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Centers for Disease Control and Prevention

National Center on Birth Defects and Developmental Disabilities

Records of the Meeting of the

National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect

February 16-17, 2006

Meeting held at the
Embassy Suites Hotel
Atlanta, Georgia

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

Minutes of the Meeting
February 16 – 17, 2006

A meeting of the National Task Force on Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) was convened on February 16 – 17, 2006, in Atlanta, Georgia by the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD).

Thursday, February 16, 2006

Call to Order

Dr. Jean A. Wright, Chair, called the meeting to order at 8:45 a.m. and introduced Dr. José Cordero. Dr. Cordero welcomed the Task Force and thanked them for their time. Mary Kate Weber greeted the group and reviewed the information provided in the meeting packets. Task Force members and liaisons then introduced themselves.

Introduction of Task Force Members, Liaisons, and Attendees:

Chair:	Jean A. Wright, MD, MPA, Backus Children's Hospital, Savannah, Georgia
Executive Secretary:	José Cordero, MD, MPH, Director, NCBDDD, CDC
Designated Federal Official:	Mary Kate Weber, MPH, Fetal Alcohol Syndrome Prevention Team, DBDDD, NCBDDD, CDC
Standing Member:	Faye J. Calhoun, DPA, MS, National Institute for Alcohol Abuse and Alcoholism, National Institutes of Health

Task Force Members Present:

Kristen L. Barry, PhD, Department of Veterans Affairs, Ann Arbor, MI
Carole W. Brown, EdD, Catholic University of America, Washington, DC
Raul Caetano, MD, PhD, MPH, University of Texas School of Public Health, Dallas, TX
Deborah E. Cohen, PhD, New Jersey Department of Human Services, Trenton, NJ
Mark B. Mengel, MD, MPH, Saint Louis University School of Medicine, St. Louis, MO
Lisa A. Miller, MD, Department of Public Health and Environment, Denver, CO
Colleen A. Morris, MD, University of Nevada School of Medicine, Las Vegas, NV
Melinda M. Ohlemiller, MPH, Saint Louis Arc and parent of a twelve-year-old with FAS, St. Louis, MO
Heather Carmichael Olson, PhD, University of Washington FAS Diagnostic Clinic, Washington State FAS Diagnostic and Prevention Network, Seattle, WA

Task Force Members Absent:

James E. Berner, MD, Alaska Native Tribal Health Consortium, Anchorage, AK
Raquelle Myers, JD, National Indian Justice Center (NIJC), Santa Rosa, CA

Liaison Representatives Present:

American Academy of Pediatrics (AAP): George Brenneman, MD

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

March of Dimes (MOD): Elise Linden Antrobus (attending on behalf of Karla Damus)

The Arc: Sharon Davis, PhD, Professional and Family Services, Silver Springs, MD

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

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

Guest Speakers:

Peter A. Briss, MD, MPH, Chief, Community Guide Branch, Division of Scientific Communications, National Center for Health Marketing, CDC

Tom Donaldson, President, NOFAS, Washington, DC

Randy Elder, PhD, Community Guide Branch, Division of Scientific Communications, National Center for Health Marketing, CDC

Alina L. Flores, MPH, CHES, Prevention Research Team, Division of Birth Defects and Developmental Disabilities, NCBDDD, CDC

Brick Lancaster, MA, Office of Smoking and Health (OSH), National Center on Chronic Disease Prevention and Health Promotion (NCCDPHP), CDC

Mary Schauer, MSPH, Division of Reproductive Health, NCCDPHP, CDC

Tanya T. Sharpe, PhD, Division of HIV/AIDS Prevention, National Center for HIV, STD, and TB Prevention, CDC

Other Attendees:

Jacquelyn Bertrand, PhD, FAS Prevention Team, NCBDDD, CDC

Ammie Akyere Bonsu, MPH, SAMHSA FASD Center for Excellence, Washington, DC

Callie Gass, SAMHSA FASD Center for Excellence, Washington, DC

Sherry Ceperich, PhD, Department of Psychiatry, University of VA, Charlottesville, VA

Yvette Dominique, MS, FAS Prevention Team, NCBDDD, CDC

Shahul Ebrahim, FAS Prevention Team, NCBDDD, CDC

Karen Howell, Emory University, Atlanta, GA

Alberta Mirambeau, Atlanta Alliance on Developmental Disabilities, Atlanta, GA

Patricia Price-Green, MSPH, FAS Prevention Team, NCBDDD, CDC

Alison Spitz, Division of Reproductive Health, NCCDPHP, CDC

Mandy Stahre, Division of Adult and Community Health, NCCDPHP, CDC

Myra Tucker, Division of Reproductive Health, NCCDPHP, CDC

Jacqueline Vowell, FAS Prevention Team, NCBDDD, CDC

Kenneth R. Warren, PhD, Office of Scientific Affairs, NIH, NIAAA, Washington, DC

Kendra Myers, Writer-Editor, Cambridge Communications

Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS) Update
Faye J. Calhoun, DPA, MS

Dr. Faye Calhoun presented the recent accomplishments of the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS). The ICCFAS was created in response to a recommendation from the Institute of Medicine (IOM) that NIAAA coordinate the federal response to FAS-related disorders. Its purpose is to improve communication, cooperation, and collaboration among the federal agencies that address health, education, developmental disabilities, alcohol research, social service, and justice issues related to prenatal alcohol exposure. The Committee includes three governmental departments: Department of Education (DOE), Department of Health and Human Services (HHS), and Department of Justice (DOJ). Relevant organizations under each of these departments are represented on the ICCFAS. The largest number of representatives are from HHS and include CDC, the Health Resources and Services Administration (HRSA), the National Institutes of Health (NIH), Substance Abuse and Mental Health Services Administration (SAMHSA), Agency for Healthcare Research and Quality (AHRQ), and the Indian Health Services (IHS). The ICCFAS has been meeting since 1996. The themes that the Committee bases its work on include: prevention of drinking during pregnancy, intervening with children and families affected by prenatal alcohol exposure, improving methods for diagnosis and case identification, increasing research on etiology and pathogenesis, and increasing information dissemination.

The ICCFAS last met on November 18, 2005. Their member organizations presented several keynote talks. Harriet McCombs from HRSA's Bureau of Primary Health Care Programs and Resources shared her work in collaboration with NOFAS and NIAAA to increase screening in care settings for women of childbearing age. A presentation on brief intervention for prenatal alcohol use was given by Grace Chang of Harvard Medical School. Catherine Hargrove presented on the work of the SAMHSA FASD Center for Excellence Juvenile Justice Courts projects. Anne Smith, the ICCFAS Education workgroup leader, provided a presentation on systems approaches to educational issues. These presentations set the tone for the rest of meeting, which consisted of working group discussions. The Committee is working to regenerate its working groups, which include the Education Working Group, the Juvenile Justice Working Group, and the newly formed Women, Drinking and Pregnancy Working Group.

The ICCFAS is currently obtaining approvals and clearance for the ICCFAS Progress Report and Strategic Plan. The Progress Report will reflect the Committee's activities from 2001 to 2005, and the five-year Strategic Plan will address plans and projections for 2006 to 2010. Each workgroup examined the draft action items and progress made and discussed how they might implement some of the activities that the Committee membership felt should be accomplished in the next five years. These discussions were a "reality check," since the Committee does not wish to plan unrealistic activities.

The Educational Working Group worked on its own and met in conjunction with the Juvenile Justice Working Group. The two examined their areas of common interest. The Juvenile Justice Working Group recommended that the ICCFAS address issues such as sentencing guidelines, fetal alcohol spectrum disorders (FASD) and juvenile sex offenders, victimization/vulnerability of youth in juvenile justice settings, FASD and incarceration rates, and implications for transfer/waiver statutes moving youth with FASD into adult courts.

The Women, Drinking, and Pregnancy Working Group reviewed programs and resources of the ICCFAS agencies related to FASD prevention. They considered recommendations from 2000 - 2005 and recommended activities to give momentum to their areas of concern. They further considered the draft action items for the 2006 – 2010 Strategic Plan, and discussed Senate Bill S-1722.

The DOE chairs the ICCFAS Education Working Group. DOE is currently conducting asset mapping and evaluation of FASD education materials. DOE has formed a working group within the Office of Special Education Programs (OSEP) with representatives from their Monitoring and State Improvement Division and the Research to Practice Division, thus broadening DOE's FASD interests.

The Office of Juvenile Justice and Delinquency Prevention (OJJDP), located in the Department of Justice, held a national conference in January 2006 which included a presentation and discussion panel on FASD. This is the first time that a formal presentation was given on FASD at this biennial meeting. This fiscal year, OJJDP funded an FASD project to the Marcus Institute to increase community outreach to educate parents, professionals, and students about FASD. OJJDP has had no earmarks to prompt this work. The initiative comes from their involvement with the ICCFAS. They will be releasing two solicitations in 2006. One will address field-initiated research and evaluation, and the other will be a field-initiated demonstration project. The solicitations are not FASD-specific, but projects that address FASD are appropriate and will be encouraged. Dr. Calhoun encouraged members of the Task Force to let others in the field know about these opportunities.

The Maternal and Child Health Bureau (MCHB) at HRSA plans to add information on FASD to the HRSA publication on best practices called "Bright Futures." They are also working on several ongoing projects on bundling assessment tools for identifying domestic violence, depression, substance abuse, and alcohol use to reduce reimbursement problems. There was a presentation on FASD at a recent grantee meeting for participants from the 96 Healthy Start projects. As with DOJ, these projects are occurring not as a result of earmarks or specific language, but through involvement with the ICCFAS.

IHS established a working group on FASD in 2004 which consists of nine Canadian and 12 U.S. members. The scans done by the working group identified several gaps, including a lack of awareness and sensitivity, inconsistencies in screening, a lack of adult diagnosis, and variability in physicians' attitudes (done in Spring 2005). The purpose, goals, and objectives of the IHS March 2006 conference in Ottawa are: to facilitate understanding, networking, and cooperation among the various groups, to build capacity for prevention and early intervention programming, to explore mentorship as a successful model of prevention, and to transfer knowledge about best practices.

The National Institute on Child Health and Human Development (NICHD) has funded a number of FASD-related research proposals. One project is examining alcohol and other substance abuse and self-regulation. NICHD also facilitates funding for computer-assisted support for underserved pregnant women to assess risk factors for pre-term birth, including smoking, depression, and substance abuse. With other NIH Institutes, they co-fund a meeting on

substance abuse in urban communities. FASD will be featured at that meeting. They are also co-funding work with NIAAA.

Discussion:

- Dr. Cordero inquired as to whether the computer-assisted support project includes the development of computer programs that will allow clinicians to ask certain kinds of questions on risk factors. Dr. Calhoun replied that she would gather more information about the project and share it with the group.

- Dr. Cordero commented that the preconceptional care approach is important to identify risk factors and to address all aspects of pre-pregnancy. CDC's work on this could intersect with this project. Dr. Calhoun advocated for collaboration, as they all hope to avoid overlapping activities.

- Dr. Wright asked about the frequency of ICCFAS's meetings. Dr. Calhoun replied that their meeting schedule varies. This year, they will have a large workshop, which will be open to the public. They try to meet every quarter, avoiding meetings of the SAHMSA Center for Excellence and the National Task Force. Two meetings are planned so far for 2006.

National Institute on Alcohol Abuse and Alcoholism (NIAAA) Update
Kenneth R. Warren, PhD

For the past two years, Dr. Warren has been involved in other NIAAA activities, but he hopes to return to FASD issues and responsibilities. He worked with the Task Force to prepare the revision of the Surgeon General's Advisory on Alcohol Use in Pregnancy.

Since the 1970s, NIAAA has been the major supporter of research activity in FASD at the federal level. NIAAA has therefore built a large portfolio of research projects. The current funding level for research addressing FAS and FASD issues is approximately $25 million. Close to 100 projects are supported.

The Collaborative Interactive Fetal Alcohol Spectrum Disorders (CIFASD) Study, encompasses 15 research groups from within the United States and around the world. They are building a large network to work on issues that can best be addressed collaboratively and on an international basis. Currently, the countries involved include the United States, Finland, Russia, the Ukraine, Italy, and South Africa. This program was initiated three years ago, and results are coming forth from these efforts. When data are ready for dissemination, they will be shared with the Task Force. The collaborative network is very beneficial in addressing the issue of translational research; that is, moving from the basic science level to the clinical level, to the health services level. If clinical research is not translated effectively for use in everyday healthcare practice, then it is not possible to know how effective the interventions are. They are: moving from basic science to medication development, better defining the behavioral profiles of children and the most appropriate behavioral/educational interventions, and addressing issues related to identification and diagnosis.

A significant component of the work is improving case recognition, which has always been a problem. Individuals with full or partial FAS have facial characteristics, which are the only

biomarker. It is likely that there are others who are as affected by prenatal exposure to alcohol who do not have the facial characteristics. Because these individuals do not have the facial features, clinicians are failing to identify a significant portion of the affected population. They hope to find a way to improve the biomarker profile. They have adapted 3D contour technology, typically used by engineers as they search the terrain for minerals or oil. 3D cameras helped to develop a self-learning algorithm to recognize the facial features and to improve the biomarkers. Few persons can recognize the facial features and distinguish them from other birth defect syndromes. The 3D technology can help the field move beyond dependence on individuals who have specialized training. The cameras and other scanning technology are becoming commonplace in many medical centers and settings, where they are used by plastic surgeons and dentists. Similar to the way in which clinicians and researchers taught themselves to recognize FAS, the 3D camera is "teaching itself" to identify affected individuals. A large population of individuals from the U.S. and international partners are "feeding" the education of the computer and the camera. The population includes children with full and partial FAS as well as controls and children with other syndromes and disorders. The computer program is identifying features and deficits in the same areas as the dsymorphologists, but they are not the same features. The camera recognizes small contours and identifies a number of areas. This work is leading them in new directions that will help pediatricians and others in public health.

One of the other major goals of CIFASD is to better define the behavioral profile for FASD. When CIFASD started, it was clear that although a number of individuals had been affected by prenatal alcohol exposure, investigators were assessing different deficits so that it was difficult to create a single database. CIFASD intends to use the same instruments to look at all populations across the world. The project will then create a profile that will not only help with diagnosis and differential diagnosis as compared to other deficits, but also provide insights as to the most appropriate behavioral and educational interventions. Three types of interventions are being tried in small-scale pilot projects. Two approaches are working well, and one is not working at all, which indicates that they are narrowing down the areas of the brain that are most affected. This work holds a great deal of promise for the future.

The other collaborative study at NIAAA started at the same time as CIFASD. The Prenatal Alcohol SIDS and Stillbirth Consortium (PASSC) is a joint project with NICHD that involves a laboratory at CDC, which is working on analyses. PASSC grew out of findings in the 1990s which showed that alcohol is a significant risk factor for Sudden Infant Death Syndrome (SIDS). NICHD proposed a study that would address the mechanisms by which alcohol is a risk factor in SIDS. It is not unusual to find that individuals who have given birth to a child with FAS may also have had children with SIDS or experienced stillbirth. The epidemiological data are stronger with respect to SIDS because of early work done by CDC and NICHD, but it is indicated that there might be a relationship with stillbirth as well. It appears that SIDS will be included in the full spectrum of FASD, at least as a risk factor which increases the occurrence of the disorder. He believes that data will emerge regarding stillbirth thanks to work in Denmark, North Dakota, South Dakota, and South Africa.

Discussion:

- Dr. Cohen remarked that the Surgeon General's Advisory on Alcohol Use in Pregnancy was one of the Task Force's first priorities, and she commended Dr. Warren on his work to see that this priority was accomplished. She thanked him on behalf of the group and led a round of applause for his efforts.

- Dr. Calhoun offered comments regarding Senate Bill S. 1722, "Advancing FASD Research, Prevention, and Services Act." It is a bill to amend the Public Health Service Act to reauthorize and extend federal FASD Prevention Programs. It was introduced by Lisa Murkowski, a Republican Senator from Alaska, in the Senate on September 19, 2005. Senator Murkowski is a strong advocate for FAS work. The bill is currently in committee. The bill has several sections on FAS surveillance and prevention, including building state FASD systems; promoting community partnerships; and developing best practices, transitional services, and community health center initiatives. It is an important bill to encourage and this work takes years to come to fruition, but Senator Murkowski is a great asset, and the work is underway.

- Dr. Wright noted that they could take action positions as individuals and hoped that they could learn more about the bill later.

Substance Abuse and Mental Health Services Administration (SAMHSA) Update
Ammie Bonsu, MPH

Ms. Bonsu, Project Officer for SAMHSA's FASD Center for Excellence, presented the group with an update on their activities. The FASD Center for Excellence was authorized by the Children's Health Act of 2000. The mandates for the Center are: to study innovative clinical systems and service delivery improvement strategies; identify communities with exemplary comprehensive systems of care, provide technical assistance to communities without comprehensive systems of care, train persons working with individuals with FASD and their families, and develop innovative techniques to prevent alcohol use by women of childbearing age. The Center is a hub for training, technical assistance and materials on FASD, a trusted source for accurate and up-to-date information, and a place to have questions answered.

