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U.S. Public Health Service
Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities

Records of the Meeting of the

National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect
Doubletree Hotel Buckhead Atlanta, Georgia December 14-15, 2000

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Summary of First National FAS/FAE Task Force Meeting

The first meeting of the National Task Force on Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) was held on December 14-15, 2000. In addition to the Task Force members and CDC staff, the meeting was attended by representatives of Federal agencies, partner organizations and interested members of the public.

Opening comments reviewed the committee's mandate to advise and provide information and recommendations on FAS and FAE, to educate professional and paraprofessionals, the lay public, and individuals at potential risk, and to prevent FAS and FAE. CDC support was pledged. It was announced that the Division of Birth Defects and Developmental Disabilities, now siting the FAS/FAE activity, will soon become a separate CDC Center for Birth Defects and Developmental Disabilities.

A brief overview of CDC work to date on birth defects and developmental disabilities was provided, on its research priorities, and on current data on FAS/FAE rates. The latter are significantly higher among Native American and Alaskan populations, and among acculturated immigrants to the U.S. CDC activities in monitoring (FASSNet), epidemiologic studies also were outlined.

Video and in-person presentations on this committee's organizational structure and membership requirements under the Federal Advisory Committee Act (FACA) were provided. Specific advice on relating committee discussions was given, as was counsel

that while e-mail as a public record is a gray area under FACA, business conducted by its workgroups is not. Unlike subcommittees, workgroups meetings are not open; the requisite public disclosure occurs when they report to the parent committee. Subcommittees and workgroups were defined. Task Force recommendations will be published in the meeting minutes (and also can be in CDC's MMWR) and constitute a CDC recommendation. The minutes will regularly be sent to organizations, state health departments, etc., dealing with FAS/FAE. Every recommendation made by the committee will be addressed and responded to. Direct communication to the DHHS Secretary, through the DFO and CDC, can be done by committee letter (or perhaps a meeting) if the committee determines that something requires address at that policy level.

The Task Force reviewed the priorities identified at the 1999 preplanning meeting. Among the many topics raised for potential Task Force address were: crafting recommendations to advance agency efficiency; definition of needed FAS/FAE research; education of the public and health care professionals; identification of a national spokesperson; helping to coordinate the research and service provision areas; family groups' participation in planning research; supporting research on promising interventions; pursuing alcohol industry funding of FAS/FAE work; pursuing a multi-level approach; and the inclusion of FAS in medical schools' curricula.

Advice was provided on the latter to not address curricula, but that CDC/NIAAA develop curricula for medical records and provide specialty-specific curricula to the relevant societies for promotion to their specialties. FAS/FAE materials may be implementable in graduate specialty-training curriculum.

There was general agreement to recommend the inclusion of FAS in any curriculum that deals with education, developmental psychology, midwifery, or anything involving Ob/Gyn, but no formal motion was proposed and passed. Considerable discussion also occurred about exploring models and guidelines for FAS/FAE. This included targeting audiences for FAS/FAE education, developing a standard presentation on FAS/FAE (and involving parents in doing so); and supporting research and a national meeting on FAS.

Workgroups were proposed to address these many issues, and several were formed: 1. National Visibility/Public Awareness Workgroup will develop FAS/FAE presentation modules adaptable to various audiences. Its discussions will include a national spokesperson. Work will begin with a Conferences and Presentations Sub-Workgroup to develop FAS/FAE presentation modules. The draft plan will be presented in April. Initial work will be completed by the RSA Conference Subgroup and will include rapidly developing materials for the upcoming conference of the Research Society on Alcoholism. 2. Survey Workgroup will explore how FAS is addressed at the State and local level by conducting a survey of state programs to identify each states' strengths and weaknesses, and develop a plan built upon that information. 3. Broad-based Campaign Workgroup will explore ways to raise the awareness of FAS/FAE among professionals and will include a Provider Education Sub-workgroup. Emphasis will be placed on the education of individuals involved in primary prevention; then secondary and tertiary prevention. Issues to be addressed include diagnosis; evaluation of effective intervention strategies, as well as evaluation of outreach outcomes. 4. Multi-level Collaborative Project Workgroup was formed to help advance the field by recommending, based on good science, research areas of focus. Topics to be discussed by this group include the creation of a national registry of children with FAS and the potential use of meta-analytic techniques with pooled data sets from different sites across the country.

It was agreed that the object is to address exposure, consequences, and management. One challenge is that children with FAS/FAE often do not fit in to the traditional service categories. Since earlier identification may prevent some long-term consequences, altering the definition of developmental disabilities to include FAS/FAE becomes more important.

Detailed presentations were provided on SAMHSA's mission and activities, and on those of the Interagency Coordinating Committee on FAS (ICCFAS). Similarities in some of the goals of the ICCFAS and this Task Force were noted, as were the potential gains from cooperation between the two.

Committee discussion addressed education strategies. A Task Force recommendation was proposed for: 1) implementation of a systematic nationally-published awareness campaign, to include radio and TV informational announcements about exposure and consequences, with a spokesperson; development of presentations for community groups, professional organizations, etc.; and sponsorship of a national conference; and 2) development of a broad educational initiative involving medical, vocational rehabilitation, chemical dependency, and other specialties (e.g., National Organization on Fetal Alcohol Syndrome' (NOFAS) eight service delivery systems). The Task Force agreed to develop recommendations for a public awareness campaign, resulting in the establishment of several related workgroups. Recommendations will address developing TV/radio/information announcements, including ones to discourage any drinking during pregnancy; seeking a national spokesperson to help raise funding and awareness of FAS; developing conference and presentation modules on FAS; and working to develop a national conference, perhaps attaching it to a national science conference to encourage the desired attendance of scientists. The goal of the national conference will include elaborating on the families' experience, discussing the various treatments used, and sharing information on how that affects children, in order to stimulate research.

While the national meeting might better be held after some of the Task Force recommendations are in place, encouragement to the families in the meantime is essential. The Task Force can: 1) reiterate and recommend that agencies preparing to fund programs

addressing FAS interventions include parents in planning the research; and 2) explore assembling scientists, agencies, organizations, and families to brainstorm about a national research agenda in a workshop in the next two years.

There was consensus to develop an FAS/FAE session for the June RSA conference. It must be carefully crafted to allow a useful interchange for both families and researchers. To succeed, sufficient time is necessary. It may be sufficient to introduce the topic to the plenary and invite the attendees back later to a workshop. Further consensus was reached to identify 3-4 geographic regions to target for FAS/FAE workshops at which scientists, agencies, and parents can meet.

In developing the Multi-level Collaborative Project, the research issues discussed included: 1) the need for a national collaborative FAS project, with a multi-representative board to identify the research questions and protocols to be carried out. 2) the need for a national registry of children with FAS. (For both of these, advocate organizations offer access to affected families and blinded data in their member databases); 3) the need for a research agenda to be developed with contributions by both researchers and parents; 4) the urgency of addressing the issues of families, who want most to know how to synthesize research information into practical daily application; and 5) the need for a multi-level collaboration at the national level, ranging from basic science to the transfer of experiential knowledge to practice. This discussion resulted in the final formation and member recruitment of all the workgroups.

A discussion of new business listed still other areas which the Task Force might address: adoption and foster care; development of a Task Force mission statement; discussion of primary prevention; involvement/collaboration of other agencies doing FAS related service programs needed by families with children with FAS; research exploring generational FAS (up-line from a baby with FAS); and discussion of the name "FAS" in view of the need to address adults with FAS and of a diagnostic code for it.

