GA), University of Oklahoma, Children's Research Triangle (Chicago, IL), and UCLA.
 - b. A longitudinal international (Danish) cohort study of 1,500 five year old alcohol-exposed children is also ongoing. Gestational exposure will be collected at 8 and 26 weeks and the children will be assessed at 5 years of age.
2. *Develop a uniform surveillance case definition for FAS and begin formative work on a uniform surveillance case definition for ARND.* Progress includes:
- a. CDC established the FAS Surveillance Network (FASSNet) in 1997 to develop a uniform surveillance case definition and methodology and to define FAS prevalence. Participating states (Arizona, Colorado, New York, Alaska) used the same data collection methodology gathering data from multiple sources. Overall, prevalence rates from 1995-97 (taken from existing records) were found to be .4 per 1,000. In Alaska, rates were higher in American Indian/Alaska Native populations (5.6/1,000), as compared to whites (0.3/1,000).
 - b. CDC published a case definition for FAS surveillance in 2002, now considered the gold standard for FAS surveillance. An article with that case definition has been published (*Teratology* 66:541-549; 2002).
3. *Relevant epidemiologic research addressing the scope of the problem.* CDC's Behavioral Risk Factor Surveillance Survey (BRFSS) includes data on alcohol exposure, reporting changes in frequent/binge drinking among both pregnant and non-pregnant childbearing age women. One in eight women of childbearing age report binge drinking. Patterns are not uniform across states. A paper was published this year on prenatal alcohol exposure trends and available monitoring data sources. It indicated the importance of preconceptional approaches, as women continue binge drinking before they are aware they are pregnant.
4. Test prevention approaches to contribute "*to the evidence for effective prevention and treatment strategies.*" Progress includes:
- a. Project CHOICES began in 1994 to identify women at risk of heavy drinking and to intervene before pregnancy. Its three goals were to identify women at risk of heavy drinking to intervene before they became pregnant; characterize that population, and design and implement an intervention. High-risk settings included: treatment centers (where to 1 in 4 fertile women were at risk); jail (1 in 5 were at risk), gynecology services at a large metropolitan hospital (1 in 8 women were at risk), and primary care settings (1 in 20 women were at risk). Media outreach also revealed that overall 8% of the women who called in reported themselves at risk for

an alcohol-exposed pregnancy (5% polled in primary care settings). Motivational interventions were conducted offering the choices of reducing alcohol use, using effective contraception, or doing both. The intervention group received general information plus counseling, while the control group received the information-only method. The results of the pilot study indicated that 66% of women counseled at their gynecological visit were no longer at risk six months post-intervention. The study is to end in Fall 2004.

- b. Project BALANCE is a study in a college-age population, using a modified (and briefer) version of Project CHOICES. The will end in Fall 2004 and suggests promising results.
5. *Develop a science research agenda and translate research into practice.* CDC is working to move surveillance and monitoring (BRFSS) approaches and adaptations of effective interventions into the practice arena.
- a. To accomplish this, five state-based FAS prevention projects were funded in 2003 for five years. They are targeting communities with high prevalence rates of FAS and/or high rates of alcohol consumption among women of childbearing age. These states will apply evidence-based prevention strategies and adapt and utilize existing technologies to monitor prenatal alcohol use and track outcomes. Getting children into services is another key focus of these projects.
 - b. CDC also has 3 biomarker studies underway.
6. *Media campaign efforts.* Three targeted media campaigns to increase women's knowledge about alcohol use during pregnancy have been developed, implemented and evaluated. These projects conclude in Fall 2004.
7. *Educational efforts (13) and Credentialing.*
- a. Four FAS Awareness and Education projects focus on training parents, teachers, health care professionals, and law enforcement personnel to recognize FAS symptoms, to develop effective techniques in working with these children, and to link children to existing services and resources.
 - b. FAS Regional Training Centers (RTC) are training providers in academic centers, medical schools, and allied health schools. The curriculum will be disseminated after they are piloted and grantees will work to get related questions on the state board exams. The RTCs are using a variety of training techniques and approaches. These projects will conclude in Fall 2005.

Much more work needs to be done. The first set of Task Force recommendations should be revisited to identify what areas still need to be addressed.

NIH/NIAAA. Dr. Faye Calhoun expressed appreciation for the sustained interest of this National Task Force on FASD. Its new members represent state and local leaders with practical knowledge of FASD who can offer important recommendations on how to move forward. In the mid 1990s, few federal government entities addressed FAS, despite a recommendation calling for an Interagency Coordinating Committee to assemble agencies relevant to FAS issues, and to request that they incorporate FAS into their work. However, at that time, no funding was

allocated to support this.

A similar interagency group recommended addressing perinatal exposure to drugs in 1991. It proposed addressing such problems through local community team training of professionals across disciplines; developing state, local, and national level networks to enhance existing and develop new policies and procedures; and treating women of childbearing age who are alcohol or drug-addicted. State and local child welfare and religious institutions were also involved.

Addressing FASD at the federal level is more difficult. “What cannot be seen cannot be counted,” Dr. Calhoun said. Treatment cannot be uniform when it manifests so differently in every individual. The damage to the fetus depends on the trimester in which mother drank. Exposure in the first trimester produces the classic FAS facial and neurological outcomes, but they are not as apparent from second trimester exposure. The third trimester exposure sequelae of cognitive and other difficulties emerge later, and are difficult to causally distinguish from other disorders.

This complexity and multiple unknowns led NIAAA to accept the term of Fetal Alcohol Spectrum Disorders. CDC is evaluating the application of interventions for children prenatally exposed to alcohol, but more research in this area is needed. The Interagency Coordinating Committee on FAS (ICCFAS) is critical to this. Its diverse federal agency representation provides the expertise needed for interaction at the federal level in the areas of research, professional training, pediatrics, reproductive health, juvenile justice, healthcare services, information dissemination, demonstration projects, and alcohol treatment.

The challenge to progress, however, is its iterative nature. Some member agencies cannot advance until other agencies involved provide the necessary knowledge. Each agency has different issues and problems to address. Dr. Calhoun provided several examples.

- C The Agency for Healthcare Research and Quality (AHRQ) writes a position paper to put research into practice and the Department of Education’s FASD group wants to transfer that experiential knowledge to teachers. But how can a teacher of 30 children identify the five who may be affected by FASD but do not have the face; and what are the legal/ethical aspects of trying to so identify them? So, while the Department of Education can try to make teachers aware, the appropriate ensuing actions remain unknown.
- C The same is true for juvenile justice, trying to identify children with FASD in detention centers, most of whom do not have the face. For both agencies, training their professionals in collaboration with SAMHSA is difficult. How can it be proven that the child’s antisocial behavior is FAS-induced; and once identified, how can that be addressed given their individual differences?
- C Health Resources and Services Administration (HRSA)’s Bureau of Maternal and Child Health (MCH) has access to high risk populations. They want to work with the ICCFAS to test interventions that have been shown effective in research, but the questions used in a research setting are sometimes inappropriate if asked in a community clinic setting. A different approach is needed.
- C The Indian Health Service (IHS) has screening guides and are developing curricula, guidance manuals, etc. They have identified a number of children in some tribes who might be affected and have conducted neurobehavioral tests, but tailoring the education and

treatment approaches is likely to take some time.