In 2003, SAMHSA's FASD Center for Excellence explored ways to better integrate FASD prevention and treatment services into existing systems. They sought strategies to ensure that these services would continue after federal funding subsides. In 2004, the Center subcontracted with states, local community-based projects, and juvenile justice courts. These projects are ongoing across the nation, and they include subcontracts with other entities so that work is conducted across multiple sites. The Center has provided training and technical assistance to help the subcontractors build and enhance their existing infrastructures for the provision of FASD treatment and prevention services. The Center has subcontracted with 35 entities. Thirty-three of those groups are still at work. Eighteen local community-based projects, ten state projects, and five subcontracts with juvenile courts comprise the program. The juvenile courts have completed their needs assessments and have developed viable plans. They are midway into their implementation year. These projects are building capacity to provide screening in court systems. Last November, the Center sponsored training on the University of Washington Screening Tool to detect children with FAS or partial FAS. Subcontractors have also been

trained in other screening tools. The Center held its first annual subcontractor meeting, in which the Funding Foundation Center advised them on how to pursue funding opportunities when federal dollars are no longer available.

The Center for Excellence offers many publications and products. Their new products include "FASD 101," which is available on a CD as well as downloadable from the Center's website. The Center also has several fact sheets and a new brochure. Their new FASD course is undergoing the SAMHSA clearance process and should be available soon.

Upcoming efforts include "Tools for Success," a curriculum developed for juvenile justice professionals. It should be available in six months. An online curriculum for certified addictions professionals, a SAMHSA-NOFAS collaboration, includes live training with more advanced FASD content. Finally, a series of "what you need to know" fact sheets are in the pipeline. Their topics include the effects of alcohol on a fetus, the effects of alcohol on women, and other topics. The Center is pursing publication opportunities to share findings from their various activities. One activity was a series of 15 town hall meetings. The results of these meetings are the basis of an article, "Sobering Thoughts: The Town Hall Meetings on Fetal Alcohol Spectrum Disorders," which will be published in the spring in the *American Journal of Public Health (AJPH)*.

Native American populations have some of highest reported FAS rates. Given these high rates, SAMHSA urged the Center to develop an initiative to address FASD in Native American communities. They created the American Indian, Alaska Native, and Native Hawaiian Stakeholder Group, whose initiative includes convening two regional "Building FASD State Systems" type meetings. These regional meetings will be co-located with the training institutes for Native American professionals. They will also adapt their existing material for use in Native American communities. The stakeholder group is developing a website to highlight and address FASD in their communities. A large number of field trainers met, and the Center provided them with training and updated materials. The Center calls on these trainers to respond to requests for training and technical assistance in Native American communities.

One of the Center's strengths is its ongoing provision of training and technical assistance. It has conducted over 250 trainings of nearly 13,000 individuals. The Center receives inquiries for information from all over the world through their website and toll-free phone line. The Center is also engaged in a "Promising Practices" effort. To date, this effort has identified 315 practices (147 in the United States and 168 in Canada). Of these, 80 focus on prevention, 181 focus on treatment, 40 focus on both prevention and treatment, and 14 are unknown. The Center's report on promising practices in the United States will be available in June or July.

The Center has a number of meetings planned. The Building FASD States Systems (BFSS) meeting has helped states to develop plans to address FASD in their states and communities. Last year's meeting was held in San Antonio, Texas. Two hundred attendees represented the U.S., Puerto Rico, the Navajo Nation, the Mississippi Band of Choctaw, the Omaha Tribe of Nebraska, and the Cherokee Nation. Nearly forty-one states have increased their FASD-related activities since this state systems meeting was implemented. This year's meeting will be held in May 2006 in San Francisco.

Because of the BFSS meetings, the Center formed the National Association of FASD State Coordinators. Sixteen members represent 14 states and the Navajo Nation. The group is working to incorporate itself as a 501(C)(3) non-profit agency so that it will be sustainable. One of their tasks is to include the Surgeon General's Advisory on Alcohol Use in Pregnancy on early pregnancy tests. They will meet at BFSS in May along with the Center's Steering Committee.

Last year, the Center led the final Hope for Women in Recovery Summit. NOFAS has been involved in these annual summits. These meetings are designed to teach women in treatment, treatment counselors, and policymakers about FASD prevention and treatment efforts in the state where the meeting is held. The final meeting, in Raleigh, North Carolina, was held in conjunction with a Town Hall meeting. Many policymakers and government officials were in attendance, and it was clear that they learned a great deal about the lack of services, awareness, and resources around FASD. Their subcontractor in North Carolina is particularly vocal and strong.

The Center held its first "Circle of Hope" Birth Moms Network, conceptualized by Kathy Mitchell of NOFAS. This group's objectives are to help improve the lives of birth families, provide peer support, decrease stigma, guilt, and shame, and educate high-risk women, policymakers, and professionals about FASD. The first meeting of the Network was in 2005; membership has increased from 4 to 20.

Last year was Year Four for the Center. Based on 2003-2004 evaluation data, 41 States had experienced positive changes in FASD service delivery, largely as a result of BFSS meetings and related activities. Of those states, 10 made one positive change, 17 made two positive changes, eight made three positive changes, three made four positive changes, and three states made six positive changes. All of the states had very little or no capacity before the BFSS and other Center-sponsored meetings and workshops began. They are pleased to know that they have had a great impact on the field.

The Center's original authorization will expire in September 2006, but SAMHSA remains committed to addressing FASD beyond that time.

Centers for Disease Control and Prevention Update
Jacquelyn Bertrand, PhD

Dr. Bertrand is Acting Team Lead for the FAS Prevention Team at NCBDDD. She updated the Task Force regarding the Team's activities since their last meeting. She reminded them that her presentation represented only a "slice" of FASD work that the team is currently involved in at CDC. Federal and state agencies are experiencing great transitions in their budgets, organizational structures, and in how they think about healthcare at the federal level. Fortunately, FASD has remained a prominent issue in this time of change. The Task Force has helped the federal agencies and others keep FASD visible.

Project Choices is a brief intervention designed for high-risk preconceptional women that utilizes motivational interviewing techniques. It focuses on reducing alcohol consumption and/or using contraceptives effectively. The randomized control trial has been completed with positive results. Its article is under review at the *Journal of the American Medical Association*. Key

findings were that a motivational brief intervention is effective in reducing the risk of an alcohol-exposed pregnancy. This intervention was employed in a variety of settings, including healthcare settings and places such as jails and STD clinics, and through media advertisements. High proportions of women took advantage of both aspects of the intervention, reducing their drinking and becoming more effective in contraceptive use, thereby maximizing their avoidance of an alcohol-exposed pregnancy.

CDC has funded translational projects to adapt interventions for children with FASDs to community-based settings. They re-funded the five initially-supported programs to develop intervention programs so that they could move those proven-effective interventions into community settings. Project sites are partnering with community agencies to adapt and implement interventions specific to FASDs, developing mechanisms for estimating cost of these interventions, and planning to develop "train the trainer" programs for dissemination. A wide variety of behaviors and interventions were tested across the sites, from challenging behaviors to peer relationships and friendships to stability in the foster care system. CDC is pleased to move these effective interventions into the community. The project sites are planning a half-day meeting in Anaheim, California, next January as part of the second National Conference on Substance Abuse, Child Welfare, and the Courts, which will be a good forum to share information on the interventions.

CDC also funded the next phase of their FASD Regional Training Centers (RTCs). Four sites are implementing curricula for medical students and allied health students. The RTCs will extend their efforts to additional schools and programs. CDC is also conducting a survey of knowledge, skills, and attitudes among psychiatrists. While literature documents good surveys of the knowledge of obstetricians and pediatricians, psychiatry is the next focus because psychiatrists represent the intersection between prevention and identification of affected individuals. Psychiatrists who work with adult women will see individuals who are at risk for alcohol-exposed pregnancy due to a mental health disorder, self-medication, or a substance abuse issue. Further, psychiatrists who work with children are in a position to identify children with behavioral problems and to consider whether those problems are due to prenatal alcohol exposure. Psychiatrists, therefore, are likely to be a high-yield group of providers that should be educated regarding FASD. After surveying this specialty's knowledge and awareness, curricula can be adapted to address their training needs.

CDC funds two new international programs. One is a comprehensive FAS prevention program in the Western Cape and Gatueng provinces in South Africa. Previously-conducted surveillance work in South Africa established very high rates of FAS and alcohol-exposed pregnancies. This new grantee will conduct epidemiological surveys of women, healthcare centers, and providers. They will then develop prevention activities and provider education programs in urban and rural settings adapting existing CDC materials. Working with the University of Oklahoma, CDC is also funding an FASD education program in St. Petersburg, Russia. They will be translating and adapting CDC provider education materials and working to increase awareness about FASD and the dangers of drinking alcohol during pregnancy.

While this is not a new funding cycle for the FASD state-based prevention projects, they are adapting various FASD prevention models into state-based public health systems. In working

with these programs, CDC has learned that states are incredibly diverse. It is not possible to create "one size fits all" prevention or intervention programs. Some states have worked in FASD and birth defects for a long time, including conducting surveillance and developing prevention and intervention programs. Other states began their efforts with no background in this work. Providing technical assistance to the eight states has required individualized work and adaptation to each state system.

There is a great thirst for knowledge regarding FASD. Dr. Bertrand shared CDC statistics regarding the materials that they generate and distribute, including posters and brochures, the FAS guidelines, and the Surgeon General's advisory. In November 2005, a Morbidity and Mortality Recommendations and Reports publication was released. This is a streamlined version of the *FAS Guidelines for Referral and Diagnosis*, released in 2004, and it has been in great demand.

Dr. Bertrand also shared CDC FAS website data with the group. The report indicated that 78% of visitors reach the CDC website via a search engine, and 13% come from liaison and partner organizations such as the March of Dimes. These patterns indicate that many people are starting from "ground zero" when they seek FAS information. The site received over 54,000 hits from individual users in one month. Visitors look at all aspects of the site, including the fact sheets, frequently asked questions, publications, specific project pages, and Task Force minutes.

NCBDDD has been working on a preconception care initiative. Alcohol issues figure prominently in the development of this initiative. They will focus on the message that damage from alcohol consumption can occur before a woman recognizes that she is pregnant. This initiative seeks to bundle a variety of messages, combining alcohol with other issues such as smoking, folic acid intake, and maintaining a healthy weight to avoid gestational diabetes. In April, an *MMWR* will include recommendations developed from last year's Summit on Preconception Care and will present the evidence behind preconceptional care and specific items such as folic acid intake. A supplement of the *Maternal and Child Health Journal* (*MCHJ*) on preconception care issues will be released in Spring 2006. Some of these papers specifically address alcohol and including alcohol in the preconceptional care message.

Discussion:

- Dr. Wright asked how the collaborations with international grantees were initiated. Dr. Bertrand replied that CDC requested applications for work in South Africa, and they were able to fund one grantee. Dr. Cordero indicated that the proposal for the Russia project came through the Association of University Disability Centers (AUDC), formerly the University Affiliated Programs (UAP). CDC has a cooperative agreement with this group that allows access to the expertise of their Centers throughout the country. They have a mechanism to attract and fund proposals not only on FASD, but also on Down's Syndrome and other disabilities. CDC has had a longstanding collaboration with Russia that includes sharing public health information. The weekly *MMWR* is translated and published immediately in Russian and 23 other languages.

- Dr. Wright commented that Fogarty seeks projects that work well with dual funding. Dr. Bertrand noted that Russia's formative work was funded through the Fogarty mechanism.

Dr. Cordero added that they are working with Fogarty on newborn screening in the Middle East.

- Dr. Barry asked whether these groups were working with HIV initiatives as well. Dr. Bertrand replied that HIV will be factored into the work in South Africa. There is a large amount of HIV work proceeding on the continent of Africa. Those clinics do not overlap significantly with the FASD clinics, so there is little danger of the populations being over-studied. She further commented that China will be an interesting country for work in preconceptional care. Because of the "one child only" policy there, women think about their pregnancy carefully. A number of counseling sessions precede marriage, and the folic acid message is included in these sessions.

- Dr. Sokol noted that the issue of FAS in China will also be important because of the number of people who are adopting babies from China.

- Dr. Cordero said that they have worked on folic acid in China for some time. There is an ongoing follow-up of the infants who were born as part of this community folic acid trial. He was not sure whether cases of FAS were identified during that process, but it is an interesting area for examination. Over 90% of the pregnancies in the trial were intended, which offers a different perspective from other parts of the world.

- Dr. Calhoun commented that there are communities within China where FAS is likely, such as in groups that are engaged in high-risk employment areas. NIAAA is working with universities there and will be expanding into these large communities in China.

- Ms. Bonsu reported that the FASD Center for Excellence website received over 300,000 hits. Dr. Bertrand said that knowing where people are going on their website will help them move forward and provide information that people need. Part of CDC's work as they develop their new Prevention Branch will include examining information on the web, perhaps using focus groups to target their information better.

- Dr. Calhoun suggested that since people are searching both the Center's website and the CDC website, the groups could work together. Dr. Wright supported the idea of making information available for a variety of groups, including professionals, researchers, parents, and adoptees.

- Dr. Bertrand commented that the web has grown fast as a portal of information. Now that they have information available, they will constantly work to make that information better.

Liaison Updates
March of Dimes
Elise Linden Antrobus, MSW

On behalf of Karla Damus, Ms. Antrobus updated the Task Force on the March of Dimes (MOD) National Prematurity Campaign launched in 2003. The mission of the March of Dimes is to improve the health of babies by preventing birth defects, infant mortality, and premature birth. Premature birth was added to their mission statement last year in response to the Prematurity

Campaign. Improving the health of infants requires looking at the entire spectrum of reproductive health prior to conception, and preconception health is a cornerstone of healthy infants.

The MOD revised their goals to align with the Healthy People 2010 Objectives. The Prematurity Campaign includes six aims to: generate concern about the problem of prematurity; educate women of reproductive age about risk reduction and warning signs of preterm labor; provide affected families with information, emotional support, and opportunities to help other families; assist health practitioners to improve prematurity risk detection and to address risk-associated factors; invest public and private research dollars to identify causes of preterm labor and prematurity and promising interventions; and expand access to health coverage to improve maternity care and infant health outcomes. Three advisory committees and 30 alliance members work with on MOD campaign efforts. MOD also works with three national partners: The American College of Obstetricians and Gynecologists (ACOG), the American Academy of Pediatrics (AAP), and the Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN). Many alliance members also worked with MOD on the National Folic Acid Campaign.

November is Prematurity Awareness Month, and National Prematurity Awareness Day is the third Tuesday of November. MOD is focused on preterm birth as its next initiative because it is the number one obstetric challenge in the United States, a major cause of loss (e.g, perinatal, neonatal, and black infant mortality), and a leading problem in pediatrics (e.g., neonatal morbidity). Preterm birth is serious, costly, and common. Preterm infants represent about half of all hospital charges for infant stays. Preterm birth meets the criteria for a common, complex disorder. Since 1983, the rate of preterm birth has increased by about 30%, and it is continuing to increase. One out of every eight babies is born premature. The Campaign's goal is to reduce this number to one out of every ten or better. African American women tend to have a higher risk for preterm birth, and while more than 12.3% of births in many states are preterm, the southeastern states have higher rates of preterm birth. Near-term infants have significantly more medical problems and increased hospital costs compared to full-term infants. In addition, near-term infants represent an unrecognized, at-risk neonatal population. While there are three distinct pathways to preterm birth (spontaneous preterm labor, spontaneous premature rupture of the membranes, and medical indication), many of the risk factors for all three are similar.

Ms. Antrobus showcased a new campaign message that premiered at the end of 2005. It features the singer Thalia and the slogan, "I want my nine months." The effort includes a number of preconception planning messages, including reduction and elimination of alcohol. A number of risk factors are associated with preterm labor and delivery. Alcohol use is among those factors. Additional factors contributing to the increasing rate of preterm births include more women over 35 giving birth, increases in multiple births among all populations, indicated deliveries, substance abuse, bacterial and viral infections, and increased stress. The interplay among stress, substance abuse, and infections is increasing and can contribute to preterm birth, but more research is needed on the role of stress and appropriate and effective interventions.

It is known that using alcohol during pregnancy contributes to miscarriage, premature birth, low birth weight, fetal alcohol syndrome, alcohol-related birth defects, neurodevelopmental

disorders, and birth complications. MOD has invested over $15 million in research on preterm delivery. They created innovative community intervention trials in the late 1980s. MOD's Perinatal Epidemiological Research Initiative (PERI) grants were effective from 1998 until 2004. These included six research initiatives that defined biomarkers and mechanisms, epidemiological approaches to test biologically plausible hypotheses for major determinants of preterm labor, and examination of the interactions of risk factors associated with prematurity and relevant biologic samples. They now have a new set of grants, the Prematurity Research Initiative. The first group of grants was funded in 2005, and another set will be funded in 2006.