Final discussion, of data on demonstrably successful FAS/FAE prevention programs, acknowledged that such depends on the outcomes. For example, while adolescent awareness can be raised, there is no proof that behavior is changed. There is much to be done.

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Centers for Disease Control and Prevention, National Center for Environmental Health

Minutes of the Meeting of the National Task Force Fetal Alcohol Syndrome and Fetal Alcohol Effect

December 14-15, 2000

DECEMBER 14, 2000

The Centers for Disease Control and Prevention (CDC), National Center for Environmental Health (NCEH), convened the first meeting of the National Task Force on Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) on December 14-15, 2000, in Atlanta, Georgia.

The members present were:

Members Michael E. Charness M.D., Harvard Medical School

Claire D. Coles, Ph.D., Emory University School of Medicine

Nancy L. Day, Ph.D., University of Pittsburgh School of Medicine

Jocie C. DeVries, FAS Family Resource Institute, Seattle, WA

Fred W. Garcia, State of Washington Director of Alcohol and Substance Abuse Prevention and Treatment Programs

Theresa M. Maresca, M.D., University of Washington Kathleen T. Mitchell, National Organization on Fetal Alcohol Syndrome (NOFAS)

Edward P. Riley, Ph.D., Chair, San Diego State University

Luther K. Robinson, Jr., M.D., Dysmorphologist, Buffalo, New York

Charles M. Schad, Ed.D., South Dakota, retired faculty member, College of Education.

Standing member: Faye B. Calhoun, D.P.A., M.S., National Institute for Alcohol Abuse and Alcoholism (NIAAA), National Institutes of Health (NIH).

Michael F. Fleming, M.D., Dr.P.H., was absent due to a family emergency.

Guests present were:

Diouna Baker, M.P.H., Substance Abuse Treatment and Mental Health Services Administration (SAMHSA)

Deborah E. Cohen, Ph.D., guest representation of The Arc of the United States (formerly Association of Retarded Citizens); Director of New Jersey Office for Prevention of Mental Retardation and Developmental Disabilities; and aunt and former guardian of child with FAE.

Executive Secretary R. Louise Floyd, D.S.N., R.N., Acting Chief of the Fetal Alcohol Syndrome Prevention Office

Committee's Designated Federal Official (DFO), Ms. Connie Granoff.

CDC staff attending over the course of the meeting were: Dr. Michael Adams, Dr. Jacquelyn Bertrand, Mr. Jon Baio, Dr. Coleen Boyle, Dr. Charlotte Dickinson, Ms. Kenya Ford, Dr. Juliet Kendrick, Ms. Paula Kocher, Ms. Helen Kuykendall, Dr. Jasjeet Sidhu, and Ms. Jacqueline Vowell.

Others in attendance included: Karla Damus, R.N., Ph.D., March of Dimes, Office of Medical Director; and Albert Einstein College of Medicine. Ms. Marie Murray, Writer-Editor, Atlanta, GA Deidra Roach, M.D., National Institute of Alcohol Abuse and Addiction (NIAAA), Bethesda, MD Robert Sokol, M.D., Wayne State University, Detroit, and Institute of Medicine Ms. Barbara Wybrecht, parent of an FAS child, and a public health and pediatric nurse who does community education in Michigan. Mr. Jeff Wigren, MPH, Fellow, Association of Schools of Public Health, CDC.

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Opening Comments Chair Dr. Edward Riley convened the meeting at 8:40 a.m., summarizing the committee's mandate to advise and provide information and recommendations on all aspects of Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE), including to educate professional and paraprofessionals, the lay public, and individuals at potential risk and to prevent FAS and FAE. The Task Force will try to define what FAS and FAE are, and will review the entire spectrum of alcohol-related disorders and the effectiveness of the interventions developed. Additional expertise will be provided to the members as needed to supplement the expertise provided by its own membership. The latter represents the experience of parent groups, to advise on the practical state of living with FAS/FAE; that of state agencies, to advise on how best to deal with those bureaucracies; and of academicians, to suggest how best to evaluate the outcome of the committee's recommendations to assess its own success.

In welcoming the attendees, Dr. Coleen Boyle, Director of the Division of Birth Defects, Child Development, and Disability and Health, recalled the DHHS Secretary's request to CDC 18 months earlier to assemble an FAS Task Force of experts to help advance the science forward from a scientific and policy perspective. She expressed her own and CDC's commitment to making this committee as productive as possible, as it meets its challenge to help the field, policy, and affected families make progress. She reported that, as part of the Child Health Bill signed by President Clinton in October, the Division will become a separate CDC Center for Birth Defects and Developmental Disabilities. The name may expand with the Center if additional units are incorporated. She saw this development as a positive move to raise birth defects and developmental disabilities to another level at CDC, hopefully including resources.

Task Force Executive Secretary Dr. Louise Floyd thanked Ms. Granoff and committee management specialist, Ms. Jacqueline Vowell, for their work in assembling the committee. She conveyed CDC's pleasure in convening this Task Force and its commitment to provide the funding and logistical/programmatic support necessary to its work. As a supplement of the information book previously provided to the members, she provided a brief overview of work to date by CDC on birth defects and developmental disabilities, and its research priorities.

The FAS Prevention Office currently resides in the Division of Birth Defects, Child Development, and Disability and Health, soon to be a Center. All of CDC's work is captured under the categories of surveillance systems, epidemiology studies, and prevention programs. For FAS/FAE, surveillance activities investigate FAS surveillance methods, establish prevalence estimates, and monitor outcome/exposure trends. Epidemiologic studies are done to identify the risk factors for FAS and alcohol-exposed pregnancy (AEP), and to identify target populations for prevention of AEP. Prevention programs, both primary prevention of AEPs, and secondary prevention strategies for individuals at risk are underway at CDC, including education of public and private health care providers to raise their related skills to best practice levels.

CDC's FAS prevalence estimates from its Birth Defects Monitoring Program (1979-1993) indicate a rate of 0.67 per 10,000 live births. Of live births in the metropolitan Atlanta area, data from the combined Metropolitan Congenital Birth Defects Surveillance and the Metropolitan Atlanta Disabilities Surveillance Systems indicate a rate of 2.5/10,000. Other data in 1995 indicate rates of 2.7/1000 live births in Native American populations, and in 1998, 3/1000 live births in Alaskan Natives. The University of New Mexico's FAS program study of three racial and ethnic populations (Native American, Hispanic, White) indicates rates of 3/1000 in Native Americans; and 3.1-6.8 in Hispanic and White communities. The lower rates in Hispanic population tend to occur in recent

immigrants; the higher rates seem to reflect the effects of acculturation in the U.S.

To ensure uniform FAS monitoring, in 1997 CDC established the state-based FAS Surveillance Network (FASSNet). Its purpose is to: 1) enhance or develop a multiple-source surveillance system; 2) generate population-based surveillance data; 3) establish relationships with diagnostic and service programs; 4) evaluate the completeness of the surveillance system methodology; and 5) implement provider training/education.

Monitoring is done in FAASSNet's five participating states (which are funded for at least two more years). The medical records data from multiple sources (e.g., hospital, medical practice) are entered onto laptops and uploaded to state systems, cleaned and identified with a case number, then forwarded to CDC for pooling. About 1400 potential cases have now been abstracted, and refinement of the case definition and prevalence estimates are expected later in 2001. In the past five years, alcohol use in pregnant and nonpregnant women of child-bearing age women has been monitored. This showed little change in the number of women of childbearing age who drink alcohol or in the trend of binge drinking previously established for pregnant and nonpregnant women. A 1997 decline in moderate to heavy alcohol use among pregnant women subsequently rose again to levels previously established in 1995. An estimated 3% of pregnant women are binge drinkers.