After research, the question then remains of how results might be tested. For example, one Minnesota school treatment facility for children with FASD uses a “safe space” (a large blanket-lined box) into which children who act out can retreat until they felt calmer and ready to come out. Among the questions related to translating that intervention is the practicality of such a method in a normal classroom setting, ethically and legally. Many interventions (e.g., biofeedback, horseback riding, calligraphy, etc.), have also been proposed, but there is no research evidence for any of them.

NIAAA currently has 104 grants funding FASD research and intervention programs (e.g., brief interventions, training of bar owners, etc.), but work is only beginning on the translational research that will move the basic science up through increasingly complex animal models to human testing. NIH’s fundamental, basic research includes:

- C Establishing the neurodevelopmental effects from FASD
- C Developing a differential diagnosis -- work to correlate brain substructures and functions with vulnerability to alcohol is being done, as is work to identify the molecular targets of alcohol in the brain. Hopefully, these will lead to potential therapies for children.
- C Examining women’s differing susceptibility, to determine why one woman’s body can handle alcohol without affecting the fetus while another’s will not. Among the antioxidants, choline and some peptides appear to offer some protection from fetal injury, but much work with animal models is still needed.

Research challenges include the difficulty of conducting cross-cultural assessments and brain imaging studies, improving behavioral tests and maternal interviews, and the use of new technologies in this area. NIH is trying to build international teams of clinicians/researchers to facilitate data sharing between countries. For example, one country’s study of 100 children in boarding facilities, separated according to IQ, will allow children with FASD to be identified and allow the comparison of their neurobehavioral deficits to other children with similar IQs.

International studies have shown that children with FASD benefit from structure and the reduction of distractability. While stimulation in a classroom might be good for regular children, it is not good for children with FASD. Experience abroad of reducing stimulus for children with FASD may explain why those children will attend to adults, while U.S. parents report the opposite. But whether adopting the foreign methods can be done legally and ethically in the U.S. is an open question, since this could potentially deprive the other children in the classroom.

Toxic insults were discussed during the last ICCFAS meeting, relative to the differential diagnosis of FAS from, for example, mercury or lead poisoning. Mothers of children exposed to these toxins might also have consumed alcohol during pregnancy. A team of researchers (the Jacobsons) are investigating a number of compounds. Dr. Calhoun agreed with the opinion that the current “silo” mentality of agencies’ work and research should give way to approaches used for other disorders; determining current research, how to address problems across multiple disorders, etc. She distributed a chart from a 1991 report presenting a model of perinatal alcohol and drug abuse prevention, intervention and treatment. It emphasized the intergenerational aspects of FASD, a basis from which this Task Force may be able to craft some

recommendations.

Discussion included:

- C Dr. Berner agreed that there is no “silver bullet” with which to address all of FASD’s challenges. In Alaska, even with few resources, they can identify the most severe cases. They have found that, even given the five very different major cultural groups in the state, effective interventions involve structure and attention from a patient adult. They have also learned about the variability of fetal susceptibility, beyond maternal differences, through twin pairs in which one baby was more affected than the other. There is no safe dose of alcohol during pregnancy; the response seems to be linear. Another big issue with Alaskan natives involves the presence of persistent organic contaminants (e.g., lead and mercury) in their subsistence foods, an unstudied area. A more sensitive model to look at these is needed, as is grant support. This should end the competition between the “contaminants du jour,” in which one set of grants looks at one contaminant versus and one set looks at another.
- C The ethical, legal and social implications, including privacy issues, of FASD also pertain to autism and developmental defects. These could be addressed collectively. Every child has the right to have deficits identified early to help them overcome them, but the issues involved relate to the effect of identifying a disability in a child’s record. It may be more ethical to simply describe the child’s deficits in the school system. In fact, some states do that before the children enters kindergarten.
- C On the other hand, the Individuals with Disabilities Education Act (IDEA) lists diagnosed conditions for which special education must be given (e.g., autism). If a “label” for the children is to be avoided, then the IDEA paradigm needs to be changed from diagnosis to functional limitations. Another aspect to this is research evidence’s suggestion that issues of sensory overload, sensory integration, etc., can be addressed independently of the diagnosis. But the law requires diagnosis, as opposed to management based on specific functional limitations.

SAMHSA. Dr. Callie Gass, Project Director of SAMHSA’s FASD Center for Excellence, related how the Center brings science and practice evidence into communities by building comprehensive systems, building state system capacity (integrating activities proven effective into their existing systems, rather than creating new programs), and providing training and technical assistance. The Center’s website is comprehensive and they have a large on-line FASD resource database.

Building state systems: The Center convenes the National Association for FAS State Coordinators (NAFSC) in bimonthly meetings. These generally involve the state public health, mental health, and maternal and child health agencies, although not the education and criminal justice systems. State coordinators for FAS were added in Mississippi and Maryland, and work is being done with Ohio, the District of Columbia, Mississippi and Texas to develop their state plans. A second national meeting of state representatives was held in May 2004, with 170 participants representing 44 states. They were updated on the science, diagnostic criteria, and approaches/plans available for use. All 44 states began writing their plans (without new money initiatives). Four tribes were involved for the first time.

Ms. Gass shared several state-based examples of progress in addressing FASD:

Mississippi: After a town hall meeting, FASD 101 trainings were done for policy makers (how FASD affects systems when people are not treated, lack of interventions). Mississippi developed a multi-representative state Task Force on FASD that includes parents, government, private health agencies, and community leaders. With the Mississippi Task Force, the FASD Center for Excellence held a symposium to discuss what could be done in the state.

Ohio: A multi-agency work group to address FASD was formed and a town hall meeting is being planned. They are applying for a CSAP state incentive grant to work FASD into their “Children’s Cabinet,” focusing on policy resources for children, particularly for early prevention and intervention of FASD.

South Dakota opened an FASD clinic and is one of CDC’s state-based prevention grantees working on surveillance, intervention and services activities. They also launched an affiliate chapter of NOFAS and are working with the Indian Health Service.

Texas: FASD was supported by the state’s First Lady as a priority. They are doing a FASD 101 workshop, with a focus on early screening and diagnosis. They have a Task Force, consortium and FASD website.

Training. Since the last Task Force meeting, the Center has provided training and technical assistance at 58 sites, to about 3,000 people. FASD 101 for policy makers is the most popular training. A meeting to train the first field trainers was held in Reno, Nevada in March 2004, with 30 participants. A training packet, including FASD 101 slides and notes is provided. The training covers presentation skills and the roles/responsibilities of a field trainer. Emphasis was on issuing consistent messages, such as that there is no proven safe amount of alcohol that is okay during pregnancy, and, if the woman cannot stop drinking, she should abstain from sexual intercourse or use birth control.

The Center’s website was upgraded significantly last winter and its hits have quadrupled. The searchable database has over 3,200 resources, either linked to the material, or with directions on how to obtain them. A wide range of materials is available (teaching aids, research articles, outreach materials, etc.). The Center also has a non-circulating viewing library of database materials at their offices in Rockville, MD.