MOD has an online resource for practitioners called "Genetics and Your Practice." An article on recommendations from MOD's research agenda appeared in the *American Journal of Obstetrics and Gynecology (AJOG)*. Their National Research Agenda for Preterm Birth examines disparities, inflammation and infection, genetic and gene-environmental interactions, stress, high-risk interventions (multifetal, ART), and promising clinical interventions. Clinical interventions include smoking cessation, progesterone therapy, and infertility and multiple births. MOD funds Centering Pregnancy, a model for group prenatal care. They are also participating in national conferences, meetings, and summits with a number of partners and agencies. They collaborate with entities such as CDC and the World Health Organization (WHO).

Many factors affect preterm birth, and many of them cannot be controlled. Therefore, the "prevent the preventable" initiative focuses on the factors that can be controlled to bring down preterm birth rates. These factors include alcohol use. Ultimately, it is important to realize that preterm birth is a common, complex disorder that is a public health priority. It is important to intervene throughout the continuum of reproductive health for woman and men with culturally sensitive, literacy-appropriate risk reduction interventions. All providers have a role in the success of primary and secondary prevention. All pregnant women are at risk for preterm labor and should be taught the signs and symptoms. A multidisciplinary approach is needed, and everyone can make a difference.

Ms. Antrobus mentioned two pieces of legislation that MOD is pursing at the federal level: the PREEMIE Act and the Prevent Prematurity and Improve Child Health Act of 2005. The PREEMIE Act seeks to expand research into the causes and prevention of prematurity as well as to increase federal support of public and health professional education and support services related to premature birth. The second bill calls for improved access to health coverage for pregnant women, infants, and children. It would provide states increased flexibility and federal resources to expand access to maternity care for income-eligible pregnant women and increase access to health care coverage for infants and children with special health care needs.

Discussion:

- Dr. Wright inquired about a link between having a previous abortion and having a child born prematurely. Dr. Sokol said that no relationship between a previous abortion and premature births has been established.

- Dr. Wright asked for clarification regarding "multiple births." Dr. Cordero replied that with advances in reproductive technology, the number of multiple births has been increasing and represents an increasing percentage of premature births. An interesting issue emerged in

Sweden, where there appeared to be a connection between folic acid and twinning. This study did not take in vitro fertilization (IVF) pregnancies into account, and all IVF pregnancies by definition include folic acid as part of their protocol. When the study controlled for IVF pregnancies, the connection disappeared.

American College of Obstetricians and Gynecologists (ACOG)
Robert Sokol, MD

Dr. Sokol reported that ACOG has been involved with FAS prevention since 1977 when the College released its first statement. ACOG has worked with various federal agencies, including NIAAA initially, and more recently, CDC. ACOG has conducted surveys regarding obstetricians'/gynecologists' (OB-GYNs) knowledge regarding FAS. The College developed a set of interventions in the medical specialty's language and, with CDC's support, has measured the impact of that intervention. The result of this work is one of the few examples of good evidence that educational interventions can make a difference. The intervention was funded by NIAAA, and practitioners now know a great deal more about FAS.

At the last Task Force meeting, Dr. Sokol reported that CDC awarded ACOG funds to develop, print, and distribute materials to inform and assist OB/GYNs to recognize, intervene with, and follow women who are pregnant or at risk for pregnancy and drinking at risk levels. ACOG and CDC have worked over the last six months to create a useful document. The task has proven to be challenging. There have been studies of what physicians want from such a document: it must be concise, science-based, and implemented easily in the office in minimal time. The first draft of the document was 36 typed pages. They have worked to break this document into pieces, including a patient carry-away, a carry-away for the patient's partner, and a "one-pager" for the doctor. While they are behind their planned timeline, the effort is proceeding well. A great deal of work regarding needs was done previously. Dr. Sokol expressed his hope that the document would be completed soon.

Discussion:

- Dr. Warren asked about focusing on alcohol-dependent women, who are at the greatest risk. Dr. Sokol replied that ACOG did discuss how to focus its efforts. FAS occurs in chronic alcoholic women at a high rate (1 in 1000 women). If there are 20 women out of 100 who drink alcohol in pregnancy and the risk of FAS is one in 1000, the issue is how much more common are the rest of the abnormalities. The most recent figures estimate that for every child that has FAS, 3 more have an FASD other than FAS. This is probably an underestimate. Some studies have reported up to 10 to 1. There are probably 1 in 100 children that have an adverse consequence from prenatal alcohol exposure. If 20% of women drink in pregnancy that means that 5% of children exposed to alcohol have some measurable impact. It is important to decide where, and to whom, to aim prevention efforts. Dr. Sokol felt that emphasis should chiefly be placed on women reporting any drinking over what NIAAA has defined as the upper limit of "normal," as the fetus and embryo are more sensitive to the impact of alcohol than the adult. They are not solely focusing on alcoholics or alcohol abusers. The literature to support this focus has evolved over the years. The interventions for the highest risk population is different, referrals might be the intended result. Brief intervention is well-documented as a technique for the heavy drinker or "problem drinker." Obstetricians are not trained in Diagnostic and Statistical Manual of

Mental Disorders-IV (DSM-IV) diagnoses or in interventions appropriate for this group. They should make a referral.

- Dr. Warren said that NIAAA has a clinician's guide, which is intended for all physicians. Dr. Sokol replied that ACOG referred to this guide in developing their materials and has included the "standard drink" graph from it. He noted that the revision of the guide is too long and less likely to be applied in an obstetrician's office. When the average length of a return visit to the obstetrician is three minutes, added time can be significant. Another challenge in developing this product is that they are finding it difficult to not only teach the principles of brief intervention to those who are not familiar with it, but also to teach the clinicians what to say and how to say it.

- Dr. Caetano wondered whether, given that physician-patient contact time is decreasing, consideration has been given to assigning the screening to a physician's assistant. Dr. Sokol answered that they had considered this option. There is reasonable evidence that screens can be built into the standard patient history published by ACOG. Further, almost all OB-GYNs use pre-printed patient forms, and it is possible to get this information via these forms or via a computer. The physician could refer to this information and then conduct a brief intervention if needed.

- Dr. Warren agreed that obstetricians are not trained in administering brief interventions or in other techniques associated with psychiatry. It is becoming clear that many diseases have a strong behavioral element, such as hypertension, obesity, and diabetes. These conditions are also complicating factors in pregnancy as well as issues that family practitioners and other clinicians face. Medical school and residency training programs across all specialties will have to include training in how to address these behavioral elements.

- Dr. Sokol commented that the history of obstetrics is rooted in prevention, as all prenatal care is designed to prevent death, prematurity, and other adverse effects. Alcohol is one of many pregnancy risks that obstetricians address. It is one of the few areas, however, with a set of fully preventable abnormalities and effective intervention strategies. Now that brief interventions are recommended, they are struggling with how to implement them. A recent paper stated that if family physicians were to screen for every recommended condition, then the average visit would be prohibitively long. The issue, then, is how to focus enough attention on FAS. Project Choices has indicated that a brief intervention can work. Linking this work to women's contraception use may be successful, as gynecologists work with contraception issues every day. The concept of harm reduction is appealing to physicians. ACOG has tried to tailor the intervention to the kind of practitioner who will intervene. It is a challenge to make FAS important, but the timing is likely good to bring it to the forefront through ACOG.

- Dr. Warren pointed out that it is possible to screen for high risk alcohol use with a single question which does not appear to be looking for alcohol dependence per se, such as the "tolerance question" or the "max drinks" question. It has a few forms, but the question is close to, "What is the maximum amount of drinks you have consumed on one occasion?" People who are alcohol-dependent will likely respond with a high number. Alcohol use

during pregnancy is the leading environmental cause of birth defects in the United States. Pairing alcohol abuse with pregnancy potential is appropriate. Physicians should know how to do a minimal brief intervention, because as few as three questions can make a difference, whether the physician is qualified to make a DSM-IV diagnosis or not.

- Dr. Sokol clarified that a brief intervention can help abusive drinkers, and perhaps dependent drinkers. The big "bang for the buck" may not be FAS, but problems that are further down the pyramid of neurobehavioral abnormalities.

- Dr. Cordero asked about ACOG's stance regarding using electronic medical records (EMRs) to flag high-risk patients so that interventions can be possible in the future. Dr. Sokol replied that ACOG has granted one company, DigiChart, the rights to computerize their records. Obstetrics is an island from the rest of medicine, however. EMRs are more common in gynecology, but not in obstetrics, so it will likely be some time before they become frequently utilized. There are few people with the skill set required to use EMRs.

National Organization on Fetal Alcohol Syndrome (NOFAS)
Kathleen Mitchell, MHS, LCADC

Ms. Mitchell updated the Task Force regarding NOFAS's recent activities. NOFAS has changed its mission statement. The mission now reads: "The National Organization on Fetal Alcohol Syndrome is the leading voice and resource of the FASD community. NOFAS, the only international FASD non-profit organization, is committed to prevention, advocacy, and support. NOFAS effectively increases public awareness and mobilizes grassroots action in diverse communities and represents the interests of persons with FASD and their caregivers as the liaison to researchers and policymakers. By ensuring that FASD is broadly recognized as a developmental disability, NOFAS strives to reduce the stigma and improve the quality of life for affected individuals and families."

NOFAS acts in a number of capacities for a number of constituencies, from lobbying to training health professionals. They are involved with public awareness, advocacy, professional education, and constituent services. Their website includes a wealth of resources as well as public service announcements (PSAs). NOFAS conducts FASD seminars at Northwestern University and Georgetown University Schools of Medicine. They also work with and promote the CDC Regional Training Centers (RTCs).

With funding from CDC, NOFAS developed materials for use in kindergarten through 12th grade classrooms. These materials will be finalized in June 2006. For children in kindergarten through second grade, they created a storybook that helps students identify their own strengths and weaknesses while embracing things that make them special. The Grades 3-5 curriculum includes a lesson plan for teachers that provides general information on FASD and accompanying health and nutrition worksheets. The grades 5 through 8 materials include a lesson plan that provides information on FASD focusing on specific brain areas affected. Middle schoolers work with a model brain that helps them understand that when drinking occurs during pregnancy, the size of the brain can be altered. The model compares parts of the alcohol-exposed brain and the exposure-free brain. Children will see that when a mother drinks, there can be problems with learning and functioning for the rest of a child's life. The high school curriculum provides

general information on FASD with an accompanying videotape of an episode of NBC's "Law and Order." The episode on alcohol use and pregnancy was modified into a 20-minute segment for high schools. The piece sparks a series of debates around the legal and ethical issues around alcoholism and the rights of the mother and the baby. NOFAS hopes to distribute these materials nationwide, and they are working on a second episode related to FASD with "Law & Order" staff.

NOFAS has developed prevention materials with the Cherokee Nation in Oklahoma. All aspects of the materials were generated through the Cherokee Nation, and they produced the materials themselves. The NOFAS *Public Awareness Guide* is in its final stages. The *Guide* will assist individuals who want to do work in FASD. It leads the reader through the various systems of care and provides information on how to become an advocate, to organize, to create coalitions, and to become a voice for FASD prevention.

NOFAS is also working with four different Native American tribes through its Reducing FASD through Education, Advocacy, Community Coalitions, and Health Information Dissemination (REACH) project. Youth peer educators plan awareness campaigns designed to encourage their peers to make healthy choices about alcohol use, pregnancy, and lifestyle. These participants will join NOFAS at their Leadership Benefit in Washington, D.C., in June.

NOFAS hopes to grow the Circle of Hope, a program to increase understanding and support and to strengthen recovery for women who drank during pregnancy and their families. NOFAS is also working with the FASD Center for Excellence to develop a curriculum for addiction professionals. NOFAS continues to conduct Women in Recovery summits for women in treatment and their counselors, addiction professionals, state agencies, state legislators and other key stakeholders. They have provided technical assistance to two Native American tribes and summits are planned for 2006. The NOFAS Affiliate Program also continues to grow, and their goal is to have an affiliate in every state. There are nine affiliates so far. They will create a unified voice among constituents.

NOFAS is working with HRSA on a two-pronged project. They are developing a risky drinking health disparities collaborative and are working to increase prevention of FASD in community health clinics (CHCs), including training health professionals and disseminating materials. They also want to increase the identification of persons with FASD in CHCs as well as increase treatment for persons with FASD in CHCs.

Ms. Mitchell then introduced Tom Donaldson, President of NOFAS. He showed the group a new PSA created by Women in Film in Los Angeles. NOFAS assisted them with the script for this PSA. It is available for use in local communities, and local groups can add their phone numbers or other information onto a tagline at the end of the message. Other PSAs and radio spots are also available through the NOFAS website.

Mr. Donaldson discussed NOFAS's legislative and policy advocacy efforts, which take on two forms. The group works with affected families and individuals, helping them in a range of areas, from working with school districts to securing diagnoses. Their *Public Awareness Guide* draws on their years of experience with the public. NOFAS also works in legislative and policy

advocacy, constantly building constituencies, organizing individuals with needs, and educating policymakers. They also consider the work of other agencies and how that work can evolve to meet the needs of citizens. NOFAS accomplishes these goals by proposing legislation and by supporting relevant legislation at the state and federal levels. Each state operates differently from a policy standpoint, and individual agency statements must be updated as research is developed.

NOFAS also generates a monthly legislative and policy report. Their website features CapWiz, which is a means to discover legislators by zip code and to access lists of current bills that address FASD. The website also includes information regarding media outlets. The group creates policy papers and action alerts as well. Mr. Donaldson encouraged the Task Force to submit new research or new issues and they will help promote them.

NOFAS will conduct separate Senate and House briefings in April. Their annual Hill Day will be June 6th, and a week of activities in Washington will culminate in the Annual Leadership Awards Benefit on June 7th. Last year, 50 delegates attended 45 separate meetings on Capitol Hill. This year, they hope to double that number and represent 25 states in at least 100 office visits with family members and persons who are affected by prenatal alcohol exposure. The benefit event is their largest fundraiser and an opportunity for those who care about the issue to interact with policymakers. Their overarching goal is to increase attention to, and investment in, this condition. He listed those who would be attending or honored at the event, including former Senator Tom Daschle, Senator Lisa Murkowski, Senator John McCain, Senator Thad Cochran, Senator Christopher Dodd, and Senator Byron Dorgan. The benefit will also recognize advocates and scientists in the field.

NOFAS has been working to promote the "Advancing FASD Research, Prevention, and Services Act" (S. 1722, HR 4212) in both the House and the Senate. The bill is available at the Library of Congress website. Unfortunately, the bill is not likely to pass. There are many components of the bill, and all of them are vital. Senator Daschle introduced many bills related to FASD issues throughout the 1990s, but none passed until he attached an FAS provision to Senator Frist's broader Health Professions Act of 1998. Their best prospect is to remain visible on Capitol Hill and to encourage select provisions of the bill to move forward. They will not abandon the issues, but Congress is not interested in stand-alone bills or bills that deal with a single issue. They must modify their approach based on the climate. The bill is comprehensive, with more than three dozen provisions, some of which could be incorporated into other bills.

Individuals who have been affected by FASD are the strongest advocates for work in this area. NOFAS helps these individuals understand the ongoing research and other efforts related to the condition. The work that is being done is critical, researchers are on the right path, and more work needs to be done. Relationships with policymakers at the federal and state levels are key. The issue is important to a number of groups, and these groups can speak together. He urged the Task Force to communicate with NOFAS and these groups so that they can keep FASD on the list of priorities, even in this time of budget deficits. There are opportunities for funding, and NOFAS has an obligation to ask for that funding. He hopes to hear from researchers and to work with them to promote their work and to help them meet with their elected officials and their staff members.

The Arc of the United States
Sharon Davis, PhD
Dr. Melinda Ohlemiller (St. Louis Arc)
Dr. Davis explained that the Arc advocates for people with intellectual and developmental disabilities and their families. They are concerned about all aspects of life, from birth to death. They are also interested in the prevention of disabilities. FASD has been one of their focus areas since the mid-1980s. The Arc's chapters have focused on bringing awareness to the general public in their communities about this topic.

The Arc, which has 900 chapters and 150,000 members throughout the United States, advocates for prevention and supports families. Some of this support occurs in collaboration with NOFAS. They developed a curriculum that focuses on families raising children with FASD. The Arc of New Jersey recently celebrated the 20th anniversary of the New Jersey Coalition for the Prevention of Developmental Disabilities, honoring the 12 chapters that conduct "Pregnant Pause" programs. The Arc awards chapter grants for the prevention of intellectual disabilities. One of the grants last year funded Clark County, Alabama, to collaborate with a state substance abuse agency to reach out to 14 high schools and educate teenagers in FASD prevention.