Epidemiologic studies of prevention strategies to reduce in utero exposure to alcohol have yielded some promising results. A University of Washington case series study of biological mothers of children diagnosed with FAS indicate that only about 20% still live with the child. Their mean age was 27 years at the birth of the index child; average IQ was 90; 61% were not high school graduates; 78% had an income of <\$10,000 at the child's birth; 95% were physically and/or sexually abused; 96% had one or more mental health disorders; and only 20% used birth control.

Based on that and other studies, Project CHOICES was created with the goals of identifying settings with high proportions of women at high risk of an AEP; characterizing the population to identify levels and predictors of risk; and designing/implementing an intervention aid to prevent AEPs. Three universities were awarded grants in 1997 for epidemiologic surveys and to help in cooperative agreements to develop motivational/behavioral interventions to these women in various settings. About 3000 women in various settings (prisons, recovery centers, Ob/Gyn clinics/health centers, media sample) completed a survey to determine what proportion were at risk of an alcohol exposed pregnancy because of risky drinking or ineffective contraception use.

An estimated <2% of the overall population of women at child-bearing age are at risk of AEP. Overall, 13% of the population of women across all sites were at risk from AEP. A behavioral intervention was developed, which included an exercise book to accompany counseling sessions (four over 10-12 weeks), personalized feedback, decision making, goal setting, and self-tracking of the participants' own behaviors in a diary. The women also receive gift packs whose contents vary from study to study (e.g., condoms; breath mints and bus tokens for women in prison to get home); all tailored to their particular areas. The data from three months is in and that from six months is nearing completion. Conclusions to date on the prevention activities indicate that these are ideal settings. Preliminary evaluation supports an efficacy trial, and the first planning meeting was just held with the same grantees who conducted the Phase I study.

Future priorities include: 1) continuing to monitor FAS and alcohol abuse by women of child-bearing age; 2) implementing the Project CHOICES efficacy study and expanding it to diverse populations; 3) enhancing public/provider awareness of FAS prevention strategies; 4) implementing intervention studies of FAS and Alcohol-Related Neural Disorders (ARND -- pending funding to do so); and 5) supporting the National Task Force on FAS/FAE.

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FACA Presentation: Ms. Paula Kocher, of the CDC/ATSDR Office of General Counsel, discussed the regulations, including those pertaining to ethics, of the Federal Advisory Committee Act (FACA). A video was shown explaining the history of FACAs and the members' responsibilities. FACA allows consensus advice to be provided to the government; ensures a balanced membership on the committee; and requires a structured management and open access to committee deliberations. FACA committees operate on a renewable two-year charter. The DFO arranges meetings, publishes meeting notices in the *Federal Register*; ensures that the meetings are open to the public; makes committee records available (including detailed minutes) and provides open access to financial matters affecting the committee.

The members are "special government employees," defined as "a temporary government employee who works with or without pay either full-time or intermittently for no more than 130 days in 365 consecutive days." As such, members must comply with the same rules as regular government employees, and some carry criminal consequences if violated. The FACA's regulations address seven components: conflicting financial interest; appearances of conflict of interest; use of confidential information known due to advisory committee membership; acceptance of gifts; outside activities which can/not be engaged in while a member of a FACA committee; restrictions on seeking employment while a member and after membership. Any questions were invited to be directed to Dr. Floyd or Ms. Granoff.

Ms. Helen Kuykendall also reviewed the FACA's history, procedures, and membership aspects. FACA was enacted by Public Law

92-463 in October 1992. It defines a FACA as "any committee, board, commission, council, conference, panel, task force, or other similar group, or any Subcommittee or other subgroup thereof for the purpose of obtaining advice or recommendations on issues or policies which are within the scope of his or her responsibilities." GSA assumed the responsibilities for FACAs in 1977 and further defined FACA committee guidelines. Each agency must have a committee management officer; the agency is accountable to the GSA, and the GSA is accountable to Congress for all FACA activity. FACA requires each committee to have a charter, balanced membership and public access, specific requirements for detailed meeting minutes, and open access to all committee documents. Membership must be fairly balanced in terms of the points of view and geographic, ethnic and gender representation. Members are selected without discrimination based on age, sex, ethnicity, gender, sexual orientation, disability, or cultural, religious, or socioeconomic status, and serve as special government employees for terms of up to four years.

FACA committees are structured around the DFO, Chair, and members. The DFO supervises the committee's day to day operations, calls the meetings and their agendas, attends all meetings and ensure that meeting notices are published in the *Federal Register* at least 15 calendar days before the meeting. The Chair is a member selected by an agency official, who manages the committee with the DFO, presides over meetings, ensures that public comment periods are held, and certifies the accuracy of the meeting minutes. The members are special government employees serving with or without compensation for 130 days or less within 365 consecutive days. They represent only their personal opinion or view, not that of any organization, and are legally liable under FACA's ethical regulations.

Subcommittees are subgroups composed entirely of parent committee members, but may include consultants for needed expertise. They are subject to the same FACA rules on meeting announcements, and be open to the public. On the other hand, workgroups consist of two or more parent- or subcommittee members convened to gather information, conduct research, or analyze facts to provide input on a narrow issue or to address an issue short-term. They are not covered by FACA regulations, but its report back to its parent group is. Ms. Kuykendall referred the members for further information on FACA to the GSA Website (www.policyworks.gov).

Discussion: Dr. Riley asked if, since the meetings are public, anything discussed therein could be discussed elsewhere such as in conference presentations, etc. Ms. Kocher said yes, but advised caution in giving presentations; while the content could include work done on the committee, it should not be the presenter's sole subject matter if the individual is being paid an honorarium to give the talk. Beyond that, compensation is a critical factor; if not compensated, such discussion should be allowable. She invited the members to call with any questions.

Dr. Riley then asked if e-mails are part of the public record and Ms. Kocher defined this as a gray area. Unimportant e-mails such as on committee housekeeping items (agenda, etc.) would not be included, but an area of substantive issues might trigger FACA and require public notification. She suggested that e-mails be kept to housekeeping matters. But as noted, workgroups are not open meetings, and requisite public disclosure occurs when they report to the parent committee.

Ms. DeVries, who wanted a product to result from this meeting, asked if a Task Force recommendation would be issued on CDC letterhead. Ms. Granoff stated that it would be published at the end of the minutes and would constitute a CDC recommendation. CDC will develop a data base of organizations, state health departments, etc., who deal with FAS/FAE, and regularly send the minutes to them. She requested input on this list. Dr. Boyle added that recommendations also could be published in an issue of CDC's *Morbidity and Mortality Weekly Report (MMWR)*. This involves a more formal process requiring more work, but it affords a wider distribution to state health departments.

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Committee Description: Dr. Riley asked the process by which the committee would make and track a recommendation. Ms. Granoff responded that they would be published in the meeting minutes, forwarded to the CDC Director and tracked by her office. Every recommendation made by the committee will be addressed and a response provided as to whether it is implementable. The DHHS Secretary delegates such responses to the CDC Director, but direct communication with her can be done by a letter from the committee. FACA groups have met with the Secretary; if something requires address at the policy level, it can be done. Dr. Floyd noted that the committee's broad mandate infers that it will address various targets, but the process will be to direct communications to her or the DFO (Ms. Granoff), and then on to CDC OD for response.