The Center’s next steps include:

- C Curriculum development: an online FASD 101 slideset to be downloadable by field trainers.
- C Certification curriculum for certified addiction counselors, coordinating with NOFAS.
- C Spanish language website enhancement.
- C Translation of research: the Center supported the development of a recent journal article on the costs of FASD, co-authored by Larry Burd, Charles Lupton, and Richard Harwood, published in the *American Journal of Medical Genetics* (Vol. 127c(1):p.42-50). The SAMHSA FASD Center for Excellence is <http://www.fascenter.samhsa.gov>.

Liaison Presentations

American College of Obstetrics and Gynecology (ACOG). Dr. Robert Sokol discussed ACOG's 1977 recommendation to screen pregnant women for alcohol use, which came before the Surgeon General's report, and has been cited in numerous documents since. ACOG has worked with the AAP, CDC, and NIAAA in developing and implementing professional education on FASD (as early as the 1980s), and in conducting and reporting studies. The result of that training has been measurable among OB/Gyns, who now screen approximately 97% of pregnant women for alcohol use. However, only 25% of practitioners use standard screening tools, and only 20% of OB/Gyns surveyed knew that only abstinence from alcohol during pregnancy can definitively avoid the risks of alcohol use on the developing infant.

The ACOG Committee on Ethics published an opinion in May 2004 on the ethical issues involved in OB/Gyn practice, related to at-risk drinking and illicit drug use of pregnant women (*Obstetrics and Gynecology* 103:1021-1031). The Committee's opinions were based on research evidence that showed:

- C The rate of abstinence from abused drugs after treatment is comparable to the level of medical compliance achieved in diabetes, hypertension or other chronic illnesses. This is important in that it relates the problem of drinking in pregnancy to other reproductive problems, and supports the argument that it should be given the same attention.
- C Brief physician advice was shown unequivocally to be both powerful and feasible in the clinical office setting.
- C The U.S. Preventive Services Task Force (USPSTF) recommended screening and behavioral counseling interventions in primary care settings to reduce alcohol misuse by adults, including pregnant women. This well-considered review cited good evidence for screening and intervening in primary care settings, although not specifically during pregnancy, but among women in general. It repeated that even brief but repeated advice works better than a single caution.

The ACOG Ethics Committee noted that OB/Gyns have an ethical obligation to learn and to use protocols for universal alcohol screening questions, brief intervention, and referral to treatment. Their statement acknowledges that this is complex due to the ethical and legal issues involved (e.g., some states have considered reporting woman who drink during pregnancy to authorities).

Dr. Sokol will discuss next steps with ACOG official, Dr. Jan Chapin, in the coming week. He plans to propose the following:

1. There is room for improvement in screening. The official ACOG obstetric record advises conducting a T-ACE or TWEAK¹ test, but there are no data on how well that information is used.
2. There can be improvement in the conduct of a brief intervention. The progress toward improvement needs to be tracked, at least for some of the simpler things, since guidelines do not automatically translate into cognitive behavior change.
3. Dr. Sokol will also talk with NCBDDD (Dr. Floyd) to see if another OB/Gyn survey could be done to assess if there is a major change in knowledge among younger physicians since

¹ T-ACE: Tolerance, Annoyance, Cut-down, Eye-Opener; TWEAK: Tolerance, Withdrawal, Eye-Opener, Annoyance, Cut-Down

FASD was added to some medical school curricula. Reports of such surveys are published in the highly-read OB/Gyn journal and are presented to opinion leaders. Although most of the alcohol-induced damage occurs in women who are (or are close to) alcohol dependency, few studies look at the issue of behavioral interventions for abusive or dependent drinking at the early stage, as opposed to the addiction stage of risk drinking. Those interventions need to happen before major FAS neurobehavioral damage in infants can decline.

Discussion included:

- C Dr. Cordero reported that CDC's cooperative agreement with ACOG could be tapped to conduct another OB/Gyn survey, as suggested by Dr. Sokol. ACOG's reach is considerable; virtually every OB/Gyn is a member. They also work closely with the AAP and AAFP, so the impact could be far reaching.
- C Dr. Barry reported the Department of Veterans Affairs' conduct of stepped interventions, and success in 40% of those involved. They are considering the addition of case management approaches to behavioral interventions. Dr. Sokol reported that behavioral interventions reduce drinking for about 12 months. The separation of pregnancy and alcohol exposure works to reduce harm, although more may need to be done for the mother.
- C *Is ACOG working with CMS/Medicaid to make screening for alcohol and drug abuse a standard of care?* This relates to reimbursement issues, since state Medicaid programs have moved to managed care. But screening is always part of the OB/Gyn record and probably could be advocated for if it is considered to be a standard of care.
- C ACOG's approach to this as an ethical matter could effectively lower the medical community's concerns about stigmatizing women or raising an issue with no proven intervention.
- C Dr. Carmichael-Olson supports a stepped intervention process to prevent FASD among alcohol-dependent chronic drinkers, rather than a less-effective brief intervention to moderate or light drinkers. She suggested linking this to the early mother-infant interaction, especially if the FAS prevention step taken is contraception rather than stopping drinking.
- C Dr. Sokol asked that comments be e-mailed to him before his meeting upcoming meeting with Dr. Chapin and he urged the Task Force members to review the article that he distributed today.

Dr. Floyd reported that the scientific group developing the CDC guidelines report did address the need to identify and intervene with affected individual and families as well as women at risk. The guidelines approved at the last Task Force meeting include a section on women of childbearing age, recommend universal screening of women of childbearing age, provide a review of the most commonly used screening tools (e.g., T-ACE, TWEAK), and reference NIAAA recommendations, the Dietary Guidelines for Americans, and the recent U.S. Preventive Task Force screening guidelines. The intersection of these documents all promoting the same message could produce a very powerful public health movement.

National Organization on Fetal Alcohol Syndrome (NOFAS). Ms. Kathleen Mitchell applauded ACOG's message that addicts can change behavior and its refuting the "no solution, no

problem” pattern of ignoring the problem. She outlined NOFAS’ five priorities:

1. FASD public awareness and education includes media outreach, conference and workshop participation, creation of materials like public service announcements with NIAAA in Spanish and English for the community at large, exhibits, etc.
2. National FASD Information and Resource Clearinghouse – includes a resource database, a web site, newsletter, resource directory, support/guidance for those affected by FASD (families, lawyers, policy makers, etc.), and a calendar of events.
3. Public health intervention development and implementation -- working with NADAC, NOFAS is completing a Certified Addiction Counselor (CAC) accreditation course for those doing FASD training/awareness work in community health centers. NOFAS programs also target Indian youth, with a project in the Cherokee nation now promoting community intervention as well as education. A K-12 FASD curriculum is in draft form and will be released soon. This includes a story book for elementary school children, which addresses the stigma, strengths, and weaknesses of a child with FASD. NOFAS also is working with Dr. Ed Riley on a model of a brain, divided as alcohol-affected and unaffected, to explain the resulting anomalies and behaviors. All of their work focuses on reducing stigma and understanding differences. NOFAS is adapting a “Law and Order” program for use in high school settings to address the ethics of drinking during pregnancy and of people with disability (PWD) generally. This particular episode promotes the concept of alcoholism as a disease and of PWDs as having different needs. NOFAS will have a Women in Recovery Summit with CSAP in Phoenix, AZ on June 28-29 for women in treatment. Funding is also being sought to conduct a national education drive in community health centers.
4. Collaboration: A NOFAS affiliate guide book is being developed and state/local and international NOFAS affiliates are growing. NOFAS is sponsoring summits, forums and work groups to help drinkers quit.
5. Advocacy activities include a mentoring program with CSAP (Circle of Hope) to help birth mothers quit drinking. It includes support groups, policymaker briefings and education, and outreach to federal/state legislators and associations/accrediting organizations.