The Arc National Convention will take place in San Diego, CA in October. Three hours have been set aside to address the prevention of intellectual disabilities, with a focus on FASD. They are soliciting their chapters for innovative programs and ideas. The Arc of Riverside has suggested that they invite Kenneth Lyon Jones to speak. The Arc also has a research fund, and their early support led to his research that led to the labeling of FAS. This fund also received a proposal in the early 1990s and funded a small seed grant for researching fatty acid ethyl esters and their impact on assessing whether a fetus has been exposed to alcohol. This work has grown and made an impact on the field.

Dr. Davis introduced Melinda Ohlemiller from the St. Louis Arc to provide an update on their activities. Ms. Ohlemiller reported that her group received a grant from a local foundation for $330,000 to implement a primary prevention campaign in high schools and junior colleges in St. Louis. The program targets young adults ages 14 to 21 in the six-county metropolitan St. Louis area, as well as some rural areas. Its core messages are that "When you are pregnant you should not drink, and when you are drinking, you should not get pregnant." Further, people who have been impacted by alcohol are worthy of our care and compassion. In the first semester of the effort, 1,400 students have been served via direct presentations in groups of eight to 20. The program will reach 5,000 youth in 50 high schools over the three years of the project. The University of Missouri is independently evaluating the project. They are conducting pre- and post-testing around the presentations and providing teachers with resources. They have borrowed materials and used advice from the following organizations: the Diagnostic Prevention Network at the University of Washington, NOFAS, NIAAA's "Better Safe Than Sorry" curriculum, SAMHSA's Building FASD State Systems, SAMHSA's Recovering Hope videotape, CDC media campaign projects, curriculum projects, education projects, the RTCs, and the state prevention projects. This effort is a good example of how ongoing work all over the country can have a large impact on a community and support community efforts toward prevention. Ms. Ohlemiller was eager to present the program's progress. Their goal is to expand the program to a kindergarten through 12th grade initiative.

Center for Science in the Public Interest (CSPI)
George Hacker, JD
Dr. Hacker reminded the group that the mission of the Center for Science in the Public Interest (CSPI) is broader than pregnancy and FASD. They have been involved in these issues with regard to universal education regarding drinking during pregnancy. Some of their activities also have an impact on the issue of drinking among young people and drinking in general.

He echoed Mr. Donaldson's sentiments regarding moving initiatives and good ideas in Washington. CSPI has pursued two strategies. One involves breaking larger ideas into small pieces and attaching them to other vehicles. The other strategy is to use the appropriations process to direct an agency's work or to direct funding streams. With NOFAS, CSPI has developed a "blueprint of options" for work during the next Congressional session, both in the appropriations area and in trying to move pieces of Senate Bill 1722 into other vehicles.

CSPI has joined with the American Medical Association (AMA), Mothers Against Drunk Driving (MADD), the Center on Alcohol Marketing and Youth (CAMY), the National Association of Children of Alcoholics (NACA), the American Academy of Pediatrics (AAP), Community Anti-Drug Coalitions of America, and the Leadership To Keep Children Alcohol Free (a group of governors' spouses) to form the National Alliance to Prevent Underage Drinking. The group promotes legislation called the "STOP Act: The Sober Truth On Preventing Underage Drinking." This omnibus legislation has several pieces, including research, community and college programs, funds for a national media campaign, federal coordination, and monitoring of alcohol advertising and alcohol consumption among young people. The legislation has broad, bipartisan support from both houses, but it is not on a "fast track." Pieces of it have been included in an education bill and a SAMHSA bill, but it is not clear that either of those bills is on a fast track, either.

CSPI is engaged in the Campaign for Alcohol-Free Sports TV. Sixty percent of television advertising for alcohol is broadcast during sporting events, and many of the advertisements are youth-oriented. About a year ago, CSPI began College Commitment, an effort to recruit college presidents and athletic directors to pledge to help eliminate alcohol advertising during collegiate sporting events. They have recruited about 250 participants representing more than 23% of the NCAA membership. The issue arose before the NCAA's Executive Committee last August. The group recognized the problem but did not face the hypocrisy of alcohol advertising in the context of the mission of NCAA and its member schools. They did, however, recommend that schools review their alcohol advertising policies and other alcohol policies. CSPI is focusing on the primary athletic conferences as they renegotiate their television contracts.

Dr. Hacker addressed a controversy involving American skier Bode Miller, who recently admitted to drinking prior to competing. Miller was denounced by many individuals and groups involved in amateur and youth skiing. All of these associations, however, are sponsored by a major brewery. CSPI drew attention to this hypocrisy and is working to remove alcohol advertising from the Olympics. Anheuser Busch operated "Club Bud" in Turin, Italy during the Olympics and has held a series of parties, one of which honored the United States snowboarding team. Six of the 16 snowboarding team members are under the legal drinking age. The gold medal winner and guest of honor, Shaun White, is 19 years old.

Last summer, the Alcohol and Tobacco Tax and Trade Bureau released a proposed rulemaking on a variety of labeling issues concerning nutrition information, alcohol content information, standard serving sizes, and other issues. The proposal from industry focuses on nutritional aspects and standard drink definitions for alcohol labeling. Another proposal, which CSPI advocates for with the National Consumers League, focuses on alcohol facts such as calories, alcohol content, serving sizes, ingredients, and the definition of "moderate drinking" based on the dietary guidelines released in 2005. There is still a strong interest in warning labels among medical and professional groups in the field.

Researchers at the University of Connecticut reported on the first longitudinal study that looked at the effects of alcohol advertising on young people in terms of their exposure, likelihood to drink, and likelihood to drink heavily. There is a small but clear association between advertising and drinking. The relationship is not causal, but the data are strong enough to indicate an association.

The World Health Organization (WHO) is interested in alcohol and underage drinking. As a result of a World Health Assembly Resolution, WHO is developing a report that may translate into guidance for member states of WHO on how to prevent, treat, and reduce underage drinking throughout the world.

Mr. Hacker also indicated that SAMHSA recently released a congressionally mandated report to Congress on a national plan to reduce underage drinking. According to Mr. Hacker, the report sets modest goals and targets, is silent on the need for resources, and fails to mention important prevention policy measures identified in the 2003 National Academy of Sciences, Institute of Medicine report on preventing underage drinking.

American Academy of Pediatrics (AAP)
Dr. George Brenneman

Dr. Brenneman indicated that the AAP is an organization of 60,000 pediatricians with chapters in every state. The group is dedicated to the physical, mental, and social health of children from birth to the age of 21. They are very interested in the outcomes of prenatal alcohol exposure. Their challenge is having an effective influence in unborn children. These issues are also important in their work with adolescents.

A collaborative survey between CDC and AAP examined pediatricians' knowledge and experience regarding FAS. This survey produced several subsets of data. An article was submitted for publication in *Pediatrics* but was not accepted. The authors are working together to resubmit a revised article to *Pediatrics*. It will discuss pediatricians' understanding of FAS as well as their needs and weaknesses in this area. Pediatricians know about FAS, but are less comfortable making diagnoses and identifying resources to treat diagnosed children.

AAP is revising two policy statements. One is "Fetal Alcohol Syndrome and Alcohol-Related Neurodevelopmental Disorders." This policy was originally released in 2000. A second policy, "Prenatal Substance Exposure and Its Long-Term Effects" is also being rewritten and revised. Both are being reviewed by AAP's Committee on Substance Abuse. A third policy with a

tangential relationship to FAS is a policy on inhalant abuse. This revision is in its final stages and will be released soon.

New Business

Continuation of the Task Force After Sunset (October 24, 2007)

Dr. Cordero briefed the group regarding the "sunset" of the Task Force. As of October 2007, the Task Force's authority will end. He hoped to obtain feedback from the Task Force regarding next steps.

Dr. Cordero also provided a brief overview on CDC's reorganization efforts. Instead of working in "silos;" that is, each specialty or Center functioning separately, they are considering how to work together so that issues such as alcohol use, folic acid, HIV, and other concerns are addressed more collaboratively.

The budget is very tight, so they need to do more with what they have. A key strategy will be to engage in more integrated activities. They are reaching out to high-risk women by "bundling" messages about HIV prevention, alcohol, folic acid, and other issues. This approach reflects CDC's goals and can show health impact. In the new government atmosphere, it is not only important to prove that programs are doing what they say they will do, but also to prove that they are having an impact. The Center must align its strategies, goals, and investments to show greater health impacts.

To this end, NCBDDD seeks to ensure that children are in their best health and to reduce and eliminate health disparities. CDC's goals lie in four areas: Ensuring that people are healthy from birth throughout the lifecycle; ensuring that the places where people live, play, and work are healthy; ensuring that we are prepared for disasters; and addressing global health issues. CDC has a total of 24 specific goals across the four themes and actively seeks input into how to achieve these goals.

The new goals process has resulted in an examination of CDC's advisory committee structure. CDC has over 20 advisory committees, and there are gaps between the advice they provide and the overall CDC goals. There is a need for broader advisory committees. The CDC Director has an advisory committee that assists with planning the agency's strategic direction. NCBDDD has been authorized to create a Board of Scientific Counselors. Similar committees will be created for each of the new CDC Coordinating Centers as well.

As the Task Force goes into sunset, discussion is needed on whether to continue as a Task Force and consider reauthorization, or whether the group should be a subcommittee within the NCBDDD's new Board of Scientific Counselors. There are pros and cons to each option. The group is very important to NCBDDD, as its advice and direction in FASD has been invaluable, both in primary prevention of FASD and in helping individuals and families that have been affected by FASD.

Discussion:

- Dr. Wright noted that even if the Task Force was not going into sunset, the larger question of the committee structure at CDC would still have been raised. Dr. Cordero concurred, noting

that there are two kinds of committees—those that are organized at the discretion of CDC and the CDC Director, and those that result from Congressional mandates. This Task Force is congressionally mandated.

- Dr. Olsen commented that this Task Force represents a unique, multi-disciplinary set of inputs and has developed methods for giving feedback to the research community. It has also achieved synergy and provides a mechanism for keeping each other informed regarding activities and promoting each other's goals. She hoped that there was a way to continue that guidance role.

- Dr. Cohen acknowledged that it took 20 years to bring attention to FAS. Agencies are very committed to the issue now, but there is a possibility that the attention given to FASD, and the strides that have been made in bringing its issues to the general public could be lost. If FASD is incorporated into a CDC structure that continues to focus attention on it, then there is no need for legislation. However, there should be an institutionalized effort to continue programs to address FASD. She compared FASD to childhood injury pointing out that they are both incremental and will not be well-known or well-studied without a continued force. A program at CDC will make sure it continues. The importance of having a structure overrides the question of whether that structure is legislative or voluntary.

- A CDC staff member in the audience commented that the Task Force could be vulnerable because of the great changes occurring at CDC. There is an advantage to being a distinct entity. She suggested that they challenge the organization to integrate them and their interests, rather than forcing themselves into the reorganization process.

- Dr. Sokol said that the current Task Force structure has been successful. The congressional mandate has been a great help. The group is administered by CDC, but has an impact across the field. This position is stronger than if the Task Force functioned only in an advisory capacity to CDC. A major strength of this group is its span and that the mix of members and interests work well together. They have formed a unique resource. He expressed his hope that the group could be sustained in its current format.

- Dr. Cordero thanked Task Force members for their comments. They have time to consider their actions, as they are early in the process. In the end, Congress will determine whether the Task Force will be re-chartered as-is or be reauthorized in another form. Ms. Weber encouraged members to share any additional comments regarding this issue with her, Dr. Cordero, or Dr. Wright by phone or via email.

- Dr. Wright said that this group has a dynamic that she has not enjoyed with previous federal advisory groups. She hoped that CDC staff would remember the "value added" component of the group. As Task Force members assemble from different perspectives and disciplines, they help to enlarge the scope and the vision of the entire field.

- Ms. Mitchell spoke as a family member who has been affected and who deals with the public on this issue. One of the things she would like the group to consider is that we have the ICCFAS, SAMHSA Steering Committee, and the Task Force. Perhaps the paradigm needs

to change. Many of the same people attend these meetings. The original concept of the Task Force was to convene a committee that could speak to all of the agencies and their concerns so as to keep uniformity in what is going on and not replicate efforts. She wondered whether they could reconsider the paradigm of what goes on. She would like to see the Task Force become more vocal in responding to media issues and other timely issues that come up online and in other areas. The Task Force should respond to these kinds of issues.

Post-Exposure Working Group Update and Discussion of Future Activities
Heather Carmichael Olsen, PhD
Deborah Cohen, PhD
Melinda Ohlemiller, MPH

Dr. Olsen was asked to provide an update on the activities of the Post-Exposure group but also to have the group consider how intervention efforts can actually be part of the next real serious focus of the Task Force which is prevention. Dr. Olsen indicated that most members of the Post-Exposure Working Group work directly with families or conduct intervention research. The group wants to promote services at the systems level. The working group wanted to tackled the question of how the Task Force can accomplish something "real in the world." As a result of her involvement in the Task Force, Dr. Olsen has mobilized the FASD Study Group, conducted training with psychiatrists, and helped to start a chemical dependency treatment center. All of the funding and efforts that have been spearheaded by people at this table manifest themselves in the lives of children and families. As the Task Force moves toward a discussion of prevention, she expressed her hope that they would not lose this important aspect of their work or the momentum behind it. FASD is a trans-generational issue, and prevention and intervention are inextricably linked.

Dr. Olsen has been in the FASD field since 1989, and commented that the number of concrete and important initiatives discussed at this meeting so far was remarkable. Further, information is collated as Task Force members work together and support each other's efforts. Synergy and support come from informing each other in this venue. They are working to ensure that systematic, pragmatic translational research occurs that affects families. She further praised the focus on evaluating programs and developing an evidence base, which are essential for securing funding for services to families. Intervention efforts are underway.

The Post-Exposure working group worked to develop a concrete statement, which was ultimately endorsed by this Task Force, to formally recognize FAS in the reauthorization of IDEA. A letter was sent from the Task Force to the Department of Education. The working group has also made an effort to influence the American Psychiatric Association to consider FASD in the next versions of the DSM-IV CR. This effort made some progress, but might have been "too innovative" at this time. They should consider education efforts to get mental health "on board" with the concept of multi-axial assessment with a child and a family. These efforts take time and in order to have an impact on DSM-V, they must begin work now and stay mobilized. A position paper is being written, which should be very informative.

The working group noted that multiple interventions are being deployed, and SAMHSA is documenting the number of efforts that are underway and are potentially viable candidates for program evaluation to build the evidence base that will, in turn, convince systems and physicians

that interventions can make a difference. These interventions are ongoing because we have increased diagnostic capacity, which is due to the people who have created systems and to the development of the FAS guidelines that have begun to have an impact on the community standard of practice. Dr. Olsen is involved in several of these kinds of grassroots research efforts, such as, CDC-supported, translational research built on tested interventions. They documented that their work was not only promising, but also had an impact. This is now being translated into the community.

NIAAA continues to publish and support ongoing research. A great deal of work is occurring in Canada. The Western and Northern sides of Canada are deploying province-wide diagnostic intervention efforts. Family advocacy has become very popular and successful, and natural supports are building for the services that are needed in this population. Many organizations such as the Arc and the March of Dimes are also doing a great deal of work. There are a number of literature reviews being done as well. SAMHSA has collated intervention data. Ultimately, many efforts are taking place in a variety of settings, and this work can guide the Task Force. These intervention efforts are important to prevention.

Dr. Olsen asked the group to think about how intervention efforts can accomplish FASD prevention and what the data are supporting at this time. She distributed a chart of efforts in Washington State that described the relationships between their efforts and the effects. She pointed out that because of a screening program at their diagnostic clinics, they have been able to document, not causally, the fact that from 1993, when they first could capture data on FAS prevalence in the largest county in the state, there has been a decrease in the number of full-syndrome births that have occurred. This is statistically significant. The lessons learned in Washington State can be useful.

The chart indicates that work in FASD has a cumulative effect that is likely the reason for the documented reduction in prevalence of full-syndrome births. A combination of prevention, screening and diagnosis, treatment/intervention, and public education has had an effect, which is reflected in other prevention literature. One thing is if you are going to know if you did prevention, there also needs to be a method to establish base prevalence rates and to track changes. In Washington State, they learned that it is helpful to have a clinic and to screen in as large of a population as possible. It is especially helpful to capture an entire population, as they were able to do with their Foster Care Screening Program. This program used photographs, which have clinical reliability, to track the rate of FAS over time in all foster care in one county. They realized that they needed a method to associate their work with impact.

Dr. Olsen commented that alcohol treatment for women is probably one of the most significant activities that occurred in Washington State to “kick everything into action.” Efforts in this area tripled the number of gender-specific inpatient residential treatment beds for women. They then included therapeutic child care so they were able to monitor children and educate moms and counselors in FAS. Some direct efforts in prevention created interventions, and some diagnostic and intervention efforts laid a foundation for prevention. Chemical dependency programs that offer alcohol treatment can provide opportunities for preconception risk assessment as well as early assessment and intervention, which CDC is interested in. At their FASD diagnostic clinics, they offer outreach to the birth mothers of children who are identified in the clinic, even if the

birth mothers did not present for treatment. This diagnostic clinic, an intervention, can accomplish prevention, hopefully in a trans-generational way. Based on these data, it seems that alcohol and drug treatment for women, rather than family planning, has changed over time. It is possible to infer, then, that the alcohol and drug treatment strategies affected their FAS prevalence rate. They are beginning to grow an evidence base. Dr. Olsen noted that every state is different, so she introduced Dr. Cohen to discuss activities in New Jersey.