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Topics to Address

- Dr. Calhoun, who chairs the Interagency Coordinating Committee on FAS (ICCFAS), hoped to assist the channeling of recommendations through to the appropriate agency, effectively, efficiently, and with resources. She noted that since the committee's broader mandate allows the address of broader issues than simply making recommendation on the agencies' programs. For example, it could advise on policies and issues regarding FAS, with direct input from physicians and families, to the appropriate associations and scientific societies (e.g..Ob/Gyn, The ARC, March of Dimes). **Potential topics to be**

address by the Task Force. Dr. Riley introduced discussion to prioritize the listed priorities from the 1999 preplanning meeting (Attachment #1), on which he had provided several notes prior to the meeting. Potential topics suggested were as follows (with the proposer identified):

- *Discussion of the desired breadth of the committee's work:* such as whether to address the alcohol beverage and/or advertising industries' social norming work; and/or federal agency involvement with such work). (Garcia)
- *Recommend block grants on disabilities and health;* for example, SAMHSA block grants to address prevention of binge drinking among those aged 18-44. These could focus on areas relevant to physicians, medical services and diagnosis; prevention efforts by physicians, alcohol and drug counselors, and by preventionists working with the media to try to impact the industry. (DeVries, Garcia)
- *Craft the recommendations for maximal agency efficiency:* craft recommendations to help avoid interagency rivalries, minimize overlaps, and better work together (e.g., between those agencies doing primarily surveillance and others that encompass that). This committee should address the coordination of efforts government-wide on prioritized issues while those agencies are present at this meeting. (Charness)
- *Define the research needed on FAS/FAE:* Ms. Day suggested definition of what needs to be prevented, segmentally, such as FAS' specific diagnosis and screening issues. The same is needed for FAE, which is a far less clear area, but potentially providing greater impact. The targets must be selectively chosen and require different approaches. The Bill's final text included specific language about interventions for children, adolescents, and adults, and its consistent use of FAS and FAE is the basis of this Task Force's mandate. Other language of the appropriation bill sets aside funding for specific areas, including FAS/FAE, to remain allocated until so used. (Day, Riley, DeVries)
- *Address education of the public and health care professionals* to counter declined public attention to the adverse effects of prenatal alcohol use since PSAs have decreased, and warning labels are ineffective. Greater public awareness can impel professionals to be more aware of, seek, and make this diagnosis. (Riley)
 - Identify a national spokesperson; help to assemble a constituency to battle FAS/FAE. A national spokesperson could advance this agenda (e.g., as seen when celebrity promotion spurred Congressional funding of five Autism Centers in 2000). (Schad, Riley)
 - Help to coordinate the research and service provision areas to bring together these two stakeholders, whose past communication has been less than effective. For example, post-diagnostic needs must be addressed, and the message conveyed that something can be done for children or women associated with FAS/FAE (e.g., identifying the teen at high risk of continuing behavior that will result in FAS/FAE). (Robinson)
 - Require family groups' participation in federal agency meetings with grantee researchers (Charness)
 - Support research on promising interventions: e.g., anecdotal reports from FAS families cite two things as helpful in managing the child: sensory integration therapy (also reported as beneficial by teachers), and the availability of a different kind of parenting class based on neurological differences. Talk therapy has been demonstrated as ineffective. Other interesting research cited included women attending a low-income Ann Arbor clinic for a pregnancy test, who were provided a short education piece on FAS. (Wybrecht)
 - Support advocacy for broader interventions, (e.g., the Yakima tribe's attempt in Washington state to legislate a dry county). (Maresca)
- *Pursue alcohol industry funding of work on FAS/FAE.* NOFAS interviews identified as one problem the insufficient numbers of physicians able to correctly diagnose FAS/FAE. Alcohol industry funding for PSAs to address this could make a difference, but some oppose using alcohol money to address FAS, but such funding would at least provide a beginning. Mr. Marcus Grant leads an alcohol industry group in Washington, D.C., and could arrange a meeting with the industry if desired.
- *Pursue a multi-level approach;* involve the Department of Education (DoE). Potential multi-level models have been described in the literature. Present state services for the disabled do not necessarily include FAE. The DoE's involvement is essential. Broad-based education is ineffective except when institutionalized as part of a curriculum (e.g., medical school, or high school delivery of repeated messages). The alcohol addict may not be helped, but perhaps the binge drinkers could be. (Coles, Cohen)
- *Pursue the inclusion of FAS in medical schools' curricula,* a path being developed by the NIAAA and generally necessary to

ensure implementation of knowledge. However, Dr. Robert Sokol, who was a member of the IOM study team which reported on FAS, discouraged this idea. Inclusion in medical curricula is universally desired, and lack of no standards prevent enforcement. Rather, he suggested that CDC and NIAAA build specialty-specific curricula and provide them to the relevant societies for promotion to their specialties (e.g., ACOG has found providing CME credits to be more successful than pursuing such mandates). He also advised that systemic recommendations be crafted, to address physician training. And, rather than pursuing a post graduate curriculum, FAS/FAE work could be implemented in a specialty-training graduate curriculum (e.g., Ob/Gyn, Family Medicine, Pediatrics, Psychology residencies), where there is some knowledge of what works.

There was general agreement to recommend that FAS be included in any curriculum that deals with education, developmental psychology, midwifery, or anything involving Ob/Gyn. Drs. Maresca and Schad agreed to develop a workgroup to identify the targets of this recommendation. Dr. Floyd noted that, once identified, those target groups could be invited to participate as guests at meetings of the Task Force.

- Explore models and guidelines for FAS/FAE. CDC wants to change health care practice by providing skills and tools to intervene and effect change. A CDC survey of Ob/Gyns found varying professional organization endorsements on addressing FAS. Improving the knowledge of front-line clinicians and recommending on how to get the materials to them (e.g., providing easy access to CMEs) could help.

Conveying the research and findings to the field, such as through the liaison representation at this Task Force, is essential.

- *Target the audiences for education.* Since 25-30% of babies are delivered by family physicians, include them in the target groups (e.g., through the AAFP). (Kendrick)
- *Develop a standard presentation on FAS/FAE.* Formulating a standard presentation suitable for any organization such as national or regional meetings of the Pediatric or Midwives Societies, etc. (Riley). Be sure to emphasize the need to also provide a referral source for the practitioner. (Coles) Extend the presentation's audiences to include the prevention level (e.g., through the National Association of Alcohol and Drug Counselors, for whom many states are considering accreditation standards). (Garcia)
- *Involve parents in developing the presentation.* The FRI investigated the qualifying criteria of eight systems of service delivery in the last ten years (e.g., education, developmental disability, mental health, vocational rehabilitation, the education system itself, child welfare, etc.), as well as to whom one must go to gain policy exceptions. When no services were available, they began lobbying for a funding stream on the national level, because states will implement programs if funded. They mentor families through the necessary steps to get the needed services. Parents should be involved in developing the proposed presentation, which also should consider the demonstrated inability of professionals (research by Streissguth et al) to translate research into practice. (DeVries)
- *Include a national resource guide success stories!* in any presentations, educational process, etc. Physicians need that to counter the stigma and fear of diagnosing these children and adults, as was done with the alcohol model. (Mitchell)
- *Support research and a national meeting on FAS.* To counter physicians' reluctance to identify women/children affected by FAS without referral sources, support a pre-research meeting on interventions with children, to explore and document common areas that might support research. And, along with finding a national advocate to be an FAS spokesperson, convene a national meeting as well as regional conferences to discuss successes that might support research on interventions appropriate in specific settings. Hundreds of families could help begin that discussion. (Calhoun, DeVries)

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Strategy. Dr. Robinson summarized this discussion in terms of prevention: a national spokesperson for primary prevention; then secondary and tertiary prevention to address diagnosis; and evaluation of the effectiveness of intervention strategies, as well as evaluating of outreach outcomes.