Discussion included a question regarding dissemination plans for these various educational materials (e.g., the brain model). Ms. Gass indicated that anything done with the SAMHSA FASD Center for Excellence will be disseminated through their national clearinghouse (e.g., the brain model, or waiting room FASD video developed for birth mothers).

March of Dimes (MOD). Dr. Karla Damus reported that MOD began 30 years ago to prevent infantile paralysis (polio). The MOD now focuses on the prevention of birth defects. Its mission is to improve infant health by preventing birth defects and infant mortality. The current focus is on preconceptional and interconceptional health as the cornerstone of healthy infants, children, families and communities. After MOD’s successful folic acid campaign and since January 2003, the MOD campaign has focused on preventing the problems associated with preterm birth.

The infant death rate has risen for the first time since 1958. The interplay between substance abuse, coping mechanisms, and sexual activity is well known. The MOD is interested in better understanding how these issues (and others) influence low birth weight and preterm delivery. In 2002, one in eight babies were born preterm, most among African-Americans women, followed

by Native Americans. The two best predictors for preterm birth are having multiple births at one time (twins, triplets or more) and having a history of preterm delivery or prior low birth weight. A chart of many other risk factors was shared. More research is needed to better understand the risk factors associated with preterm delivery (e.g. alcohol use, smoking, drug use). The linkages between all of these risk factors need to be made clear, particularly the prevalence of poly-drug use.

The MOD recently updated its Peristats website (<http://www.marchofdimes.com/peristats>). This website provides detailed maternal and infant health data on a variety of issues, including low birth weight (<2700 gm), preterm delivery (<24 weeks), and many other indicators. The database allows for comparison from state to state. A white paper is also being prepared defining preterm birth as a common complex disorder, like Alzheimer's, cancer, diabetes or heart disease. Preterm birth follows the definitions of a common complex disorder, with a well-defined phenotype, high incidence, and genetic-based definitions. An MOD grantee published a paper in *Human Molecular Genetics* (2004, 13(7): 68-91) identifying five potential genetic predispositions to preterm delivery. Other risk factors include stress and susceptibility to environmental toxins. Promising research directions include the roles of progesterone and stress; and papers are scheduled for publication on basic scientific issues and mechanisms as well as behavior and the environment. The objective is to convince the obstetric field that there are ways to prevent preterm delivery.

MOD recently supported two bills to advance the prevention of preterm delivery, which are proceeding through Congress. MOD is also supporting the National Children's Study.

Discussion included Dr. Berner's comment that Alaska's low preterm and low birth weight rates (approximately 6%) may be associated with Alaskan natives' higher dietary levels (2.5 to 5 times) of Omega 3 fatty acid. While some factors may be genetic, this could be a very important intervention to consider.

Center for Science in the Public Interest (CSPI). Mr. George Hacker, Director of CSPI's Alcohol Policies Project, discussed CSPI's involvement in work to prevent underage drinking. This is one issue the Task Force may want to consider working on as well. The entire federal budget to reduce underage drinking was \$72 million a few years ago, as reported by the GAO, a small amount when compared to the \$53 billion of costs associated with underage drinking. Science-based recommendations were issued in the NAS report, "Reducing Underage Drinking: A Collective Responsibility," but the report received strong industry opposition. In 2004, the Interagency Coordinating Committee on the Prevention of Underage Drinking was convened. The National Alliance to Prevent Underage Drinking (NAPUD) was also formed. This group is a coalition comprised of public health, law enforcement, religious, treatment and prevention, and other organizations who works to ensure that the recommendations set forth in the NAS report are implemented. Bipartisan legislation on this issue is expected to be introduced soon. Priorities, as outlined in the NAS report, are to conduct a national media campaign aimed at adults, to improve federal coordination and leadership, and to increase resources for states and communities to prevent underage drinking. One recent CSPI-sponsored media campaign, "Pouring It On" focuses on how to remove alcohol advertising targeting youth from televised sports (87% of Budweiser's ad budget goes to advertising during televised sporting events). CSPI is also

pursuing an increase in alcohol excise taxes. This has not been done in many states since the 1960s, and where it was done, the increases are minimal compared to tobacco product price increases. The CSPI and the Robert Wood Johnson Foundation are providing technical assistance to NAPUD on the alcohol excise tax issue. The CSPI is providing input into the next version of the dietary guidelines, which also includes guidelines for pregnant women. With regards to alcohol, the dietary guidelines advise drinking in moderation (one drink a day for women and two for men, taken with meals to slow alcohol absorption) and avoiding drinking before or when driving, or whenever it could put one at risk (e.g., during pregnancy). Visit CSPI's website at <http://www.cspinet.org/booze>.

Discussion included the mention of CDC's work with local advocacy groups to post warning materials at point of sale locations. Changes to alcohol licensing requirements which affect underage drinking are also very helpful. A recent *MMWR* article also cited increased compliance by teens in states with underage drinking laws and in those whose state liquor boards conduct underage compliance checks. Some states suspend driving privileges for 6-12 months for teens who have alcohol in a car.

The Arc of the U.S., formerly known as the Alliance for Retarded Citizens, was described by Ms. Sharon Davis. To avoid the stigma, the original name was dropped. The term "intellectual disability" is now used instead of the term "retarded." Ms. Davis has worked with the Arc since 1984 to develop and disseminate its community education materials, high school curriculum and other FAS education and awareness materials. CDC funded the conduct of focus groups for the Arc's revision of their primary FAS prevention piece, a brochure called "Think Before You Drink." Primary prevention needs include ongoing education and awareness training. The Arc will distribute a primary prevention project called FASTrack to their chapters. FASTrack was developed by their Arc Riverside (California) chapter. FASTrack trains high school juniors and seniors to give a one-lesson class on FAS to the ninth- and tenth-grade health classes. Outreach to families is a secondary priority area for the Arc.

With CDC funding, the Arc is developing a curriculum (now in the pilot phase) for alcohol-affected families and the professionals who support them. With the help of seven state Arc chapters, the Arc developed a six-hour curriculum of three modules on FAS basics, parenting skills, and how to obtain support and services for children and their families. Arc chapters have been asked to host support groups as well as to provide support through their listservs.