Dr. Cohen commented that sometimes the most effective interventions come from unexpected sources. Two major issues caused New Jersey's comprehensive drug and alcohol treatment services to begin to be established. The state underwent welfare reform in the mid-1990s. Funds were given to screen and identify women and to guide them to treatment so that they could then be trained for employment and get off of welfare. It is her agency's responsibility at the state level to see that these efforts also include FAS. Where are the children in these treatment centers? If you are looking to build treatment services, one of the places to look toward is welfare reform efforts because that is where the funds are.

Another important event in New Jersey was court intervention in the child welfare system. This resulted in an expansion of drug and alcohol treatment abuse services at all levels. These efforts concentrate on getting people, particularly women, the help that they need. The Addiction Services Division was moved from the Health Department to Human Services, where Child Welfare Reform is occurring. Any woman who enters the Youth and Family Services System, who is suspected of being abusive and neglectful, is immediately sent for drug and alcohol screening and referred to treatment, if appropriate.

In New Jersey, they are working to establish preconception and prenatal screening as a standard of obstetrics care. They have had demonstration projects throughout the state through the Maternal and Child Health Consortia. The projects are working with the federally qualified health centers, hospitals, and other public clinics to do the screening. In an 18-month period, they screened about 20,000 women for drugs, alcohol, cigarettes, and domestic violence. About one-third of those women were referred to services, but it is not clear how many of those women were already actually in the system. Because those data are beginning to show good results, some local health departments and the Maternal and Child Health Consortia recently received a three-year grant from a New Jersey-based foundation to have the five Medicaid-managed healthcare organizations in three cities use the screening as a part of a standard of care for obstetrics. If those five healthcare organizations find that including this screening is worthwhile, then it is expected that the Medicaid-managed organizations will make the screening a standard of care, which would encourage all of the other HMOs to adopt the standard.

In 2001, the NJ FAS Task Force published a report that underscored the need for having an FAS (now FASD) diagnostic service system. Some funds ($450,000) were allotted in New Jersey to establish diagnostic services. Training was conducted by researchers from Washington State. Now they have a service system for women, a means to identify women who need services, and a service system that can diagnose children. A system that can find the women within the public health system is also important. The New Jersey Department of Health has moved the risk reduction system from hospitals to the community service, public health system. This move has helped in educating providers as well as in identifying women. In the early 2000s, New Jersey's

Department of Education re-examined its core curriculum standards for physical education and health in schools. They incorporated and established core curriculum standards for FASD and injury. It is mandated that schools include an FASD educational piece. In sum, New Jersey has tried to establish a comprehensive system that includes both intervention and prevention issues. The major challenge for all states comes with the transition from childhood through adulthood service systems.

Dr. Ohlemiller spoke about efforts in Missouri. The state has only been active in this area since 2001. They are working at the project level. It is important to encourage states to work at this level and to build on their work. This is a good place to start. It has been critical to get buy-in from key state-level agencies. The work of CDC and the Task Force has contributed to these partnerships. Their diagnostic clinic started over one year ago, and they already have a one-year waiting list, indicating a strong need. The clinic has about a 25% hit rate on full FAS in the clinic right now, which is very high. Funding support through congressional mandates, CDC, and SAMHSA have helped to launch these projects. Saint Louis University is engaged in a number of prevention efforts as well. Missouri has an agency coalition that has been active for five years and has been instrumental in getting projects going and doing collaborative grantwriting. They are struggling with the intervention piece, as most of the projects have focused only on prevention. She hoped that the new clinic will open new avenues for intervention work. She felt strongly that the integration of intervention and prevention needs to include the diagnostic clinics.

Dr. Olsen offered ideas for the Task Force as they work on the prevention document. The Post-Exposure working group considered interventions in the treatment and family support arena that might have a prevention aspect and an evidence base. Brief intervention for women screened to be at higher risk can have a prevention aspect in reducing problems in a current pregnancy as well as in future pregnancies. Gender-specific drug and alcohol treatment and therapeutic childcare programs are building an evidence base. Paraprofessional and professional support programs for the highest-risk women, such as P-CAP, hold promise. This research is difficult, but the programs have a solid evidence base. A pilot project is currently underway considering paraprofessional support for women with FASD and who are doubly vulnerable. There is also talk of creating special programs for young women in treatment who may be at risk for having alcohol-affected pregnancies. There is no evidence based yet, but this would be a wonderful area to put funding towards.

It is crucial to remember that FASD is a trans-generational issue. Therefore, efforts such as the NOFAS Birth Mother Support Network can be beneficial. Washington State is experimenting with out reaching efforts from the diagnostic clinic. A small pilot study is demonstrating that using motivational interviewing techniques to link the highest risk birth mothers to a support program can be successful. This intervention should have an impact on prevention, as these women are at risk for having another alcohol-affected pregnancy. Natural supports through family advocacy organizations need an evidence base. We hear anecdotally that families and children are being helped. These programs need to be evaluated. Parent support organizations could also be robust prevention and intervention aspects of our continuum of services.

The notion of very early detection does not have an evidence base. It could effect intervention efforts and also have a prevention aspect as it affects decision-making regarding another pregnancy or potentially improving a child's neurological development. Another area lies in working with affected youth themselves. Models are being developed and need to be evaluated. This is another high-risk group in terms of prevention. Adolescents who don't have great judgment or are highly active or who may come from a family with genetic or familial predisposition for alcohol or drug use are at high risk. FASD is a trans-generational issue in prevention as well intervention.

Dr. Olson commented that interagency collaborations are making a difference. Individuals with FASD do not fit into specific service categories, so those who conduct the research and those who work with the population must communicate. The greatest referral into their diagnostic clinic is not from healthcare providers or schools, but families who seek help for their children. Increasing recognition by service systems and educating other specialties, such as obstetricians, psychiatrists, and medical students will have a prevention impact. Surveillance and diagnosis are key. Diagnosis leads to screening, counting, connecting screening with other databases, out reaching to birth mothers who can reach out to their families and kinship placements. Prevention can then be accomplished. Diagnostic clinics can connect families to prevention services. Research is needed to document that these efforts work so that providers will be motivated to use the tools we are creating for prevention. Dr. Olsen asked the group to consider other intervention efforts that might have prevention aspects that should be included in future prevention discussions.

Discussion:

- A CDC staff member asked about women who are intractable drinkers. This group does not respond to intensive intervention in the clinic setting and has not been mentioned, but seem to be at highest risk. Dr. Olsen replied that paraprofessional support programs exist for women whose chemical dependency is so serious that multiple treatment efforts are needed. Their support is not tied to whether they are successful in treatment. This mechanism has an evidence base.

- Dr. Sokol said that Michigan's programs are not as extensive as Washington State's. There are limited resources for female alcoholics as compared to male alcoholics. Only one agency in the greater Detroit area will provide care for pregnant women alcoholics. They have a substance abuse program that uses city funding. They needed to get foundation dollars to start their diagnostic clinic. Funding for activities like these is essential.

- Dr. Brenneman described a collaborative effort between the state of Alaska and HIS and tribal programs to establish a pre-maternal home in Anchorage where pregnant women with alcohol problems could live and receive treatment. The home was both a primary and secondary prevention tool, as it included both an ambulatory and an inpatient facility. The facility also provided a place for new mothers and their babies. Dr. Sokol added that his hospital had a drug and alcohol inpatient facility, but it was closed. The Medical Center closed the ambulatory clinic for financial reasons.

- Dr. Warren pointed out that alcohol dependence itself is a disease and a disorder which is expressed as behavior. Certain life events can be effective times to motivate individuals to change or to receive treatment. Being arrested for a DUI or the threat of losing a job are examples of these events. Pregnancy can be a positive time for engaging women in treatment, motivating them further, and helping them to succeed. Like diseases such as hypertension, alcoholism is a chronically relapsing disorder. Long-term remission is the best overall achievement. Abstaining from drinking during pregnancy can impact a woman's long-term recovery from alcohol dependence.

- Dr. Calhoun said that the ICCFAS will collaborate with SAMHSA on a major conference on "research to practice and practice to research" and women in treatment. The research base in this area is not strong. They hope that ideas from practitioners will help them develop the specifics of the research agenda and to identify what needs to be evaluated.

- Dr. Olsen reiterated that discussions such as this one, in which the funding agency directions dovetail with intervention and prevention work, are important synergistic activities.

- Dr. Wright complimented Dr. Olsen on the table outlining Washington State's activities. It could be a "road map" for other states that are less organized. Creating a similar table for each active state could help illustrate which efforts work and help to stimulate model legislation.

- Dr. Olsen said that the table describes a "natural history" of events in Washington. More research is needed, as the evidence base is not strong for some of the efforts. They know what to test, but they need the data. Another state could look at this chart and find efforts to undertake and document. Dr. Brown agreed that elements of the chart could be taken as policy-level steps. A framework can be developed from elements of successful programs and services: a collaborative, composite result. Dr. Olsen noted that the entire document was available, and she thanked Susan Astley for creating the document.

- Dr. Cohen said that the FASD Center of Excellence is trying to encourage these efforts. Ten states are funded, but another 25 to 30 states are trying different pieces of the work. State FAS Coordinators need this information. Some states will need diagnostic assistance, while others need help in screening and getting women into treatment. The Task Force's discussions over the last few years have influenced the activities on the Center's Steering Committee agenda.

An Ounce of Prevention: Lessons from Public Health

Ms. Weber introduced the speakers for the next session indicating that as the Task Force focuses its attention on FASD prevention, it may help to hear about how prevention is approached within other health topics outside of FASD and how these approaches might be able to help inform the work of the Task Force as it moves forward in developing an FASD prevention agenda.

Brick Lancaster, a national leader in health education and health promotion, was the first speaker. He is Chief of the Programming Services Branch at the Office of Smoking Health at CDC. This Branch funds tobacco control programs. Prior to joining the Office of Smoking and

Health (OSH), he served as Associate Director for Health Education Practice and Policy at the Division of Adult and Community Health at CDC. The second speaker was Alina Flores, a health education specialist at CDC's National Center on Birth Defects and Developmental Disabilities. She has been involved in the development, implementation, and evaluation of the national Spanish language folic acid campaign and has assisted in other national and international programs and the development of educational materials. Dr. Tanya Sharpe is a research behavioral scientist with CDC's Division of HIV/AIDS, where she coordinates science and technology transfer from universities and other research institutions to community-based organizations and provides leadership on national HIV prevention and education programs targeting at-risk youth and illicit drug users. Mary Schauer is a health scientist in adolescent and reproductive health at the Division of Reproductive Health at CDC. She has over 25 years of experience in both domestic and international reproductive health work. Her emphasis is adolescent pregnancy prevention program development, implementation, evaluation, translation, and dissemination.

Brick Lancaster, MA

Mr. Lancaster thanked Ms. Weber for the invitation and greeted the group on behalf of OSH. He offered a broad overview of the tobacco prevention and control world, where they focus on policy and environmental systems and normative change issues.

Tobacco is still the leading preventable cause of death in the United States with 440,000 deaths annually. For every smoker who dies, 20 more are ill due to their tobacco use. The economic costs of smoking are $167 billion annually, with an additional $75.5 billion in smoking-related medical expenses. The Surgeon General reports indicate that tobacco consumption and exposure take a serious toll at all ages, causing harm to unborn babies and young children as well as seniors. Tobacco damages nearly every organ in the body, causing multiple health conditions. A Surgeon General report on the impact of secondhand smoke will be released in June.

To help develop and sustain successful state programs, OSH published *"Best Practices in Comprehensive Tobacco Control Programs."* OSH focuses on building comprehensive and sustained programs in four goal areas: preventing tobacco use initiation among youth and young adults, promoting tobacco use cessation among adults and youth, eliminating exposure to secondhand smoke, and identifying and eliminating tobacco-related disparities. OSH's strategic priorities include: conducting tobacco product research and information dissemination, promoting sustainable, science-based tobacco control programs, strengthening global tobacco surveillance and translation of data into action, and engaging the business sector in promoting comprehensive tobacco control and prevention. States have suffered budget cuts, so OSH is working to build those dollars back up. Further, the office seeks to strengthen global surveillance. An article on their work in global youth surveillance was published in *The Lancet*. Their newest effort is to engage the business sector.

OSH is one of the few programs in the Chronic Disease Center that funds all 50 states and the District of Columbia, as well as U.S. territories and jurisdictions. Two years ago, they were supported to fund Tobacco Quitlines, and all states will have proactive Quitlines by the end of June. 1-800-QUIT-NOW is an automatic portal for support for tobacco cessation. OSH could not accomplish their goals without their partners, which include groups such as the National

Cancer Institute, American Heart Association, Robert Wood Johnson, and others. A new effort OSH is working on is the National Partnership to Help Pregnant Smokers Quit. The March of Dimes and other entities, including public health and clinical organizations, jointly work on policy and systems change interventions to see that physicians are asking pregnant women about smoking and getting them into treatment and cessation programs.

CDC's role in national tobacco control lies in coordination of state, federal and national efforts, diffusion of best practices, technical assistance and training, achieving "economies of scale", evaluating outcomes, and assuring accountability of funds. Most of this work is focused at the state level rather than at the community level. They build capacities of state health departments, who, in turn, work with their communities.

The National Tobacco Control Program framework consists of four components: community interventions, counter-marketing, policy/legislation, and surveillance/evaluation. States receive an average of $1.3 million per year to support science-based interventions in each of these areas. Some states are receiving large sums of money through the tobacco settlement, but very little of that money is devoted to tobacco prevention and control. States that do devote settlement money to these programs use CDC money to support their staff.

OSH has determined which interventions are effective. Interventions that they know work include: continued support for local community programs, increasing tobacco taxes, maintaining effective media campaigns, continuing quitline efforts, and reducing exposure to secondhand smoke. OSH utilized CDC's *Guide to Community Preventive Services* process to determine which population-based strategies were most effective. The *Guide to Community Preventive Services* tobacco recommendations included reducing initiation, increasing cessation, and reducing exposure to secondhand smoke. Initiatives to reduce initiation include increasing the unit price of tobacco products, mass media education (combined with other interventions), and community mobilization combined with other interventions to decrease minors' access. Efforts to increase cessation that are effective include increasing the price of tobacco, mass media campaigns, quitlines, reducing out-of-pocket costs for treatment, and provider reminders alone or with provider education. Research shows that a 10% price increase in tobacco prices reduces youth smoking rates by 6.5% and adult rates by 2%.

Research has also shown that the more states spend on comprehensive tobacco control programs, the greater the reductions in smoking. The *Journal of Economics* released a major paper to this effect. Further, the longer states invest in these programs, the greater and faster their impact. OSH recently released a book called *"Key Outcome Indicators for Evaluating Comprehensive Tobacco Control Programs."*

Mr. Lancaster noted that OSH has worked in sustaining tobacco efforts in states, and the states needed information to use with policymakers. They created state fact sheets on what works in tobacco prevention and control based on the literature. As OSH cannot do direct advocacy work, they work extensively with partners.

He thanked the Task Force for convening the panel, noting that it is a strong example of how they can learn from each other. He offered this quote from Paulo Friere: "To be successful in

community work, we need to have a good sense of history, humility, and a deep respect for the people with whom we work." More information on CDC's Office on Smoking and Health can be found at www.cdc.gov/tobacco.

Alina L. Flores, MPH, CHES
Ms. Flores works in folic acid and neural tube defects (NTD) prevention. She spoke regarding her group's efforts in translating research to practice in their folic acid outreach efforts. Since mandatory folic acid fortification began in 1999, there has been a decline from 4000 to 3000 NTD-affected pregnancies per year. Conclusive evidence indicates that daily consumption of folic acid can prevent up to 70% of NTDs if taken before and through the early weeks of pregnancy. Health disparities do exist with NTDs. Hispanic women are at the highest risk for NTD-affected pregnancy, even though there has been a decline in rates. This group also has the lowest reported folic acid knowledge and the lowest reported folic acid consumption.

In 1998 and 1999, focus groups were conducted with Hispanic women. Through these focus groups, CDC learned about many barriers that kept Hispanic women from taking vitamins. Among these barriers were the myth of weight gain from vitamins, the challenge of language issues and difficulty in communicating with providers, citizenship issues preventing access to regular healthcare, transportation, the cost of vitamins and folate-rich foods, lack of awareness regarding the importance of folic acid, cultural beliefs that indicate that vitamins are for children to gain weight, later entry into the prenatal care, fatalism and religiosity, and a reluctance to spend money on themselves.