Forming workgroups to address these was proposed, to address: 1) the issue of national recognition of FAS (involving a spokesperson, national campaign, etc, but not treatment or diagnosis except to reassure that such services are available); and 2) professionals (e.g., to explore different guidelines for medical and educational professionals; portion out what domains to address, and within those, what information is critical; and then, how to network between domains to help the end user decide to which medical professional to go for a response). Although not a primary prevention message, this education about a possible range of outcomes could regain lost public attention and filter down to prevention.

There was general assent that the object is to address exposure, consequences, and management, assuming that attention to the issue has been lost due to lack of explicit knowledge about what to do. One challenge is that these children often do not fit in to the traditional service categories, perhaps even more unfortunate because earlier identification may prevent some long-term consequences. Altering the definition of developmental disabilities to include FAS/FAE could perhaps "fit" them into services and allow that early identification.

Since state eligibility for benefits varies, Dr. Cohen suggested approaching this on a most restrictive or most broad level. She urged that the effort to change medical school curricula not be abandoned, since every institution has someone who can influence that and, for example, universities will change to meet state mandates. She recommended that the Task Force examine state policies and exploring states such as Washington for model service systems (which also is part of physician education); and that it examine national models as well as national spokesperson. This could perhaps be part of CDC's survey of states, to which this committee will provide input, to determine what they address regarding FAS/FAE. The survey's data will be valuable since even available services are often hard to get or are unknown (e.g., FAS/FAE children raised by foster or adoptive families qualifies them for adoption support program services).

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SAMHSA Presentation: Ms. Diouna Baker, SAMHSA's Deputy Associate Administrator for Women's Services, outlined SAMHSA's mission to improve the life/well-being of those with mental and addictive disorders throughout the nation. She expressed SAMHSA's commitment to and honor in participating in this Task Force. Her office focuses on improving the economic and social well-being of women and children, of which FAS/FAE is an important component. She discussed SAMHSA's related programs, activities, and legislation.

1. *Programs to support the ICCFAS* focus on issues relevant to the general public, research, early interventions, and treatment/services for women and children with FAS/FAE. Alaska has the highest incidence of FAS/FAE, and has a comprehensive approach to related service delivery. Upon Congressional direction, SAMHSA supports the 5-point plan of a \$5.8 million program to expand Alaska's capacity to do surveillance and document FAS/FAE problems.

2. A *SAMHSA and Indian Health Services (IHS) consortium* is partnering with four states in a \$2.7 million cooperative agreement to address FAS/FAE. The consortium has advisory and steering committees. For women and children, it will: 1) develop an information base to standardize data collection to determine high risk areas/populations; and 2) implement/test the effectiveness of population-based interventions.

In FY2000, SAMHSA was reauthorized under the Youth Drug and Mental Health Services Act. It includes, but not yet funds, several legislative proposals about FAS/FAE among Native Americans, with several components paralleling the Task Force's mission and providing another opportunity for agency collaboration. The legislation provides in grants: \$25 million to public and private entities to provide services to individuals with FAS, FAE or alcohol-related birth defects (ARBD); \$5 million to establish five Centers of Excellence to explore FAS and alcohol-related neurological disorders (ARND); and \$15 million for prevention/treatment services to Native Americans on reservations. Another grant establishes a commission to explore and recommend on the conditions of Native Americans with a first priority of addressing substance abuse.

In its work, SAMHSA heavily references the *Surgeon General's Report on Mental Health* and its companion document, *Improving Substance Abuse Treatment*. The former advances mental health as fundamental to other health issues, addresses the effects of prenatal alcohol exposure, and states the need for early intervention and treatment of FAS/FAE, especially with co-morbidity. The latter was developed by federal agencies with persons of varied backgrounds. Its workbook offers a national treatment plan that suggests ways communities can join to address treatment and develop plans to standardize treatment, as done with chronic illnesses.

SAMHSA is promoting the same parity for substance abuse treatment with physical health in insurance coverage as is now provided for mental health. The principals on which this is based include: 1) investment for results (develop a standard benefits insurance package with parity to physical health); 2) no wrong-doer (treat or refer the presenting substance abuser to a proper substance abuse facility); 3) commitment to quality at all levels of treatment (cross-training in substance abuse, mental health, and primary care); 4) effect a change in attitude to remove stigma and recognize these as public health issues; 5) build partnerships, the most important step, to blend research facilities; and 6) conduct evidence-based research in partnerships between the treatment field and individuals' organizations devoted to improving treatment.

Discussion. Dr. Floyd thanked Ms. Baker for her excellent report, and asked if SAMHSA is planning a physician training component. Ms. Baker confirmed that, both from a substance abuse and mental health perspective. This is now done under Dr. Camille Berry of her Center in collaboration with HRSA, focusing on three perspectives: community systems with a single system of care, development of adequate human resources; and revenue to develop the system of care. Although this is not now specific to FAS/FAE, they are expected to arise as they involve top priority health issues.

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ICCFAS Presentation: Dr. Faye Calhoun, Chair of the Interagency Coordinating Committee on FAS (ICCFAS), reported on its work of the past four years. A trans-agency federal effort to address FAS, the ICCFAS hopes to be a model for the states, encouraging organizations to work together, since no one organization or agency can address FAS and ARND alone. The committee's new five-year strategic plan is in draft; when complete, it will go to Congress and be released.

Congress commissioned a study that was performed and released by the Institute of Medicine, on FAS: *Diagnosis, Epidemiology, Prevention, and Treatment*. The IOM's recommendations urged integration and coordination of the work on FAS/FAE, an urgent task since the disease's many aspects fall within many agencies' mandates. It calls for cooperation, communication, development of trust over time, and collaboration, in that order. The full report, which asked the NIAAA, as the agency charged with conducting vigorous research on all aspects of alcohol-related illness and treatment, to take the lead in establishing the coordinating body. Also distributed was the NIAAA's tenth report to Congress on its domestic research. Chapter 5 discusses the status of FAS/FAE research in three areas: 1) studies (animal and human) of alcohol's effects on brain structure/function (imaging, abnormalities of brain regions, effects on behavior, etc.); 2) studies of the underlying multiple mechanisms of alcohol-induced damage to the fetus (e.g., by free radicals, cell adhesions, biochemical signals, gene expression, etc.); and 3) issues of FAS prevention. A bibliography on Alcohol and Pregnancy, a compilation of NIAAA research on alcohol and pregnancy was also published in June 2000.

The NIAAA formed the ICCFAS in August 1996 and now has ten organizational members: CDC, SAMHSA, AHCPR, HRSA, NIH (NINR, NIAAA, NICHD), the Mental Health Services Administration, the Office of Juvenile Justice and Delinquency Prevention (OJJDP), and the Departments of Education and Justice joined in 1998. The member organizations' missions include research, special education, prevention, professions training, human development, pediatrics, reproductive health, and obstetrics, patient outcome research, practice guidelines, juvenile justice, health care service, information design, alcohol treatment, and demonstration projects. The challenge is to find resources, foster cooperation, and support collaborations to contribute to each area of expertise.

FAS is an international problem, and the ICCFAS' goal is to exchange information, foster collaborative projects, and improve communication among researchers, service providers, and professional groups supported by the member organizations. They hope: 1) to improve the diagnosis, the ability to screen for and prevent drinking during pregnancy, and the quality of intervention and treatment of women of child-bearing age at risk; 2) to educate communities and health care professionals to improve health care, education, and correctional interventions for affected children; and 3) to foster the basic research needed to identify mechanisms of alcohol teratogenesis and to lead to improved interventions and treatments.