Curriculum development and implementation focused on the need for early diagnosis to enable the child to receive the proper support -- still a rare occurrence in schools and other service systems. The need is clear; outreach done in western Minnesota drew 118 people to one workshop, and a second session had to be added to the Minneapolis/St. Paul train-the-trainer program. However, interest in other states is very low, and work with the social services systems is seen as a primary task.

Discussion -- One issue that was raised related to how FAS education is presented to self-advocates (persons with intellectual disability who advocate on their own behalf). It is important to make sure that discussions on the prevention of a disability do not reflect negatively on the already-affected person. However, one self-advocacy work group agreed that FAS prevention

and promoting healthy pregnancies were important.

American Academy of Family Physicians (AAFP). Dr. Dan Vinson, the AAFP liaison, was unable to attend this meeting, but sent a written statement to update the Task Force on AAFP activities. The following is a brief summary of his comments. The AAFP supports enhanced physician awareness of FASD issues. Physicians need to be more aware of FASD and be more astute about helping to prevent them and how to refer for specialty care when needed. We also must not lose sight of the complexities of family medicine. FASD is an important disorder, one of many. We can best help family physicians enhance their care of women and affected individuals if we focus on a wide range of alcohol problems. We need to find new ways to identify and intervene with problem drinkers. According to Dr. Vinson, the average family physician's encounters with FASD are infrequent. Screening a child is challenging, especially for non-specialists. Recognizing FASD is therefore more likely to be indirect, through interventions with a mother with an alcohol problem followed up with an evaluation of the child (which would be very challenging) or through identification of a child's neurodevelopment problems with referral made to a specialist for further evaluation for prenatal alcohol exposure.

Open Discussion

For the remainder of the afternoon, two Task Force work groups were formed to discuss future Task Force recommendations over the next two years regarding (1) prevention of FAS and related conditions and (2) increased availability of essential services for individuals with FASD and their families. Before adjourning the formal meeting, however, there was a discussion about FASD prevention. The points discussed included:

- C Research on FASD has not included much detail regarding racial/ethnic disparities. While the BRFSS provides some data related to this, the numbers, as they pertain to race/ethnicity, are sometimes too small. NIAAA's survey (the National Epidemiology Survey of Alcohol Related Conditions, or NESARC) may be able to explore this. This is 40,000-person survey which includes questions about whether a woman is pregnant and whether she drinks. This dataset will be available soon for public analysis. Dr. Floyd reported that BRFSS data indicate that drinking in general is more common in Caucasian women and less so in African-American and Hispanic women. That is interesting in that these data are counter to FAS prevalence rates. This may reflect a surveillance bias (e.g., the level of drinking measured by the survey versus the level among those resulting in full-blown FAS). A white paper on this would need to address both areas.
- C Surveys confirm higher exposure rates overall among drinkers, but there is no certainty that Alaskan natives or Native Americans drink more. Dr. Caetano thought that, if the ethnic/racial rates are not different, that should be published as well. Dr. Berner reported that data collected by the IHS and the National Center for Health Statistics (NCHS) indicate a higher rate of alcohol use during pregnancy in those groups.
- C A possible Task Force statement could be that minority and special population issues should be addressed, although this would be a challenging epidemiologic puzzle. The very heavy drinkers may be in the populations missed by surveys (e.g., if they use cell phones which are not accessible through phone surveys).
- C Alaskan natives in particular have different challenges to meet than those in the lower 48 states, in terms of remote areas without access to resources and Superfund cleanup-related

problems.

- C Rates of drinking vary among tribes. Native Americans should not be lumped into one category. This population has also been over-studied while Caucasian women have not been. A Harvard study concluded that the white women, mostly upper class, drink more than anyone else, but there is no study of that cohort and their pregnancy outcomes.
- C The Task Force should look at pursuing easy fixes such as adding a couple of questions about alcohol use during pregnancy to existing data collection tools (e.g., CSAT's assessment forms) for women in treatment and follow up with women regarding their children (to determine if they have been exposed).
- C Information should be gathered about the birth mothers of all children identified as affected by FASD. These data could be added to the list of questions asked of parents/guardians at diagnostic facilities. A Washington state pilot program reached out to those women and found few who refused. Those women can advise what worked for them to attain recovery.
- C NOFAS modeled its Women in Recovery symposiums in this way. Since women in treatment are often unaware of alcohol's effect on their children, they do not come to clinics, and the clinics do not ask about prenatal alcohol exposure. Alaska found that pregnancy is a particularly teachable moment in which they achieved good compliance from women to abstinence from alcohol. Follow-up on pregnancy outcomes in Native Alaskan women showed higher rates of FAS than in the general population, but lower than would be expected. There were also lower rates of ARND than expected. Alaska evaluates abstinence after being in the Center's program (not the pregnancy outcome, since they may have entered too late to avoid having an FASD infant). The program also helps women get a GED and offers job training. The abstinence rates of women in the program exceed any other program in Alaska, and much data remains to be analyzed.
- C CDC's Pregnancy Risk Assessment and Monitoring System (PRAMS) provides data from 31 states on women giving birth to live-born infants. PRAMS includes data on drinking before pregnancy and in the third trimester. The latter is normally the period associated with the lowest rate of drinking, but PRAMS is a good tracking data set over time. It is a mailed survey, also a benefit in reaching those without a phone.
- C The focus, in terms of prevention strategies for women, should be to:
 - Determine needs and research gaps as identified by the experiences of treatment centers for substance abusing women.
 - Providing child care and involve significant others in the woman's treatment. NIAAA has data on this.
 - Although SAMHSA has little systematically gathered information, they have data from about 412 programs that reach out to pregnant women who drink. These data indicate with relative scientific certainty that an intensive case management intervention approach is effective among women in their second high risk pregnancy. However, since treating those women is seen as a medical and legal risk, many programs refuse to treat them for alcohol or drug abuse. The availability of treatment for pregnant women nationwide would be an interesting issue to research. The availability of treatment resources is critical to effective secondary and tertiary prevention.
- C Ms. Gass agreed to pass on the Task Force suggestion that CSAT do additional follow-up of pregnant women who received treatment during pregnancy. The availability of treatment for pregnant women varies among states. The treatment centers could establish connections with childcare facilities, etc., which might help to identify locations with rich

data on women, recovery factors, and children's outcomes. Certification of counselors could help to address the potential barrier of counselors who concentrate only on the interests of the mother versus her children.

- C Researched recovery factors vary with age, but some cited included stability, safety, having an income, and lowered stress levels. A Department of Veterans Administration study of pregnant women in Michigan OB/Gyn clinics that serve a fairly middle class population, showed that 17% of women drank in pregnancy, 4% binge drank, and only 50% of those at risk had discussed alcohol use during pregnancy with a physician.
- C While states receiving federal funding for drug and alcohol treatment must give pregnant women priority, that is open to interpretation by the states. CSAT regulates compliance for this. They have a directory of service providers and have been known to move women to other states in order to get them treatment. In some states, having medical insurance overrides all other considerations.

It was agreed to continue discussing these priorities in the work group sessions. While developing their goals and plans, Dr. Cordero asked work group members to consider potential FASD prevention strategies and determine how best to improve the quality of life of those with FASD. In the 31 years since FAS was first identified in the U.S. and in the four years of the Task Force's existence, no one knows how many FASD cases have been prevented. He asked the work groups to review the Task Force recommendations to date on FAS prevention and to decide which recommendations would be most effective in preventing FAS.