Based on these findings, the Spanish language Folic Acid Campaign was developed. The campaign, using Spanish language media, is in its fourth year. The work combines paid media with *promatoras*, lay health workers. There is value in paid media, but only in partnership with other efforts in communities. Ms. Flores shared some of the lessons learned from these efforts. It is important to know your specific audience. With this audience, issues such as country of origin (varies with Hispanic populations), language preferences, and citizenship status, can play a role. It was important to remember that not all Hispanic women are the same; not all Spanish is the same (e.g., terminology, slang may be unique to the country of origin). Involving men is important. The man in a woman's life may be a significant barrier to her decision to change her behavior. He should be involved or familiar with the topic. Men were wary, but reaching women required cooperation from men. Also, many Hispanic men are very family-oriented so approaching the issue of folic acid use as a strategy to keep the family healthy could be quite effective. It is important to use outlets for message dissemination that are popular with the community. The *promatoras* have been an excellent source for this. Another important consideration is to remember not just to translate English materials into Spanish. The materials need to be culturally-appropriate and tested with the target audience. Literacy can also be an issue. Finally, collaborating with local-level partners is critical. Partners should be involved with the project in the planning stages. They can provide valuable insights about the target community. They can also provide access to the target community as well as healthcare providers, and they can lend credibility to the campaign messages.

Another CDC program known as the Optimal Nutrition Program concentrates on college-age women. This work is conducted in partnership with CDC Foundation, Wyeth Pharmaceuticals,

DSM Nutritional Products, Inc, and BASF group. Formative research was conducted to determine how to focus campaign efforts. Demographic predictors of multivitamin use include age and income so the target group was segmented into these categories. User status was also examined. Twenty four focus groups in four cities were done. Results indicated that women used Flintstones vitamins as children and they had a positive effect on them. Many of the women stopped taking vitamins in middle or high school and then began taking vitamins again in their early twenties. Most non-users indicated that they would start again if the multivitamim was like Flintstones. Most women felt that they knew what "health" was, even if they did not engage in healthy practices. Most women had the similar perceptions when it came to health: to eat right (e.g., food pyramid, moderation), exercise, sleep, drink water, take vitamins, and maintain good mental health. Many of the women felt they were not successful at being "healthy." The women also lacked knowledge about specific vitamins. They did link some vitamins with healthy skin, hair, and nails. They also kept vitamins in the home.

In the focus groups, younger women did not want to discuss pregnancy, but responded to associating vitamins with beauty. Older women were more open to discuss pregnancy. Women in lower-income groups felt that the lack of money was a barrier, where women in higher-income groups felt that the lack of time was a barrier.

Based on this knowledge, the program will target college-age women on six college campuses. The project will include a variety of communication efforts includes advertisements, peer education, and other campus-wide efforts. Another program the team coordinates is the Science Ambassadors Program. It brings together middle and high school science teachers to CDC for workshops where they hear about a number of health topics, including folic acid, FAS, injury, and chronic disease. The teachers develop lesson plans based on these topic areas and take those plans back to their classrooms. The folic acid team has struggled to get pregnancy issues into the classroom. This program helps teachers to frame the messages within the context of the courses they teach.

Finally, the team developed a brochure for middle schools called "B" Your Best." It teaches young adolescents about the importance of vitamins as part of a daily healthy habit. In the focus group testing, the middle school students did not relate to pregnancy and birth defects issues, but they understood that vitamins were important for good nutrition. The first printing of 500,000 was gone in five weeks. It is very useful in schools because it does not mention pregnancy.

In conclusion, it is important to use a combination of approaches when trying to reach a selected audience. It is critical to know the audience, test the materials and messages before a product is developed, and to disseminate the message through appropriate channels.

Tanya T. Sharpe, PhD

Dr. Sharpe works in the Division of HIV and AIDS at CDC. They take research and put it into practice. Behavioral interventions for HIV prevention are programs that are designed to prevent transmission of HIV and to reduce the risk of contracting HIV through practiced behavior modification activities. These interventions are usually developed and tested for effectiveness by university researchers funded by NIH. They are also under girded by some theory of behavior change. The theoretical model of behavioral interventions includes characteristics of the target

population (e.g., age, gender, SES, family, behavioral, psychological issues). The interventions typically consist of a package of knowledge, attitudes, resources, and skills. All aspects of the model are presented to participants in different sessions, and the outcomes include reduction in the number of partners, effective use of condoms, delay of sexual behavior for youth, screening of partners, and reduction of substance use. These outcomes will help the person stay HIV negative. All of the packaged interventions are variations on this theme.

The Division has specific criteria for selection of behavioral interventions. They must be tested in clinical trials or, minimally, quasi-experiments. There must be unbiased recruitment of participants. The comparison and treatment groups must be randomly assigned, and pre- and post-test data must be collected. The results must be published in a peer-reviewed journal, and 70% of the participants who were exposed to the treatment must be retained throughout the course of the intervention. The intervention must include a minimum three-month follow-up, and the risk reduction must be observed at significant levels.

The Division discovers interventions in two ways: systematically and serendipitously. Their Synthesis Project has assembled a compendium of effective behavioral interventions. They also prioritize requests for applications and make Division-level decisions of some interventions. Behavioral scientists in the group also search the literature to seek new interventions, attend conferences and talk to researchers, hear of interventions via word-of-mouth, maintain contact from health departments and community-based organizations (CBOs), and listen to recommendations from NIH and other researchers.

Dr. Sharpe explained CDC's technology transfer process for HIV and AIDS behavioral interventions. Their Replicating Effective Programs Group (REP) is in the Prevention Research Branch. The Diffusion of Effective Behavioral Interventions Group (DEBI) is an evolving process, but they have a framework for taking interventions from research to practice. The REP process replicates effective programs. They translate interventions into "user-friendly" language, package them (create a manual and training/facilitator curricula, technical assistance guide, brochures, handouts, etc.), and field test the programs and refine materials as needed. The REP Group transfers the programs to the DEBI Group, which plans a national dissemination and marketing strategy for the intervention. They coordinate trainings, provide technical assistance, and help to monitor outcomes.

The DEBI Group begins their marketing efforts by assessing community readiness for the interventions. They fund some organizations, where others receive funding from states and other sources. They serve as liaisons with scientists, coordinate logistics, conduct training sessions for trainers and facilitators, and coordinate technical assistance.

Behavioral interventions contain a number of essentials. Core elements are required components of interventions thought to be linked to the desired behavior change (must be implemented with fidelity). Key characteristics are an intervention's recommended activities and delivery methods (may be adapted for cultural competency). Adaptation is the process of modifying key characteristics of an intervention without competing with or contradicting the core elements. Key characteristics are adapted to fit the risk behaviors and influencing factors of the target population and the unique circumstances of the agency and other stakeholders. Dr. Sharpe listed

several of their interventions for women: SISTA, VOICES, RAPP, SiHLE (in development), WiLLOW (in development), and Street Smart (for youth). All of the behavioral interventions are available on www.effectiveinterventions.org.

Sisters Informing Sisters About Topics on AIDS (SISTA), is one of the most popular interventions. It is intended for African American women aged 18 to 29 and is rooted in the philosophy of gender inequality in this population. This peer-led program consists of five, two-hour sessions that address ethnic and gender pride, HIV and AIDS education, assertiveness skills training, behavioral self-management training, and coping with the stress of being African American in a hostile society. Street Smart is a group-level, multi-session intervention with skill building elements originally designed for homeless and runaway youth; however, groups can be structured only to include young women. Core elements of Street Smart include recognition and control of feelings and emotions through labeling feelings and learning coping strategies, teaching HIV/AIDS risk hierarchy and personal application, use of peer support to identify personal triggers to unsafe behavior, and build skills in problem solving and assertiveness in social situations to reduce HIV/AIDS risk. Dr. Sharpe described the intervention kit that accompanies this intervention. The kit can include tools, marketing materials, video, a GYN model, a scripted training manual, and games and different resources. They have a portfolio of 13 DEBI interventions. The process is complicated, but it does work. Community organizations need a great deal of support and technical assistance to apply these interventions with fidelity. She noted that alcohol and substance abuse prevention is a component of every intervention.

Mary Schauer, MSPH

Ms. Schauer works with the Adolescent Reproductive Health Section of the Applied Sciences Branch in the Division of Reproductive Health at CDC. The Applied Sciences Branch's mission is to promote reproductive health by applying scientific findings to inform public health action. They use an iterative process with partners, and it is based on the premise that if research, policies, and practices are not being used, then they do not make a change in public health. Her Section's vision is to envision a world where all young people have opportunities to develop their full potential and embrace a positive vision of the future. They have a hopeful view for the future of young people, and that future does not include a potential for pregnancy, as pregnancy in young women decreases their future prospects. When young women are pregnant, they tend to be in denial and do not enter prenatal care. Their risky behaviors are likely to continue, and there is a relationship between substance abuse and sexual behavior. Further, teen pregnancy and poverty are linked.

There have been significant declines in teen pregnancy, likely due to a number of reasons and strategies. However, in 2000, 821,000 females under the age of 20 became pregnant, and almost 500,000 of them gave birth. Over 310,000 of those births were to women 15 to 17 years old. Teen pregnancy is still a significant problem. The U.S. has the highest rate of teen pregnancy in the industrialized world because young people are not protecting themselves. Significant racial and economic disparities exist as well.

Research and program evaluation have helped over the last 20 years. Much has been learned about teen pregnancy prevention and risk reduction. Many programs work to reduce sexual risk-taking behaviors; however, much of the research is not used effectively in the field. Only 15%

of school-based substance abuse prevention providers used effective content and delivery methods. Research programs must be used by programs on a large scale in order to have an impact on public health.

Dr. Schauer's division has worked directly in teen pregnancy prevention since 1995, when Congress authorized funds to empower communities to take on the issue of teen pregnancy prevention. Lessons learned from those programs were applied to three-year cooperative agreements based on capacity building at the state level. The purposes of these cooperative agreements were to promote adolescent reproductive health using science-based approaches and increase state and local capacity to select, implement, and evaluate science-based approaches.

A science-based approach includes using social science research and theory to identify risk and protective factors and to design program activities to reflect research findings; using a logic model to link risk and protective factors with effective program strategies and anticipated outcomes (which helps community programs to think strategically); using programs proven to be effective to prevent adolescent sexual risk behaviors, or with the characteristics of those programs; and listening to the evaluation evidence and changing an approach if it is not effective. CDC does not provide a specific list of programs, but gives communities the tools to find those programs and make appropriate selections.

The barriers to using science-based approaches include lack of funding for training and materials, lack of implementation funds, political controversy, lack of motivation, suitability for own community, ease of implementation, and loyalty to current strategies Many partners and states have experienced cuts in funding. It became clear, though, that programs that use a science-based approach can apply for funding because they can demonstrate that their approach is likely to work. Other barriers include political controversy, as it is difficult to discuss pregnancy in schools. They encountered barriers regarding the suitability of programs to communities. The issue of young people and sex is sensitive, and the division has helped communities learn to adapt programs so that they will be appropriate to each community and still be effective. Another barrier relates to implementation, as interventions in teen pregnancy prevention are complex. Finally, they encounter loyalty to current strategies. The evaluation of popular opinion can lead a community to continue a program that might not be effective.

The division funds three national organizations that serve as technical assistance providers. They conduct organizational capacity building and provide easy-to-use resources. They also fund four training centers in nine states. These centers work with local and state organizations to impact programming, policies, and funding. State programs choose a small number of local organizations and help them with technical assistance throughout the entire process. The endeavor is time- and labor-intensive, but effective. At the local level, communities need to be able to work in the political arena and to attract financial support. National organizations are developing trainings and tools and using them with the state organizations and training centers. They are disseminating information about science-based approaches to a broad audience. The state organizations are engaged in these activities as well, working with funders and policymakers so that grant applications require a science-based approach.

Increased capacity to use science-based approaches at the state and local levels should lead to more science-based programs being implemented and more youth participating in those programs. This would then lead to more youth abstaining from sexual activity, delaying their sexual debut, and using contraceptives and disease prevention effectively. The long-term impact will be the reduction of pregnancy, HIV, and STD rates among youth. Their program bridges the research to the practitioners who do not have the tools necessary to apply that research in their communities.

Discussion:

- Dr. Warren was impressed with these research-based approaches. The research base is extremely important, and he wished that the alcohol and substance abuse had as many positive models. Once a model is entrenched in a community, moving it out is very difficult, even if it is ineffective. He asked about the success of getting ineffective programs in teen pregnancy prevention out of communities.

- Dr. Schauer said that her group encourages working with communities where they are. One of their studies lists characteristics of effective prevention programs. If a community's program has not been evaluated, it may still be effective, but that effectiveness has not been measured. In this case, they will help the community assess the characteristics of effective programs and help the communities enhance and expand the effective elements of an intervention. Over time, the program could be moved into science, or the group could be convinced to adopt a different approach. They have also been effective in influencing funders and policymakers. RFAs at the state level do not necessarily require evidence-based approaches. Working with state personnel to ensure that an evidence base is demonstrated has enabled them to provide technical assistance to organizations who are applying for funding. The science-based approach provides a base of capacity and a commitment to science-and research-based work that helps people understand the need to implement with fidelity and to evaluate their programs.

- Mr. Lancaster noted that their tobacco prevention and control efforts are supported by recommendations like those provided through the *Guide to Community Preventive Services.* The science base is also incorporated into their funding documents. Working with communities and programs is part of the relationship-building process that will sustain programs. Many national organizations, including CDC, often drop into a community with tools and interventions, but do not engage in follow-up or mentoring. Further, their work is missing the "how-to" aspects of the work. Rather than referring to "diffusing research to practice," he referred to a "circle of research and practice." Feedback from field is crucial regarding research needs and the realities of communities. Politicians and policymakers want instant gratification, so they have to work hands-on in communities.

- Dr. Sharpe said that their programs take a different approach. They provide training and ongoing technical assistance to their partners. They work hard to build relationships. Communities undergo training in the interventions and are partnered with capacity-building assistance organizations to provide ongoing technical assistance. They consider themselves a science application team that is housed within a program branch. The application team markets the interventions in a user-friendly way, and they have thousands of groups on

waiting lists for their trainings. This program has been in place for three years, and they have trained close to 5,000 people all over the country.

- Dr. Warren asked Dr. Sharpe about her interactions with the NIH Office of AIDS Research and whether their geographical distance was a barrier. Dr. Sharpe replied that she does not find the distance to be a barrier. Her Team Leader and Branch Chief work directly with NIH. They have frequent conference calls with NIH and with researchers all over the country. They make themselves available to researchers who are testing interventions. She reiterated that all of their interventions include alcohol and drug prevention, as this dynamic drives HIV infection, STDs, pregnancy, and a host of issues. Their approach to diffusing these programs has been successful because of its hands-on and accessible nature.

- Dr. Calhoun praised all four programs. Each of the programs relates to women drinking during pregnancy, alcohol abuse, and alcohol dependence. She asked whether they had considered combining, or recommending research to combine the efforts for an over-arching, bundled, leveraged approach to a healthy life. Many communities do not have many resources, and they become frustrated when they want to address many issues. An interactive approach that is pilot-tested, researched, and implemented could help everyone.

- Dr. Coleen Boyle said that part of CDC's reorganization includes a collective approach to these problems. There are limited resources and energy at the local level, and they should be used wisely. She suggested that the Task Force make a recommendation regarding combining strategies when approaching the same population. Ms. Weber added that the preconception care initiative at CDC is another opportunity to examine the bundling of various health messages for women.

- Dr. Calhoun asked whether the preconceptional health movement was global. Dr. Boyle replied that the effort was mostly domestic at this time.

- Ms. Flores briefly described a preconception effort that members of the folic acid and FAS teams were recently involved in. In a public/private partnership, CDC, other federal agencies, and various medical societies have become involved in an electronic record program. CDC and others have developed email-based education programs that are offered through the Interactive Health Record (iHealthRecord) available free of charge online. Patients have the option of signing up for certain education programs and they then receive various messages on the topic. A preconceptional care education program is offered and includes messages on folic acid, alcohol use, smoking, nutrition, etc. It does seem to be a good way to allow groups to pool their limited resources, but she said that there has been some research indicating that messages in the middle of the "bundle" are often forgotten. Every group will want their message to be last, because that message will be the most likely to be retained by an audience. More research is still needed in bundling preconceptional care messages.

- Mr. Lancaster said that co-morbidity is another issue to consider. Tobacco use is frequently associated with mental health and alcohol. There is a high tobacco use rate in populations

with mental health and substance abuse problems. The collaboration and integration of programs at all levels can use those linkage points.

- Dr. Calhoun noted that the number one risk for all of these issues is alcohol. She hoped that their researchers could work with other researchers. In the real world, patients present with more than one condition, so their work should adapt to the real world.

- Dr. Schauer commented that feedback from the field indicates that their marketing is changing the way that their organizations are doing business. The state organizations are ensuring that all of their work, not just their work in teen pregnancy prevention, is strategic, evidence-based, and in line with their goals and objectives. She believes that the approach can be used across the field, encouraging strategic and critical thinking, planning, and believing in the value of evaluation. They do not have a great deal of funding, but they are seeing interesting and unanticipated changes.