The ICCFAS meetings of the first two years focused on education to provide a basic understanding of the problem. Each member sponsored a meeting and presented their portfolio of activity related or potentially related to FAS/FAE, which demonstrated the resources available. The first Report to Congress in January 1999 reported little progress beyond gaining cooperation among groups and increasing communication. Workgroup meetings then began, to:

- Establish a common understanding of the state of the art regarding FAS/FAE. The first meeting in April 1997 produced so little information, the proceeding were not even printed.
- Measure alcohol consumption among pregnant and child-bearing age women in clinical studies and surveys (June 1997). This stimulated some progress.
- Advance prevention of risk drinking during pregnancy (April 1998). Proceedings were written and an RFP was issued by SAMHSA, HRSA, and CDC.
- Intervening among children affected by prenatal alcohol exposure (September 1998; a formal report is available); this demonstrated some research progress.
- Explore diagnosis of children: the March 2000 report is in progress on early childhood neurobehavioral assessment for the differential diagnosis of FAS/ARND from, for example, lead poisoning or ADHD and other disorders. This is hoped to stimulate research to allay significant related confusion.
- Identify five ICCFAS priority areas for fiscal years 2000-2005, each with many sub-areas: a) information dissemination (education of health care professionals, teachers, families, etc.); b) preventing risk drinking in pregnancy; c) intervening with affected children and families; d) improving diagnosis, and e) increasing research in the etiology and pathogenesis of FAS/FAE.

Dr. Calhoun provided examples of work and potential collaboration programs:

- Current grant programs address the prevention of risk drinking in pregnancy by NIAAA (ten fairly strong applications are funded), HRSA (funded four state-level projects in high-risk areas), and CDC, and SAMHSA (already described). Each of the 5-year grantees presented at one ICCFAS meeting, stimulating ideas on additional programs/projects (e.g., HRSA subsequently began its funding of screening programs for women at risk of drinking in pregnancy). With all these projects underway, the committee hopes for an excellent conference in about two years, able to report progress.
- Projects for intervening with affected children and families are underway by NIAAA and the National Institute of Child Health and Development (NICHD); SAMHSA and IHS; the DoE and the OJJDP, to educate affected children in the juvenile justice system; and the DoE, NICHD, and NIAAA on early identification and prevention planning.
- A DoE Task Group (FICC) coordinates federal agencies, parent groups, affected families, state and local representatives, and other managing related programs. They asked the ICCFAS to co-sponsor a Task Force under the FICC to address a) how to increase the early identification of affected children, and b) how to transfer research and experiential knowledge

to practice in educational and child settings. The Task Group is also interested in the quality of interaction between the health care and educational systems in identifying the needs of affected children; and to increase interaction between educational psychologists and alcohol neurobehavioral assessment researchers. The Task Group is beginning its work; it has held conference calls and met with psychologists to understand their system.

Dr. Calhoun introduced Dr. Deidra Roach, of the NIAAA and Executive Secretary of the FICC, who also was Washington, D.C.'s Commissioner for Alcohol Prevention and Treatment. She is working with the DoE to transfer what is known about FAS into classrooms, and she outlined some of that subcommittee's work. Within a year, teachers and school nurses will examine and pilot test the tools developed and training issues identified related to FAS screening and referral, to identify age-specific screening tools to begin school-based screening. They hope to develop a training manual for teachers, school nurses, and other school personnel, as well as a one-day workshop for school teachers, nurses, and resource specialists to review and field test the training manual in the next year. She expressed the FICC's optimism about this approach.

Dr. Calhoun then outlined the next steps needed: 1) identify/address the ethical, legal and confidentiality issues related to identifying mothers who bear FAS/FAE children whose deficits must be addressed in the educational and legal systems; 2) develop guidelines for addressing FAS/FAE in the educational setting; 3) develop pamphlets, booklets, and other materials for parents, extended families, teachers, child care givers, school nurses, local health departments, etc. SAMHSA hopes to have the resources to match the interest and desire to effect these recommendations for action.

Some progress has been made and is likely to continue in accomplishing these:

- *Promoting collaboration:* SAMHSA's four-state consortium on FAS/FAE is anxious to work with the ICCFAS to develop an integrated care system and an information base to systematize data collection; to implement/test prevention/interventions; and to evaluate what has been done. The project goals address prevention, intervention, service delivery, screening/diagnosis, multidisciplinary community teams (stemming from CDC work a few years earlier), and evaluation. They are well supported by \$5.8 million of funding.
- *Improving case diagnosis:* a) The NIAAA is conducting active surveillance by two teams to identify sites in the world (South Africa and Russia to date) with high prevalence rates of FAS, to document it so the area can recognize and address the problem. They will concurrently do a mechanistic study of the prevention and treatment of FAS/FAE. The possibilities and benefits of international research on FAS/FAE could be a future Task Force agenda item; b) the NIAAA and NICHD are working on neurobehavioral assessments; and c) CDC is working on state surveillance systems and some active surveillance methods.
- *Training professionals:* a) The NIAAA, CDC, and HRSA are testing related NIAAA booklets for primary health care professionals in high-risk settings, and are working on a curriculum for health care providers; b) CDC and the IHS are training tribal physicians; the OJJDP and NIAAA are developing, with MOFAS (the Minnesota Organization to address FAS), a curriculum to be tested in Minnesota to assess the outcome of training criminal justice professionals for the more effective handling of affected children in the system (i.e., to lessen recidivism); c) the DoE and NIAAA are developing a curriculum for educational professionals; d) HRSA and SAMHSA are training in primary care settings; and e) CDC is developing an internet-based education module for health providers on identifying and intervening with women at risk for an alcohol-exposed pregnancy. The ICCFAS may sponsor a workshop to share all this activity and exchange materials to explore their broader use in the field.

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Discussion. Committee discussion included the following points:

- The result of the last spring's neurobehavioral meeting will be issued after receipt, clearance, and internal edit of a summary of the report done and of the meeting's recommendations and conclusions.
- Appreciation was expressed of the ICCFAS' accomplishments. It has similar goals to those of this Task Force, and much could be gained in cooperation between the two. Dr. Calhoun recommended a report developed by MOFAS that mirrors the work done by the ICCFAS on a national level, as well as guidelines for the care of children with FAS/FAE, similar to those of NOFAS.

Discussion: Campaign to Raise Awareness of FAS: Dr. Coles advised caution about the terminology used, such as "intervention" and "prevention", which convey different concepts to different audiences. Committee discussion about approaches included the following observations:

- Two tracks could be followed for two different populations: 1) incidence – those at risk to deliver an infant with FAS; and 2) and prevalence; how to diagnose those affected and prevent incidence (e.g., more training for counselors for women in chemical dependency clinics; universal prevention such as a media campaign). (Garcia)
- Identify areas of prevention as the umbrella and then narrow to intervention (e.g., addressing the stigma by physicians and by schools). (Mitchell)
- Discuss a national campaign, perhaps focused on (or another to address) pre- and post-pregnancy, since women who have an FAS child are at high risk to have another. For example, the Ob/Gyn could do primary prevention, as could higher education campuses to identify and intervene with college-age binge drinkers. (Riley)
- Identify/develop specialty areas' curricula: to reduce stigma, specifically related to how alcohol abuse might be manifested in that specific daily practice, and address primary and secondary prevention. (Day)

Task Force Recommendation: Ms. DeVries proposed that the Task Force recommend: 1) implementation of a systematic nationally-published awareness campaign, to include radio and TV informational announcements about exposure and consequences, with a spokesperson; development of presentations for community groups, professional organizations, etc.; and sponsorship of a national conference; and 2) development of a broad educational initiative involving medical, vocational rehabilitation, chemical dependency, and other specialties (e.g., NOFAS' eight service delivery systems).