Dr. Calhoun hoped that the Task Force would highlight the intergenerational aspect of FASD. Screening is essential to decrease the costs of FASD and to make a difference in the child's life. FASD may be a diagnosis of elimination, but if it is possible to screen for all disabilities that inhibit learning and sociability, that needs to be done.

Dr. Cordero called for recognition of developmental issues before 3-5 years of age (e.g., at 15, 18, or 24 months) to ensure the child is in an early intervention system by age three. CDC is developing a pilot program and a campaign on the signs of developmental delay (current focus on autism). The point is to reach children with all kinds of developmental delays. Dr. Calhoun recommended further discussion of how to ensure that FAS is recognized as part of that entire spectrum of delays and how we can begin to look at the issue of early identification of FASD in the broader context of identification of development delays in general.

The work groups then convened. One was to address primary prevention (co-chaired by Drs. Caetano and Miller) and the other was to address essential services for individuals with FASD and their families (co-led by Drs. Carmichael-Olson and Cohen). The charge of the work groups was to define the over-arching goal for the work group and to develop a process to achieve its goals, including resources needed, roles and responsibilities, and a timeline for completion of work group tasks. Issues for discussion could include a review of various research (describing the problems, identifying successful approaches, and identifying gaps) and policies (developing criteria to review existing policies and reviewing those policies). The work groups are expected to continue to meet between Task Force meetings to outline and achieve their recommendations and/or to develop relevant product(s) to present to the full Task Force for consideration and approval.

Public comment was solicited. There were no comments presented.

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Work group reports were provided on the following morning. Drs. Cohen and Carmichael-Olson outlined the discussions of the newly-named *Post-Exposure Work Group*. They first noted the need to be sensitive to persons with disabilities in language and documentation. Ms. Ohlemiller agreed to provide a 5-minute presentation on this issue at the next Task Force meeting.

The work group has not yet developed a goal statement. They did agree on focusing on continued work on diagnostic criteria for conditions other than FAS (hold over from 2002 Task Force recommendations), the essential services system (considering the ideal system and how to make the existing system work), and best practices. As work progressed in these areas, the group expected that a goal statement would emerge. Some of the topics discussed are highlighted below.

- C The group will not only determine best practices, but will also consider replicability and sustainability of programs after federal funding ends.
- C Education issues discussed included FASD certification for teachers, how to convey the importance of having teachers certified to the Department of Education, and how this process would be carried out by the states.
- C Early intervention needs to involve inter-generational issues, something cited in the SAMHSA Town Hall meetings. Early identification of women who were themselves exposed is needed, as is identification and tracking of their children from birth.
- C Work with systems that can do early intervention (i.e., Part C of IDEA, MCH programs)
- C FAS needs to be included in the DSM-V. Discussion of how to approach APA for inclusion of FAS in the DSM-V is needed, as is discussion of whether it is realistic to work on common eligibility criteria across states. The Task Force should work with the ICCFAS on issues of service eligibility criteria.
- C Life-long support for adults with FAS is also needed, which includes housing and the psychological and ongoing behavioral needs of adults and adolescents.

The work group's process will include either a follow-up phone conference or a meeting at the NCBDDD National Conference in July. A listserv will be set up for e-mail communication and another phone conference will be held late September or early October.

Three products were anticipated:

1. Research agenda recommendations that include moving the diagnostic criteria discussions forward, but also examining best practices, research gaps, and determining if a particular service is appropriate for children with FAS.
2. Draft a letter of inquiry from the Task Force to the APA regarding the inclusion of FAS in the DSM-V, and follow up as needed.
3. Statement or document focused on best practices and service delivery for the entire life span. Ms. Gass will provide the report of the Town Hall meetings. Her staff and the FASD Center for Excellence Steering Committee will develop a matrix for the ideal service system. Determining best practices will build on the Town Hall meeting report and the work already done by the Center for Excellence. The work group will ensure that the draft

document incorporates descriptive data from the field as well as the literature on evidence-based practices. They will ensure that this is not just another document compiling collective wisdom, but one that focuses on key concerns, identifying what people need to know about, and then crafting a research agenda with relevant best practice suggestions for practitioners and parents.

Finally, others not present at the work group meeting will be contacted about their interest in serving on the work group, which will continue to communicate between meetings. Documents will be sent out 5 days in advance of meetings.

Discussion included:

- C Early recognition of FASD often begins at the diagnostic clinic. However, other systems should get involved in early intervention. State addiction programs that treat pregnant women need to also determine if the woman's newborn or previous children have been exposed to alcohol prenatally. If the child does not meet all of the FAS criteria to receive services, at least they will have had some early intervention and will possibly be monitored if they present with neurological deficits.
- C The next meeting's agenda could include a CMS/Medicaid presentation on the Early Periodic Screening, Diagnosis, and Testing (EPSDT) program. A better understanding of this program and how it can be utilized by the states for early identification would be helpful to this work group and the Task Force.
- C The link between research on best practices and gaps also needs to address practicalities. In an ideal world, the best practices of every service system would be tailored to the individual's needs. Discrepancies have been noted between what parents say about wanting access to a service and the quality of that service. Clinical and experiential evaluation data are needed to support a best practices document. The problems of accessibility and eligibility that could be remediated need to be identified, as do descriptive population data and identification of existing services that might fill in the gaps noted by the best practices statement.
- C The Special Session on Autism at the NCBDDD National Conference in July will focus on early identification. Its review of the overlaps among several conditions of developmental delay and functional disability could be helpful to this work group.
- C The work group also wants to focus on life span issues of FASD. The Task Force should invite a representative from Housing and Urban Development (HUD) to discuss their programs, such as Section 8 housing assistance. Housing services for adults with FASD is a big issue and this Task Force could help to provide some answers. It is important to note that the HUD model that defines independence as living alone is not as effective as a community-type environment for adults with FASD.
- C Judges need a bench guide for FASD, and guidelines are needed for the American Bar Association and state bars as well. The University of Washington is developing a database of background relevant to FASD court cases. An indexing of relevant rules and standards would be useful for judges. Justice issues will be discussed at the work group's next meeting, but it will be important to identify priorities. Ms. Myers offered to share the model developed by the National Indian Justice Center, specifically created for tribal court judges. Most state bar associations have their own judicial education and research offices, which can build upon such models. What is adopted by one state association is often

picked up by others.

- C The work group can gather information for issues of particular interest and present it at the next work group meeting. Dr. Cohen also offered to provide a contact with the Arc of New Hampshire, whose Developmental Defects Offenders Program includes education and advocacy guidelines relative to persons with FASD in the criminal justice system. Other consultants could be interviewed as well.
- C Dr. Floyd offered NCBDDD's help in coordinating with the ICCFAS, which has a Juvenile Justice Work Group with similar goals. Ms. Myers also offered to work with that committee on these issues if needed.

The discussions of the *Primary Prevention Work Group* were presented by co-Chairs, Drs. Caetano and Miller. The work group retained this name and determined that its mission is to prevent the occurrence of FAS/FASD.