Public Comment/Adjourn
There were no public comments. Dr. Wright praised the group for their work. The group was adjourned until 8:30 a.m.

Friday, February 17, 2006
Call to Order
Dr. Jean Wright called the meeting to order at 8:35 a.m. She welcomed the group and opened the day's session by recognizing the Task Force members who would be rotating off in May 2006. She thanked Dr. Kristen Barry, Dr. Deborah Cohen, Dr. Mark Mengel, and Dr. Raquelle Myers for their work in shaping the Task Force. Dr. Cordero informed the group that names of possible members were suggested to the Secretary for consideration. Two nominations for each open spot are put forward to the Secretary. The Office of the Secretary has the option to select one of those persons or to choose someone else, which they often do. He hoped that they would have names of new members before the next meeting.

Prevention Working Group Progress to Date
Lisa A. Miller, M.D., Co-Chair
Dr. Miller updated the group on the progress of the Prevention Working Group. The group has had several discussions and drafted a report outline. The ambitious outline "covers the waterfront," including background, prevention, and general principles used in evaluating strategies. The group hoped to cover the breadth of strategies, from population-based to individual-level. This outline will help identify areas where additional research is needed as well as recommendations for what works, what can be implemented now, and what can be translated into communities.

The outline is vague, but addresses some of the points raised by Dr. Olsen's presentation the previous day, Dr. Miller said. It includes screening, brief intervention, and treatment. After creating the outline, the group realized that they needed more help to flesh it out. They recommended hiring a consultant to gather information and evidence. CDC staff considered several options. It was proposed that CDC's Community Guide team would focus on the population-based prevention strategies since that is what they do. There have been some reviews

of behavioral interventions, the most recent one done by the U.S. Preventive Services Task Force (USPSTF). This could be revisited and further tailored to focus on childbearing age women.

Staff from NCBDDD talked with Dr. Peter Briss from the CDC Community Guide team about the possibility of his team's involvement in these efforts. Staff then had a conference call meeting with the Prevention Working Group co-chairs, Drs. Miller and Caetano, who suggested that CDC move forward with these discussions with the Community Guide team. The co-chairs suggested that the Working Group's original report outline should be considered in planning these activities. An email was sent out to the Prevention Working Group members on progress to date and feedback on upcoming plans was solicited. Dr. Miller also commented that more is known about the individual, behavior-based strategies for FASD prevention than about the population-based strategies. This is an issue that we will need to address as these plans progress.

Discussion:

- Dr. Sokol commented that the USPSTF report did include a review of screening and brief intervention for women in the reproductive age range. He felt that their work was relevant to FAS populations. It might need to be updated, but its focus is appropriate, especially given Project Choices.

- Ms. Weber noted that the review did not target the appropriate age range and that it addressed all adults, including pregnant women. Dr. Sokol agreed that pregnant women were a small piece of the review, but the basic report addressed reproductive age. He had participated in the review process for ACOG. He added that the findings indicated strong evidence that formal screening and brief intervention are effective methods in reproductive-age women. Based on this work, the College concluded that the rates of success merit doing formal screening and brief intervention.

- Dr. Cordero commented that the report is good and that it includes their target group. One of their challenges will be to integrate individual interventions. The USPSTF directs its focus on clinical efforts; that is, provider-to-patient interventions. Dr. Cordero believes that we need to connect this work to population-based, community activities and determine how those two strategies can work together to have an impact on alcohol use in pregnancy. They also need to maintain an infrastructure for evaluation.

Community Guide Example in Progress:
Enhanced Enforcement of Laws Prohibiting Sale of Alcohol to Minors
Randy Elder, PhD

Ms. Weber introduced Dr. Randy Elder. In his six years at CDC, he has focused on evaluating the effectiveness of intervention programs, particularly of community-based interventions to prevent alcohol-impaired driving for the *Community Guide*. Dr. Elder used the topic of prohibiting the sale of alcohol to minors with the enhanced enforcement of laws to provide an example of how the *Community Guide* conducts a systematic review and to illustrate important considerations when using an evidence-based approach to evaluate effective interventions. These considerations could apply to FAS; however, as FAS is rare and difficult to measure, it may be challenging. Using FAS as an outcome for evaluating the effectiveness of population-

based interventions would be difficult. He recommended that they consider reasonable proxy variables for FAS.

Dr. Elder acknowledged the Community Guide coordination team, which includes a mix of representatives from stakeholder agencies, academia, and the public health sector. Before getting into the details, terms and definitions were discussed. Minimum Legal Drinking Age (MLDA) laws specify an age below which the purchase or public consumption of alcoholic beverages is illegal. In all 50 states, the MLDA is 21 years of age. The term "on-premise establishments" refers to bars, restaurants, and other places where alcohol is consumed on-site. "Off-premise establishments" are places such as liquor, grocery, or convenience stores where alcohol is purchased but not consumed.

In all *Community Guide* reviews, the first and one of the most difficult, steps is to specify clearly the definition of a given intervention. The definition must be clear so that every study or intervention can be classified. There should be reasonable inter-rater reliability. For this topic, the definition of the intervention is, "enforcement activities that involve compliance checks in which minors or youthful-looking adults ("decoys") attempt to purchase alcohol from on-premise or off-premise retail establishments." These efforts are implemented or coordinated with either local law enforcement or the local liquor licensing board. The effort must involve legal or administrative sanction consistent with local statute for establishments found to be noncompliant.

Despite having a clear definition of the intervention of interest, there is still variability. Areas in which the implementation of the intervention varied were: intensity and duration of the enforcement, either in the number of compliance checks executed or the frequency with which they were visited; and the media approaches to, and publicity around, these efforts. Mass media (including radio, television, local press) can either be paid or earned. Small media can include letters sent to local establishments informing them about the enforcement campaign. The context of the interventions also varied. Efforts are often part of a broader, community-based effort targeting underage or excessive drinking, which may include community coalitions, training in responsible beverage service, or changes in alcohol-related policy.

After agreeing on a definition of the intervention, the next step is to create a formal analytic framework. This framework is similar to a logic model. It specifies a causal pathway that is expected to lead from the intervention to the outcomes of interest. Enhanced enforcement of laws prohibiting provision of alcohol to minors moves through a number of different pathways. The most direct pathway is through the actual and perceived threat of detection and punishment at the retailer level for selling alcohol to minors. This will reduce retailers' willingness to provide the alcohol to minors and, in turn, reduce minors' access to alcohol through that channel. Retailers are not the only access channel for minors, however. If access is decreased through these providers, then minors may find another source for the alcohol which might attenuate the effects of the changes in retailer behavior. Another pathway is the impact on social norms. When there are clear indications that society considers underage drinking to be important, then the notion can be reinforced and have a reinforcing impact on other nodes in the model. He pointed out that the *Community Guide* includes outcomes that are clearly health outcomes, and the Task Force bases its recommendations on outcomes that have clear public health

significance. This review was primarily concerned with outcome measures that addressed consumption of, and access to, alcohol by minors. The consumption outcomes focused on the frequency and quantity of alcohol consumed. Self-reported measures of behavior were accepted as reasonable measures of those outcomes. Regarding access, they measured the proportion of buy attempts by decoys that were completed.

The Task Force focuses on recommending interventions that indicate a strong association between the intervention and real changes in public health. The review, then, focused on the link between access and alcohol consumption and whether it is justified as a recommendation. Behavioral and economic theory contends that decreasing ease of access to alcohol increases resources required to obtain it, thus decreasing demand. However, changes in ease of access may have highly variable effect on demand, depending on situation-specific factors, such as function of alternative routes of access, and perceived or real negative consequences of gaining access.

In terms of direct evidence of effect on consumption, three studies in the review had data on consumption and all show a decrease, which tended to be proportional to the decrease in availability through retailers, supporting the idea that access is an intermediate variable that has an impact on consumption. It is important to note that the effects in these studies tend to be smaller on consumption than on retailer behavior. Further, two of the three studies that examine consumption are "multi-component." That is, other related activities were also taking place in the community, making it difficult to determine whether changes in retailer behavior is the primary cause of reduced alcohol consumption versus through other pathways.

Enhanced enforcement is a natural compliment to the MLDA laws and relies on similar causal pathways as the MLDA law itself. MLDA laws demonstrate effectiveness at decreasing alcohol-impaired driving and alcohol consumption. It is important to note; however, that the incremental effect of enhancing enforcement may be small, compared to MLDA. MLDA may have a stronger effect on minors via social norms. They are also broader because they target not only retailers, but also social providers and the minors themselves.

The *Community Guide* review process includes reviewing the quality of the studies. The team rates the suitability and strength of the study design as well as how well the studies were executed. These factors reflect a level of confidence in whether a study's effect estimates reflect true effects of the intervention. The summary effect measures examined in this example were changes in consumption and frequency of sale. Relative risk calculations for comparisons with or without concurrent controls were performed for these measures. After the team reviewed study quality, 8 studies met their criteria. Study characteristics included the following: designs – 2 time-series with control groups, 3 time-series without control groups, and 3 before/after studies with control groups; follow-up periods – 2 months to 2.5 years; and threats to validity – variability in age, sex of decoys, contamination of control groups, and incomplete delivery of intervention. Most of the studies in this topic had concurrent comparison groups. Time series studies and before/after studies with comparison communities were included. Follow-up periods ranged from two months to 2.5 years, with a median period of two years. This literature base includes some common threats to validity, including the nature of the decoys, such as sex and age. Most of the studies controlled for this confounding source. Contamination of control

groups is another important issue. Especially in the multi-component studies, attempts to encourage enhanced enforcement did not actually occur in some communities that remained in the experimental group, thus biasing the results toward finding no effect. A compliment to enhanced enforcement is training retailers in responsible beverage service provision. Further, community mobilization efforts often accompany policy changes.

All of the studies demonstrated an effect in the number of retailers that sold alcohol to decoys. The effects tended to be strong, with a median effect of a 42% decrease in the proportion of buy attempts that resulted in an alcohol purchase. Only three studies evaluated alcohol consumption, but the results track with the magnitude of the effect on retailer behavior. There were similar results for binge drinking, which is expected, as most underage drinking is binge drinking.

The team assessed the sustainability of the effect of each study. There should be a sustained decrease in the provision of alcohol to minors. There is a slight increase in effectiveness over time. There is no evidence of a decrement in effectiveness over time. Some individual studies that involve multiple follow-up periods make stronger statements regarding the sustainability of effects. All of the studies took data points while the intervention was still in place. The team also examined the decay of effectiveness in interventions that were either one-time-only or were limited in scope. These studies tended to show a rapid rate of decay in off-premise establishments. Results for on-premise establishments were similar, although there was some evidence of residual long-term effect.

The *Community Guide* reviews also consider other benefits and harms. In this example, there are concerns that reducing access to alcohol will lead to the use of other substances. Other substance use may increase if reduced availability of alcohol leads to substitution. However, it may also decrease if substance consumption is secondary to drinking episodes or to drinking-centered lifestyles. There are no data to address these points but it is important to recognize them.

Although the review included relatively few studies, there was reasonable geographic diversity among them; including both small towns and urban settings, all geographic regions in the U.S., and Sweden. Both on- and off-premise establishments were studied. Other points of variance across studies included involvement of local groups, combination with other interventions, and variance in intensity of intervention. It is reasonable to assume that this intervention is likely to be generalizable throughout the United States.

The Team also recognizes barriers to implementation of enforcement efforts. Lack of community support, as well as lack of support from law enforcement and regulatory agencies would be problematic. Another barrier could be opposition from retailers.

In conclusion, enhanced enforcement of laws prohibiting sale of alcohol to minors substantially increases the likelihood of retailer compliance with existing MLDA laws, but minors may seek alcohol from alternative sources, reducing the ultimate impact on consumption. Also, few of the studies evaluated alcohol consumption. It is difficult to make a Task Force recommendation based on consumption alone.

Community Guide staff provided their Task Force with two alternative recommendations.

1) The Task Force recommends enhanced enforcement of laws prohibiting sale of alcohol to minors, on the basis of sufficient evidence of effectiveness in limiting underage alcohol purchases. Further research will be required to assess the degree to which these changes in retailer behavior affect underage drinking.
2) The Task Force found insufficient evidence to determine whether enhanced enforcement of laws prohibiting sale of alcohol to minors is effective in reducing underage alcohol consumption. Although good evidence indicates that such interventions reduce the sale of alcohol to minors, an insufficient number of studies assessed the consequent effects on alcohol consumption.

The Task Force felt that a strong enough case can be made that the effects in retailer behavior had important public health implications, so they have recommended the implementation of enhanced enforcement, selecting recommendation 1.

Discussion:

- Dr. Sokol observed that medical meta-analysis considers the costs per case detected. He wondered about calculating costs in this instance. These assessments might help to make alternative decisions. Dr. Cordero said that most of the *Community Guide's* work includes an assessment of costs. The policy decision to adopt an intervention might not follow the costs directly. He offered an example from immunization, in which it was discovered that the less expensive option was less effective, so the *Guide* recommended the more cost-effective option, which had more impact. This issue will be important in our work.

- Dr. Elder said that an economic team does separate reviews on costs and cost effectiveness in conjunction with his work. Typically, where we have found the data, almost all population-based interventions are extremely cost-effective and sometimes even cost-saving. Overall in the studies they have done, the interventions tend to meet high standards of cost-effectiveness.

- Dr. Sokol noted that labeling of alcoholic beverages was not cost effective and had no effect. It had societal as well as monetary costs.

- Dr. Hacker pointed out that there is no evidence that school-based education is effective over time. These complicated problems need comprehensive and multi-faceted solutions. He hoped that they would not exclude opportunities for interventions, but to ensure that there are a broad range of interventions that may have a possibility to have an effect.

- Dr. Sokol felt comfortable with a *Community Guide* review for FAS; looking at cost. Knowing what does not work is very important and can increase overall effectiveness.

- Dr. Caetano noted that there are changes in cost as interventions are implemented. A more intensive effort is initially required in a new community. When the effort is successful in changing the perception of the community and social norms, then effects can be sustained because the community in general has changed.

- Dr. Warren said that the effort to label alcoholic beverages was a Congressional action that met no industry resistance and did not have a high cost. It was done rapidly and had a number of deficiencies. Further, MLDAs are targeted to outcomes related to fatal traffic accidents, so they must be considered in that context. They have been effective in that area.

- Dr. Sokol pointed out that labeling cigarettes has not been proven to be effective either. He believed that time was wasted on these efforts that could have been spent on effective strategies, thereby having a negative impact on the field.

Evidence-Based Reviews of Interventions to Prevent Fetal Alcohol Spectrum Disorders
Peter A. Briss, MD, PhD

Dr. Briss noted that moving from science to practice is a complicated venture. An important question to consider is, "What are we trying to move the needle on?" The *Community Guide's* work will not answer difficult questions, but can provide information that can help to answer quality questions. He offered perspective regarding what evidence-based practice can, and cannot, yield. Information gaps make investing in prevention difficult. Reliable, valid effectiveness data can be hard to find and is often not user-ready. Ten years ago, he thought that the common problem would be "not enough information." As it turns out, the most common problem is sorting through enormous amounts of conflicting information of variable quality. For these reasons, an evidence-based approach is desirable. It is necessary to find a reliable way to find and distill the best available (or most feasible) evidence to support decision-making.

The first question to ask is what counts as evidence-based. There are a range of options including results from multiple good studies, a single, well-conducted study, expert opinion process, an appealing anecdote, etc. One needs to recognize why it is important to be evidence-based as well and what it will bring to the table. It will increase reliability – move beyond experience and anecdote; it can help streamline and synthesize enormous amounts of data and help explain variable results; and it could assist in reducing biases and making certain assumptions clear.

Evidence-based resources should provide information on the following: a description of how the current work differs from what was available previously; an understandable process for describing who participated and how; and a systematic process for identifying, evaluating, and summarizing scientific evidence about the outcomes of interventions or policies, and translating the evidence into practice recommendations.

Dr. Briss suggested that the Task Force consider syntheses of multiple good studies or single well-conducted studies or program evaluations (e.g., programs that work). There are a number of challenges in producing, interpreting, and using evidence-based information. Everyone does not agree that scientific information is needed to support decision-making. However, public health has a long tradition of harnessing science to improve the health of the public. Everyone also does not agree that accountability for outcomes is desirable. It is important to maintain perspective. As McGinnis and Foege stated: "Even if it is evidence-based, it is not certainty." There is no cookbook or a one-size-fits-all solution. Users must consider scientific information together with other factors that matter to them locally. For many issues, there may be no one "best" solution.

Advice on what to do in terms of gathering an evidence base needs to be considered in context. It is important to recognize that prevention planning is a complex process. It involves assessment, priority setting, objective setting, intervention selection, implementation, and evaluation. This cycle is repeated as adjustments are made.