- General comments noted that ensuring the resources to effect these is critical. Many substance abuse services are male-oriented, but:
 - Some states have a women's advocate, who should be enlisted to ensure such services are specifically targeted.
 - SAMHSA's block grant for substance abuse intervention and treatment had a 5% set-aside mandated to maintain "... a certain level of services to the pregnant addict with children," but this can now be waived. SAMHSA is reviewing this now. Education on needed gender-specific services (including post-natally) is required. Their national plan addresses efficacy of treatment and the need for a standardized treatment for substance abuse as a whole as well as gender-specifically. Their grants database on substance abuse should inform this (e.g., CSAT is exploring the issues of the effects of abuse on women and their children).
 - There is research on chemical dependency professionals, but NIAAA's treatment portfolio summary demonstrates that research is lacking among women of child-bearing age. NIAAA plans a large meeting with the ICCFAS regarding demonstration programs.
 - Insurance companies must be involved in this process. How to address their refusal to pay for health care and substance abuse treatment services must be addressed. This parallels SAMHSA's policy to have quality substance abuse treatment for everyone, including parity with chronic mental illness and insurance coverage parity. Dr. Riley suggested the Task Force endorse that policy.

The Task Force agreed to recommend development of a public awareness campaign and began discussion of its components:

1. Develop TV/radio/information announcements, including ones to discourage any drinking during pregnancy.
 - A. Dr. Day advises caution to avoid unintended consequences such as excessive labeling of women, and coercive treatment or jail. Confirmation is needed from the Department of Justice (DoJ) that this is a treatment, not justice, issue.
 - B. Dr. Floyd stated that the involvement of someone knowledgeable about developing and running a campaign could be invited.
2. Find a national spokesperson to help raise funding to and awareness of FAS.
3. Develop a Conferences and Presentations activity on FAS for national meetings (chemical dependency, attorneys, physicians, nurses, teachers, etc.). Varied modules would be assembled for the audience targeted (potential sources cited were the Research Society on Alcoholism, NIAAA, NOFAS, and the March of Dimes).
 - A. Dr. Damus stated that the March of Dimes will support aspects of the professional education module development. She urged the Task Force to consider several points: 1) exploring what the agencies are already doing that the committee can support; and if there are gaps, exploring where and why (there may be a policy block); 2) taking its

opportunity to make statements (e.g., as the March of Dimes does about drug abuse, alcohol, etc., strongly against punishment to women and advocating treatment instead); and 4) supporting more work on primary prevention to address the big area of pre-conception, in view of earlier age of first sexual intercourse.

B. Dr. Charness offered one cautionary comment about supporting earmarked funds for Federal agencies. This may result in an unfunded mandate that takes funds from other important activities.

4. Develop a national conference.

A. Considerations: There is a distinction between national conferences and presentations. The FRI sponsored the former in October 2000 and received good feedback about the hope it provided. But going to national/regional meetings (e.g., ACOG, pediatric clinical conferences, APHA in Atlanta in 2001) might accomplish greater progress.

B. Ms. DeVries stated that the Task Force needs to decide if it will lead or follow. A decision against having a conference due to a lack of volume of science could be perceived by the families as following. They advocate to Congress for national meetings, and they already have expressed to Senator Daschle their impatience at research being developed without family input.

C. The advantages of a conference are that it could enable a dialogue, for example, on why past efforts failed (e.g., with obstetricians, pediatricians, etc.) and could complement the CDC survey.

1. A survey of practicing physicians showed that about two-thirds do not endorse a zero drinking tolerance by pregnant women; some allow 8+ drinks/week. Federal advisories support zero tolerance. While some research indicates that some people can drink, there is no way to know who can; other data indicate effects on a child's ability to focus from only one drink a day. The various factors relate to alcohol metabolism, genetic factors, etc. A white paper summarizing the state of the science on thresholds and consequences could be pursued. It may not endorse zero tolerance, but could provide information on epidemiologic evidence that low levels of alcohol consumption might lead to physical or behavioral damage.

2. Endorsing zero tolerance at all could invite a fight with the alcohol industry. But on the other hand, it is to the industry's advantage to recommend that pregnant women not drink, since the literature shows a dose-response curve. The problem is that women don't always know they are pregnant. Industry opposition is based on the potential loss of a significant amount of business from social drinking.

3. The Alcohol Beverage Research Foundation Council recently approved funding grants on FAS. The brewers industry wants to be on record supporting all research that will mitigate adverse effects from alcohol, a different position than that of some other industry groups, and they might support public messages and provide funding. Having the industry as a collaborator also helps eliminate them as an opponent when Congress ponders legislation.

4. A national conference could elaborate on families' experience, discuss various treatments used, and share information on how that affects children, which could stimulate research.

5. It could stimulate interest in developing a registry of families willing to participate in research.

D. Since the desired attendance of scientists at such a meeting is uncertain, another method may be to attach this conference to a national science conference. That could provide scientists with a perspective from a new paradigm and indicate those scientists likely to be involved in the research.

E. Wait until more recommendations are in place (e.g., the third year), and use that as a meeting to get input from the field. A central location was suggested as the site (e.g., Denver, Salt Lake City, Dallas).

F. In the meantime, some encouragement must be provided to the families. Reiterate and recommend that agencies preparing to fund programs addressing FAS interventions include parents in planning the research. It may be possible to assemble scientists, agencies, organizations, and families to brainstorm about a national research agenda in a workshop in the next two years. This could also involve some stakeholders not commonly heard but who contribute to the discussions (or, perhaps the Task Force members could attend their meetings).

Dr. Floyd summarized that the Task Force's inclination was to recommend that a national conference be funded by an agency (e.g., CDC, NIAAA, SAMHSA) to elaborate on the families' experience, to discuss the various treatments used, and to share information on how that affects children, in order to stimulate research. With no further comment, the meeting then adjourned at 4:30 p.m. and reconvened the following morning.

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The members agreed to confer in workgroups and to circulate recommendations before the next meeting (April 25-26, 2001). This meeting would precede that of the Atlanta Alliance on Development Disabilities and FAS on "Getting to Standards of Care for FAS."

Formation of Workgroups

Conferences and Presentations Workgroup was formed to develop the desired presentations to be used in educational outreach. It was agreed to develop these in a modular fashion, to allow customization to the audiences (e.g., physicians, attorneys, educators, those in the criminal justice system, social services staff, advocates, and the affected families themselves.)

- Consensus was reached to develop a session on FAS/FAE for the June meeting of the Research Society on Alcoholism (RSA), which is being held concurrently with the Teratology Society meeting. The RSA meeting is the only time in which researchers in all fields related to alcohol assemble, and a short (e.g. one hour) roundtable or workshop could still be arranged. The session must be carefully crafted to allow a useful interchange for both families and researchers (e.g., parents could hear the physiological brain changes being researched, report their observations of their child's behavior, and explore together what this might mean). Enough time is necessary for such an interaction to succeed. It may be possible to introduce the topic to the plenary and encourage them to attend the workshop later in the conference.
- Consensus was similar in agreeing to identify 3-4 regions in which to have hold FAS/FAE workshops to enable scientists, agencies, and parents to meet together. For example, topics could be identified for the FAS parent conferences planned in Wisconsin and in Atlanta. One successful model to consider is the tribal conference within the IHS Research Conference, in which tribal members met with research groups in a full day format with breakout sessions for specific discussion. The Task Force also should reach out to groups addressing infant mortality, etc., who may not consider alcohol's involvement in this problem.