Several frameworks were proposed for the work group:

- C Option 1, by Dr. Cordero, was to develop recommendations in terms of the essential steps to effective public health action, which includes research, education and training, policy development, tracking/monitoring, and access to services.
- C Option 2, by Dr. Caetano, was to focus on the seriousness of problem, identify key target groups, develop specific approaches (selective, indicated, universal), and assess risk factors. An example of a selective approach would be to focus on mothers of children with FASD; an example of an indicated approach would focus on women at high risk of having an alcohol-affected pregnancy; and an example of a universal approach would be alcohol taxation.
- C Questions that were raised during the discussion included the following:
 - What are the mechanisms for implementing policies and recommendations?
 - Are different approaches needed in all cases?
 - What groups should be involved in moving things forward (e.g., physicians, associations, etc.)
 - How will the work group's efforts be evaluated? It will be difficult to assess impact on FAS/FASD rates; however, substitute measures could be determined (e.g., assessing policies or systems to give some insight on impact).
- C Option 3 would be to develop a "straw man" for the group's consideration and response, which would include the following key areas:
 - Epidemiology (Drs. Caetano and Miller) using the IOM report ("Broadening the Base for Alcohol Treatment") framework of a funnel. Its funnel opening is symbolic of the general population, the universe that might be at risk; and its tip, women who are heavy drinkers. In between are various target groups and a progression of interventions. Statistics would define the universe of women at risk of having an alcohol-exposed pregnancy.
 - Studies of effective interventions (Drs. Barry and Floyd).
 - Primary prevention initiatives such as educating youth about the consequences of alcohol use and FASD (Dr. Damus).

Through discussion, two prevention approaches were emerging: one focusing on high-risk populations and the other on population-based approaches. The conclusion was that a

comprehensive approach is needed for this complex problem, with different interventions used in response to the level of risk. A prioritization exercise would define areas where work on FASD might produce the greatest impact. Also discussed was using a harms reduction approach (e.g., as done with needle distribution for AIDS prevention) in order to pragmatically intervene in the problem without necessarily first going to its root causes.

Discussion included:

- C Use of CDC's folic acid campaign, which raised physician awareness and changed their clinical practices, as a good model for FASD.
- C Dr. Damus suggested changing the work group's name to the Prevention Work Group, since it is discussing primary, secondary and tertiary prevention.
- C Dr. Cordero supported Option #2. He distributed a white paper on measles, which became a national campaign and essentially eradicated measles. He asked what comprehensive group of actions could be similarly successful in preventing FAS and could affect policy development. For example, the policy to fortify foods with folic acid produced a major impact on birth defects, reducing neural tube defects by 25%. One FAS similarity to those two campaigns is the need to take advantage of many opportunities now being missed, such as asking about alcohol use at every physician visit.
- C Dr. Sokol pointed out that there is no vaccine for FASD, as there is for measles, or an effective biomarker such as there is for folate. However, reducing binge drinking is likely to bring a good effect.
- C Dr. Floyd raised the need to determine risk groups and to relate specific impacts with effect sizes, which will range across the spectrum of those at risk.
- C Ms. Mitchell defined addiction treatment centers as the primary route to those at highest risk of an alcohol-affected pregnancy. She recommended that CSAT revise their intake forms to ask women about alcohol use during pregnancy and then conduct a second screening to determine if their children were exposed. Convincing this high-risk population of the need to use contraception is necessary, and could measurably reduce incidence of FASD. This would support the public dollars spent and potentially gather information not now in the literature. She formally recommended that the Task Force consider asking SAMHSA to look at their intake forms when treating women with addiction problems, to see how better to intervene on alcohol exposure in their clients and their clients' children. Ms. Gass reported the decision by SAMHSA's Steering Committee at its last meeting to focus on identified women first and their treatment providers.
- C Dr. Cohen suggested, in a friendly amendment accepted by Ms. Mitchell, sending a similar letter to the SAMHSA administrator who oversees youth and families protective services.

Dr. Cohen offered a **combined motion to send a letter to SAMHSA asking them to review and potentially revise the data collected in their intake and evaluation process, to enable them to collect information helpful to identify exposures in their clients and their children (e.g., reproductive health data as well as barriers to prevention services)**. Ms. Myers seconded the motion.

In discussion, other suggestions were to go beyond intake form data to review the treatment centers' evaluation processes, and to address screening for organicity, since it is organic brain damage that needs to be determined. To gain some familiarity with treatment center data

collection and assessment processes, Dr. Cordero suggested that a CSAP representative come to describe that process to the Task Force, with the forms in question to be distributed to the Task Force beforehand. Dr. Cohen **moved to table the original motion and to revise it with a new motion to recommend that a CSAT representative attend the next Task Force meeting to discuss both process and data collection.** Ms. Ohlemiller seconded the motion. The forms are to be distributed to the Task Force beforehand.

Vote:

In favor: All
Opposed: None
Abstained: None

The motion passed unanimously.

Dr. Berner stressed that the highest-risk group is not women in treatment, but those who refuse treatment. An Alaskan data analysis demonstrated that women with several children with FASD had refused treatment multiple times. The only time the system paid any attention was when they were pregnant. This issue needs to be addressed to break the cycle. The correctional system is another good point of intervention. Dr. Carmichael-Olson recalled the bar graph shared on the previous day of the risks of alcohol-exposed pregnancy, which could further identify groups at risk. She also advised the Task Force to consider the important psychological factors, such as why physicians do not ask the proper questions or why people do not change behaviors. Task Force recommendations should be based on practical implementation in the world.

Business Items

SAMHSA Treatment Center Request – see previous motion.

Request for Task Force endorsement of the NOFAS Summit’s definition of FASD. To clarify common confusion about what FASD is, NOFAS assembled agencies (including the ICCFAS) and scientists working in the field to develop a consensus statement on FASD. The group defined FASD (Fetal Alcohol Spectrum Disorders) as a plural, umbrella term to describe the effects that can occur from fetal alcohol exposure. The consensus state on FASD reads: *Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis.* **Dr. Schad moved to accept the Summit’s definition of FASD** and Dr. Cohen seconded the motion. **All members were in favor and the motion passed** with no abstentions.

Discussion included:

- With the acceptance of the term FASD, it was asked if the Task Force would revise its official name. Dr. Cordero indicated that legislation would be required to change this Task Force’s name. Ms. Gass indicated that SAMHSA may be able to work with legislators on that.
- Dr. Damus suggested that effective promotion of this definition would have to include the contribution of alcohol on other perinatal outcomes, such as low birth weight and preterm delivery. Dr. Floyd agreed and reported that this has been discussed by the staff of the NCBDDD and the National Center for Chronic Disease Prevention and Health Promotion

(NCCDPHP). Focusing on FAS-related birth and developmental defects is seen as a good place to start, in view of the scarcity of conclusive epidemiologic data on alcohol-attributable risk associated with spontaneous abortions, preterm delivery, low birth weight, etc. This is a research gap that needs to be addressed. FAS effects provide the most information on the underlying science, scope, risk factors and evidence-based information. Given that, it offers the greatest route of potential impact, and is a good place to start, alongside continued research of other aspects.