One question people ask is what to do with evidence gaps? Lack of evidence means that we cannot assess whether interventions do or do not work. A conceptually important intervention may not have a convincing science base to answer questions. These gaps mean that it is not possible to assess whether an intervention works. When there is insufficient evidence for a given intervention, consider whether better-documented alternatives reach the same goals. Interventions for which evidence is insufficient should be more thoroughly researched. It is important to realize that lack of evidence is different from evidence that interventions produce no effect or produce harm(s). These kinds of interventions should not be used and more effective choices should be substituted.

Producing evidence-based recommendations takes time, patience, and practice. If this Task Force opts to undergo this review, then they must determine whether they desire an evidence-based process versus an expert opinion process. Initial decisions to be made include the following: does the group want to adopt an evidence-based process? The evidence-based process yields more transparency in reporting and consistent evidence standards. What interventions or policies should be considered? What outcomes should represent measures of success? Which available resources can be used or adapted to avoid reinventing the wheel? And what are the highest priority areas for new work?

In looking at the interventions/policies that could be included in an FASD prevention review, programs could include universal programs, programs limited to women of childbearing age, selective programs based on group characteristics, or indicated programs based on individual characteristics. Regarding outcomes, it is not likely that reductions in FASD will be feasible as an outcome measure. They might consider alcohol-exposed pregnancies, alcohol use, or other measures. Clinical literature may warn against proxy measures, but these proxies might be necessary.

Dr. Briss recommended that they not duplicate existing resources. For example, the USPSTF guidelines could be adapted. Other reviews and reports have also been done including the work done by Dr. Babor, et al, the IOM report, and the 2000 Report to Congress on Alcohol and Health. In addition to assessing what is already out there in terms of resources, the group needs to think about the potential universe of relevant programs and policies that involve FASD prevention. Clinical programs/policies could include clinical practice guidelines for screening, counseling, and treatment; referral for women of childbearing age; screening; brief interventions; referral to treatment, biomarkers; contraception programs. They could also consider programs for women who abuse alcohol, DWI interventions, and others. Community related programs/policies could include universal approaches (e.g., server interventions, mass media, alcohol advertising controls, alcohol labels) or other approaches directed at the target populations (e.g., public awareness/education, provider education, aftercare/case management). The Task Force will have to set priorities and possibly restrict their focus. The group could potentially

exclude topics or interventions already addressed elsewhere or those not under the control of the intended audience. For instance, when considering the reduction of alcohol-related motor vehicle injuries, motor vehicle design could be considered; however, opportunities to influence this factor are limited, so although it is conceptually important, it was not included. The Task Force could also exclude topics or interventions for which the preventable burden of disease is low or those where the scientific literature is perceived to be sparse. Electing to exclude those studies decreases the likelihood of erroneous conclusions, but it also does little to drive a research agenda and improve the science base over time. Some topics that are conceptually important but understudied should be noted. The Task Force could focus on elements that have a high preventable burden, or specific intervention types such as universal programs or indicated programs.

Most groups have criteria for prioritizing interventions. Typical criteria might include the potential reduction of population-atttributable risk; the potential to increase the implementation of interventions presumed to be effective, but not widely used; the potential to discouraging the implementation of popular programs that are relatively ineffective; and the current level of interest among providers and decisionmakers. Other priority-setting criteria may be added as relevant and appropriate. For example, some teams require that at least one intervention be reviewed for each of the set of predefined categories.

The Task Force's likely first step is to consider whether they want to adopt an evidence-based process, what interventions or policies to consider, what outcomes should represent measures of success, what available programs and policies can be used or adapted, and highest priority areas for new work.

Discussion:

- Dr. Miller said that their first attempt at this task was to take on all interventions, which seems to be too comprehensive. She asked how the *Guide* defines community interventions. For instance, would a brief intervention in different types of community settings qualify as a community intervention or an individual intervention? Dr. Briss replied that his group is the "population-based companion piece" to the U.S. Preventive Services Task Force. The two together cover the spectrum of prevention approaches. They have guidance regarding how to delineate interventions, but the line is not always clear. The two groups work together to ensure that someone does the work and that they do not duplicate efforts.

- Dr. Bertrand noted that the FASD group is not restricted to what the Community Guide team has done before. They can include the interventions that they feel are important.

- Dr. Briss's group narrows their work by creating a report that lists the considerations that influenced their choices. They may list why the topic is important, what is conceptually possible in a variety of settings, and other examples. They select a set of high-priority interventions based on these considerations while acknowledging that the entire scope of the field is important to grow over time.

- Dr. Caetano hoped that the report would be as comprehensive as possible. These reports have more than one function. To the Task Force, the report acts as a review and an

opportunity to update the literature. The report also has an important political value, as it attracts attention to the field from legislators and community activists. The report should have a strong public health measure to alert communities that the alcohol industry markets to underage populations, which is part of the population that can bear children.

- Dr. Sokol noted that members of the Task Force do not do the work, but provide direction and recommendations. He wondered whether there was a way to look at the process serially. The Guide group could make recommendations to the Task Force regarding how much can be done, and in how much time. Next, the team could do the work. The key questions presented by Dr. Briss are important, but individual members of the Task Force cannot make those decisions. They would do better to have a set of recommendations to respond to. Dr. Caetano added that they do not need to "reinvent the wheel." If the literature covers an intervention well, then the report can be less detailed regarding that intervention. He left that question to the judgment to group doing the reviewing.

- Dr. Cordero asked Dr. Briss whether his group had evaluated "bundles" of interventions to the same population, such as folic acid and FASD to women of reproductive age. In addition, he asked about developing recommendations for the research agenda in the area of multiple interventions to a single target group. Dr. Briss noted that the Community Task Force has been in business for ten years. Initially, many public health recommendations were "siloed." In the real world, issues such as alcohol, HIV, and smoking do not exist one at a time. His group can examine reviews of "bundled" interventions with a number of outcomes. He added that single-topic interventions are often effective as well. The portfolio will likely include some of both types of interventions. Regarding the research agenda, they are regimented about answering a set of questions. When they can answer a question clearly, they make a recommendation. When they cannot, they make research recommendations.

- Dr. Elder pointed out that issues related to generalizability and specific subpopulations or contexts rarely have clear answers. Similarly, questions of optimal delivery of an intervention nearly always need more information and research, but they are difficult to study.

- Dr. Warren said that it is possible to get good consumption measures in alcohol, although it is expensive to do so. There are informative proxy measures, however, including hours of service in bars and single-vehicle motor vehicle accidents. Such measures can indicate whether an overall effect is occurring. They are trying to measure FASD, but it is easier to measure in communities that have a high prevalence of FAS. It would be difficult to measure in a community in which there was no baseline.

- Dr. Olsen emphasized that because FASD is a trans-generational problem, interventions have a prevention function. This point is important to include in consideration of what is reviewed. The review will also have a broader scope because of the preventable nature of the defect. Different proxy measures can lead the work in different directions. Measures that consider underage drinking are not the most important direction, as older women more frequently produce children who have more clear effects. While underage drinking is important, any proxy measure will lead them away from other interventions and preventative

efforts that are important in the wide-ranging field. She felt that it is possible to measure the full syndrome in some communities. Drinking by high-risk populations of women is also an important measure.

- Dr. Elder said that they do not seek a "one size fits all" solution. Different sets of measures may be appropriate for selected interventions versus community interventions, for instance. Power is also crucial to consider. If it is reasonable to expect that an intervention will move high-risk consumption down by 10%, then they must consider a measure that will have the power to detect this decrease. Further, they will consider the measures that are reported in the literature. They could lose data if they focus on outcomes that are too specific. They can always cast a wide net and collect measures that are most relevant within a set of potentially-relevant measures.

- Dr. Caetano agreed that there should be a variety of measures and did not intend to de-emphasize the importance of other measures that would indicate effectiveness in other areas. The measures that they could use to measure universal effectiveness could be influenced by a number of other factors. Alcohol consumption in the U.S. has been declining since the 1980s, probably due to the interaction of a host of factors.

- Dr. Wright wondered whether the increase of coffee shops might have eliminated the need to go to a bar to "hang out." The group agreed that such a study would be very interesting. She further noted that the concept of "bundling" is in vogue. It might be worthwhile to use a current "buzz phrase." Dr. Briss added that people use different words for this concept, but the issue of bundling is attractive to many people. He cautioned them to design their bundles carefully.

- Dr. Caetano said that they face that problem routinely. They wondered how to make a list of items from the most effective, to the least effective, to assist groups who cannot afford to implement all activities. Many public health interventions to decrease alcohol consumption focus on high school education alone, which is insufficient.

- Dr. Cordero stressed that the intervention package must be designed comprehensively. They are considering "bundling" as a means for targeting different interventions. There are efforts to bundle multiple interventions to improve the health of individuals. He hoped that the research agenda would note the need to assess whether bundling several interventions together increases or decreases each intervention's impact.

- Ms. Weber asked the group to make recommendations regarding moving this effort forward.

- Dr. Caetano noted that they can begin with the outline. He asked about an interactive process of consultation to move forward. Ms. Weber indicated that the Task Force will be involved throughout the process.

- Dr. Briss said that the Community Guide's approach depends on what the Task Force wants. It also depends on what the team is able to accomplish in the available time and budget. He noted that these reviews might not necessarily be *Community Guide* reviews. They have

expertise in evidence-based processes. Realistically, they would not be able to provide a set of reviews that address all possible interventions. They could, however, provide a reasonably comprehensive list of possible interventions. If the Task Force wants a narrative review of each intervention, then the Community Guide Team would not be appropriate to provide that review. The Guide team can identify good, existing evidence-based resources. They can help create a list of new work that will address key priorities that come from gaps in the existing literature. The Task Force could supplement that effort with additional reviews to make the results broader.

- Dr. Brown indicated that they have some evidence, and the framework that they introduced is a good one. Large groups should be handled differently from individuals and based on the gaps in knowledge.

- Dr. Sokol said that they need a list of available interventions which might be helpful. From that list, they need to determine which could be recommended for implementation now. Further, they can determine which interventions are not appropriate or useful and areas in which more work is needed. They must also include promising areas for research.

- Dr. Ohlemiller recalled that the Center for Excellence has identified 315 "promising practices." That list could be a reliable resource, depending on its criteria.

- Ms. Bonsu said that the Center has offered to support developing the *Guide*.

- Dr. Cordero directed the discussion to the question of the Task Force's role in the development of a *Community Guide*-like document. He asked the Task Force for a recommendation regarding whether CDC should engage in the *Community Guide* process for prevention of FAS and FASD and alcohol use in pregnancy that would focus on available and effective community interventions. That report could be translated by the Task Force into specific recommendations and research gaps to address. In the next five years, budgets for projects in public health programs and systems will likely not increase, and may decrease. Providing a clear and concise description of effective work will be a powerful tool for states and local agencies.

- Dr. Calhoun agreed that this effort will be helpful to the entire field. They need specificity regarding the appropriateness of each intervention to a community, since not all interventions work in all communities. They should also consider how interventions can be bundled, especially considering how overloaded communities are. These bundles are also community-specific.

- Dr. Elder said that his group is working on evaluating community interventions to prevent excessive alcohol consumption. There is a great deal of overlap between those reviews and FAS reviews. They might think about FAS reviews that do not involve excessive alcohol consumption versus the different approaches that might be tacked onto existing alcohol reviews, allowing for synergy.

- Dr. Davis supported the development of a *Community Guide* approach, since chapters of the Arc are conducting prevention activities without necessarily knowing everything about what will work.

- Dr. Wright asked whether CDC would like the Task Force to make a formal recommendation on this issue. Dr. Cordero replied that they would like to have this recommendation on record.

MOTION

Dr. Caetano moved that the Task Force recommend that CDC develop a "*Community Guide*" approach for prevention interventions for FASD. Dr. Sokol seconded the motion.

Dr. Olsen proposed a friendly amendment: Task Force members should have the ability, in a specified process, to offer input into this process.

Dr. Cordero offered the point of information that Task Force members, both as a group and as individuals, would assuredly have input into the process. There would also be opportunities for progress reports and presentations as the *Guide* process moves forward. Dr. Caetano accepted the amendment.

Dr. Wright called for a vote. All Task Force members were in favor of the motion.

Dr. Brenneman could not vote, as he is a liaison member of the Task Force, but he expressed his support of the effort. He is working in a small Indian community in South Dakota with a great deal of prenatal alcohol exposure. An evidence-based report on prevention will be useful. It will also be useful to learn how to measure success in that setting.

Topics for Next Meeting/Next Meeting Dates

Ms. Weber said that the Task Force's next meeting would probably involve bringing speakers in to further inform their approach to the *Guide* process. She asked the group to contribute additional ideas for speakers or points of discussion to include on the agenda.

Discussion:

- Dr. Morris asked Dr. Warren about the Consortium's work with new technology for the diagnosis of FAS and partial FAS. She wondered about the Task Force's role in developing guidelines for the diagnosis of partial FAS and of neurodevelopmental disorders. Dr. Warren replied that CIFASD is an ongoing research program. It is making progress, but it will be some time before they are ready to report. However, the project's intent is to provide information that will inform guidelines regarding the diagnosis of FAS, partial FAS, and ARND. When the data is reported at national meetings, CIFASD should be invited to the Task Force.

- Dr. Cohen asked about how this work is related to the Congressional mandate that CDC define FAS and FAE. She wondered whether the Task Force should be involved in defining other conditions in the spectrum. Dr. Warren said that the Task Force should be involved.

NIAAA and CDC continue to support research so that they can continue to refine the state of knowledge. Dr. Cordero agreed.

- Dr. Calhoun noted that this meeting had not included presentations regarding specific community prevention or intervention efforts. She wondered whether a "success story" that includes bundling, whether at the state or community level, could be presented to help them understand how a public health organization faces these challenges. They could learn from other areas and perhaps bundle with them as well.

- Dr. Cordero said that the preconceptional care process has identified some success stories in certain areas. He agreed that sharing these stories could be beneficial.

- Dr. Miller added that Colorado is being funded to implement the Project Choices model, which is an example of taking research to public health and to communities. She offered to discuss these efforts and expected that she could report results.

- Dr. Calhoun would be interested in other efforts that could be included with Project Choices, such as HIV prevention.

- Dr. Miller noted that it would be helpful to hear from the people who are implementing these bundled projects. Dr. Bertrand said that Project Choices is already bundled with contraception. Dr. Calhoun concurred and suggested that HIV might be a natural addition to the bundle.

- Dr. Cordero said that they are having internal discussions among the Center Directors. He noted that the SISTA project, mentioned by Dr. Sharpe, is an example of successful bundling.

- Ms. Bonsu mentioned that the Center for Excellence has 35 subcontracts. Some of them may have bundling activities, and she hoped that some of them could present at the next meeting.

- Ms. Weber informed the group that CDC is holding its National Health Promotion Conference on September 12 – 14, 2006, in Atlanta. This time coincides with the next Task Force meeting, so she suggested scheduling their meeting at that time so that Task Force members could attend both. Dr. Cordero added that the Task Force meeting would be the day before or the day after the Conference.

- Dr. Olsen asked that they move away from the December and June schedule, as it conflicts with RSA. She hoped that the next meeting would include ample time to provide input into the *Community Guide* effort.

- Dr. Cordero said that the working groups should have a series of discussions with *Community Guide* staff. When they created the *Immunization Guide*, a team spoke with the Guide staff every week and workgroup members spoke with them every month.

- Dr. Olsen said that the Post-Exposure Workgroup desires to contribute to the *Guide*. She wondered whether the group should reformulate itself to be the "Trans-Generational Workgroup" to ensure that they would provide that input.

Other Announcements

Dr. Wright thanked their "graduating" committee members for their selfless work on behalf of the next child who will be born free from the effects of exposure to alcohol. She reflected that the opportunity that they have in the U.S. to share their dialogues is overwhelming. The voice of one person can make a large difference.

Dr. Cohen reminded the group that not only is she a Task Force member, she is also the aunt and former guardian of a young man who was prenatally exposed to alcohol. She informed the group of the young man's progress and successes. When she asked him if she could share his story with the group, he agreed and asked them to remember a few things. While they spend most of their time examining those who are in greatest need, there are many more people who are affected, but who do not have the greatest needs. They do, however, have organic brain damage. Do not forget college students who binge drink. He also asked the group to remember that their expectations, as professionals, are too low. If it is assumed that a person with a cognitive disability cannot do something, then that person invariably shows that he can. Finally, he hoped that the Task Force would remember affected adults. He is 26 years old now. After a difficult adolescence, he has grown up and not only holds down a job with the Educational Testing Service, but has been promoted. The amount of money and time that was invested in him as a youngster is paid back tenfold in that he is a productive person. Dr. Cohen thanked the Task Force on his behalf.

Public Comment/Adjourn

As there were no public comments, Ms. Weber thanked Jackie Vowell, Jacqui Bertrand, Coleen Boyle, and the rest of the CDC FAS Team for their hard work in putting together this meeting.

The group adjourned at 11:00am.

Minutes approved on 05/22/2006
by Jean A. Wright, MD, MPH
Chair, National Task for on FAS/FAE