- Dr. Barry agreed that literature on other conditions is more inferential. Measuring those effects and attributing them to alcohol will be more challenging. However, some of them will be targeted by FASD interventions such as those focused on binge drinking. Dr. Cordero mentioned a longitudinal cohort study beginning in Denver that will examine different exposures and developmental outcomes. These are also being explored in the National Child Health Study.

Approaches to handling inaccurate FAS information disseminated through the Internet.

Kathy Mitchell expressed concern regarding the inaccurate information that is on the Internet regarding FAS and drinking alcohol during pregnancy and asked Task Force members how this could be remedied. Dr. Floyd indicated that CDC, NIAAA, and SAMHSA can provide accurate scientific information to groups (i.e., Task Force liaisons such as NOFAS, MOD, and the Arc). These groups would be in a better position to contact the websites with erroneous information posted, provide the correct information, and urge correction. Direct involvement of the federal agencies in this effort may result in further publicizing the erroneous sites.

The ***Task Force Request to the Surgeon General*** to reissue the advisory on alcohol use in pregnancy has reached the Surgeon General's office. It is being considered, but practically speaking, action becomes less likely as the November election approaches.

The ***IDEA Reauthorization*** spurred a motion at the last meeting to urge the inclusion of FAS in the IDEA list of covered conditions. Dr. Cohen reported that despite work by NOFAS and the Arc, IDEA was well on its way to being approved before the Task Force motion was made. A few of the legislators contacted also did not want to compile detailed lists of conditions. The IDEA bill is now in the Senate, after which it goes to a conference committee to be reconciled, and then to the White House for signing. The Arc and NOFAS recommended that the Task Force continue to work on this with the Department of Education. Contact, preferably a meeting with Task Force members, was suggested with the new person nominated to lead the Office of Special Education and Rehabilitation (OSER), when he or she is confirmed. That person will be person the Secretary will most likely consult about FASD issues.

Teacher Certification. Dr. Schad reported work with Black Hills State University and CDC to develop a pilot curriculum that would include efforts to get teacher certification in FASD. This new curriculum will access existing curricula as it is developed and adapted to the target population. This will first be promoted in his state (South Dakota) and then with the Secretary of Education in Washington. Dr. Schad also reported that the Aberdeen Area Tribal Health Board, which represents all the South Dakota tribes, has asked to participate in this pilot. Support was pledged by the College of Education at Black Hills State University and other schools are aboard as well. Dr. Schad will meet with the Deans of the other South Dakota state and tribal schools

about the certification process on his return to South Dakota. Dr. Calhoun will provide Dr. Schad with the name of the contact at the Department of Education who could assist in this process. Dr. Schad also met with staff of Senators Tim Johnson and Tom Daschele, who will support his work in Washington. He asked the Task Force members for any advice and help to advance this teacher certification effort. Since the election was likely to stall activity, he aimed to complete the South Dakota portion of this campaign by the end of summer. He thanked CDC, Dr. Floyd, and Ms. Parra Dang for their help in these efforts.

Dr. Floyd commended Dr. Schad. After the Task Force resolution at the last meeting to find ways to implement teacher certification, it was learned that this was a state rather than a federal activity. Having a state model such as South Dakota's, as well as Department of Education endorsement and Congressional support that will ultimately be shared with other states, is an accomplishment.

CDC Futures Initiative. Dr. Cordero briefly described CDC's Futures Initiative. CDC is undergoing organizational changes to increase its ability to better respond to public health challenges and to improve health impact. This strategic planning process has a special emphasis on life stages, meaning that in planning public health strategies we need to recognize that people are moving in and out of particular age-related stages which present unique health concerns and risks. CDC's reorganization has resulted in merging various operating Centers, Institutes, and Offices within Coordinating Centers. The Coordinating Center for Health Promotion, for example, includes NCBDDD, the Office of Genomics, and the National Center for Chronic Disease Prevention and Health Promotion. Other offices will coordinate CDC work in the areas of global health, strategy and innovation, workforce development, and capacity building. The new Coordinating Center for Public Health Information and Services will coordinate health marketing, health informatics, and the National Center for Health Statistics. This Center will work to make CDC's messages address the life span. CDC's "customers" have expanded from its traditional partners, health departments, to include all of the American people. Dr. Cordero hoped that the roles of Coordinating Centers and Operating Centers will be clearer in December. They are still developing roles and functions relevant to the Coordinating and Operating Centers. Development plans are due to the CDC Director in September.

Discussion included:

- C The impact of the reorganization on financial matters as they pertain to the budgets of the Operating Centers remains unknown.
- C The CDC directorship is always a health service career appointee, but the person does sometimes change with presidential elections. The rest of CDC remains as it is and the substance of its work changes little. The budget remains the same. However, one other reason for the Futures Initiative was to make the case for better funding of work that is currently underfunded.
- C Bioterrorism response is in a separate cluster, the Office of Terrorism Preparedness and Emergency Response.

Public comment was solicited. None was offered.

Closing Comments. The date of the next meeting will be determined via email, coordinated by Ms. Jacqueline Vowell, but will be scheduled between December 1-15. The members were to e-

mail Ms. Vowell with their available dates by the following Wednesday. **Appendix A** outlines motions voted on during this Task Force meeting and provides a list action items and possible future Task Force agenda items.

With no further comment, Dr. Cohen moved to adjourn the meeting. The motion was seconded and the meeting adjourned at 11:05 a.m.

Minutes approved on September 21, 2004
by Raul Caetano, MD, PhD, MPH, Acting Chair
National Task Force on FAS and FAE

Appendix A

Motions

- **To recommend that a SAMHSA CSAT representative attend the next Task Force meeting to discuss both process and data collection done in alcohol treatment centers** (proposed by D. Cohen, seconded by M. Ohlemiller). Vote: all in favor, no abstentions. The motion passed unanimously.
- **To accept the NOFAS Summit's definition of FASD** (proposed by C. Schad, seconded by D. Cohen seconded the motion). Vote: all in favor, no abstentions. The motion passed unanimously.

Actions Pending

- Response from the DHHS Secretary's Office regarding the reissuance of the advisory on alcohol use during pregnancy still pending.
- Work with the Department of Education after IDEA is reauthorized to discuss inclusion of FAS on list of conditions as part of the administrative procedures of IDEA.

Preparation for December 2004 Task Force meeting

- The two Task Force work groups should continued communication and work through email and conference call discussions as necessary. Work group updates will be included on the December 2004 agenda.
- Task Force members will receive and review relevant CSAT assessment forms in preparation for further discussion with SAMHSA's CSAT regarding assessment of women in federally-funded alcohol treatment programs.

Items for future Task Force agendas

- Invite a representative from SAMHSA's CSAT to discuss assessment forms and processes at alcohol treatment centers.
- Invite a CMS/Medicaid representative to present on the Early Periodic Screening, Diagnosis and Testing (EPSDT) program
- Invite representative from Housing and Urban Development to discuss programs (e.g., Section 8 housing) relevant to FASD adults.