The Conferences and Presentations Workgroup was formed, beginning with a specific subgroup to develop the presentation for the Research Society on Alcoholism. Dr. Nancy Day will coordinate this effort. The workgroup will check with Task Force members on what other groups, speakers, and topics should be considered for address.

Dr. Riley suggested another workgroup to discuss who should be surveyed to explore how FAS is addressed by state entities and to identify each states' strengths and weaknesses, and develop a plan to improve services. One goal is to have FAS/FAE listed as a developmental disability. He provided CDC with a list of all state Directors for Developmental Disabilities. A Survey Workgroup was assembled to develop a list of survey target respondents, devise appropriate questions for the Task Force's review in April, and finally to send it out.

Additional items discussed included:

- Many different state agencies may address various FAS/FAE aspects (e.g., early intervention, medical help, developmental disabilities).
- FAS/FAE effects and services depend on age. Some data could be obtained from birth defects registries, although not all states collect FAS data as a birth defect. Dr. Cohen offered to help in this area. Ms. DeVries noted that Dr. Streissguth's study cited the early diagnosis of FAS and having it recognized as a developmental disability in the state services system was an important protective factor. Diagnosis of FAS for those who are affected and incarcerated can help ensure they are treated differently when they enter the correctional system.
- The states' authorities to survey for alcohol and drug abuse should be explored.
- It was noted that an agency's non-response could also indicate their response to affected families in that state and to identify discrepancies between what is allegedly offered and what actually exists. A two-stage process could explore whether the recipients of care agree with the states' service claims. If it includes enough information, the survey also could indicate to state Directors what training is needed for their staff (or follow-up could recommend that). The end product could be a summary of state approaches to providing services.
- This work likely will require a number of surveys and perhaps eventually interviews with key people (e.g., a survey of services for the affected children, another for those available for women at risk for substance abuse and alcohol problems). Work could begin with data collection and a national review of status. Contact with relevant national organizations (e.g. National Association of State Alcohol and Drug Abuse Directors or the MCH Directors Association) was recommended to gain their information about particular states' status; followed by contact with relevant state agencies. Perhaps the survey should be done in collaboration with CDC and the relevant national organizations. This will be developed further for approval

at the April meeting.

- It was agreed that the second survey must focus on the individual child, the most pressing issue, which in turn will lead to the mother. Continuing work could then focus on the woman drinking. CSAT is likely to be very interested in a survey, for example, demonstrating that Pittsburgh has no referral site for a pregnant drinking woman. Since the surveys have to be specialized to their audience, this will be a large task. A workgroup could be formed to develop the Women's Survey between the second and third Task Force meetings. The managed care aspect should be included here. The services delivered may be less than described, and there is no incentive to bring the women in to service.
- The survey workgroups were urged not just to explore where services are provided but also some idea of their cost and who pays for them.
- CDC survey data indicate that more of FAS/FAE problems occur with the acculturation of immigrants, suggesting a separate focus on ethnic populations such as American Indians and Hispanics. Dr. Maresca noted that the 550 federally recognized tribes fall under state, regional, and federal authorities. It would be helpful to the tribes to sample smaller and larger tribal units (e.g., regions already having organized tribal health units), to indicate services in local communities as well as at the state level.

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Multi-level Collaborative Project: The Task Force's discussion of the aspects of work relating to this project centered around research issues, including the following:

- No single group in the U.S. offers an identified cohort large enough to devise and analyze questions about FAS in an expedient manner. A national collaborative FAS project is needed, with a multi-representative board to identify the research questions and protocols to be carried out. To make recommendations based on good science, control groups are needed. This suggests: 1) replicated research in smaller regional groups in a national collaboration; and 2) a national registry of children with FAS, since most do not live with their biological families. The IRPG provides regional centers for research.
 - FAE children are an important group, not surveyed, perhaps more interesting to research, and probably greater in number than those with FAS. But there are big differences between the two groups, and the science requires confirmed alcohol exposure.
- Ms. DeVries was unsure how willing families will be to be on a registry, just to again be a "specimen." But her organization could serve as a shield for them by providing blinded data from their database; and since they rarely request anything of their members, they are more likely to gain their cooperation. Ms. Mitchell also reported a NOFAS database of parents that holds ten years of information. ·
- The research agenda should be developed by both researchers and parents, such as by the disparate membership of an advisory board and pursuant to what is discovered. Parents unable to respond due to lacking financial resources may have to be sought out.
 - It was agreed that, while trying to establish a national research agenda by a national coalition for FAS is a good idea, a national registry of FAS/FAE should take precedent. What also needs to be determined before action can be taken is how it would be implemented (e.g., an NIAAA IRPG; a multi-Institute collaborative effort; Congressional funding?).
 - The issues of families, who want most to know how to synthesize research information into practical daily application, must be addressed. The workgroup's mission statement must be clear from the beginning that its goal is to improve the lot of these children and their families.
 - In a related vein, it must be ensured that any "advocate group representative" called upon to advise and participate is in fact truly representative.
 - The direct value to the child will be to survey the available services, find a way to match people to them, and to try to improve services. A psychosocial study also could examine curricula and develop one that best addresses these children's needs.
 - While all that has value, it was agreed that a better job of providing services for people immediately is important. A broad based research agenda is needed. Registries, although difficult to implement and maintain, could be the missing mechanism to link the needed information to the providers and the children. Perhaps the

Center could offer that focus, or the March of Dimes (toll free 888-modimes) could be a conduit to the Center for the public without access to the Web.

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Funding: Whatever is done will require funds, and the Task Force members' work to encourage the funding needed to make this all possible. Hopefully, its having been considered sufficiently important to legislate its existence suggests that its recommendations will be taken seriously. The members agreed that a multi-level collaboration at the national level will be required, ranging from basic science to the transfer of experiential knowledge to practice. The immediate question is whether/how to do the latter, and how to generate new knowledge. Who should do this need not be addressed yet; only to describe what is desired.

Dr. Charness suggested forming another workgroup, and volunteered for it, to recommend for the Task Force's consideration at the next meeting about different potential formats for this multilevel collaboration, as well as estimates of its potential cost. The Task Force could use that information to recommend one small project to begin its work.

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Workgroup Membership Formation Ms. Granoff specified that workgroups are defined as two or more parent committee members who conduct short-term work to analyze information and report/recommend on it to the full committee. Consultants are welcome. Then, on Dr. Floyd's suggestion, the workgroups formed as follows:

Broad-based Campaign Workgroup: This workgroup will develop plans to implement the second half of the Task Force's recommended FAS awareness campaign focusing on healthcare providers. Coordinator: Robinson. Members: Mitchell, Garcia, Maresca, Floyd, Charness, Fleming. Consultants: Peggy Murray, Deidra Roach, Ann Waller, Barbara Wybrecht, Karla Damus, Robert Sokol. Subgroup: Provider Education Workgroup. Member: Schad

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National Visibility/Public Awareness Workgroup: This workgroup will develop plans for the first half of the awareness campaign recommendation. Coordinator: DeVries. Members: Mitchell, Day, Riley. Consultants: Damus, Waller, Wybrecht. Subgroup:

Conferences and Presentations Workgroup. The estimated time frames agreed upon were as follows: develop agenda (January); develop a basic plan (by end of February); committee members to respond (month of March). Circulation of documents for review by e-mail and then approval in April was suggested. Informal straw polls can check for agreement on the workgroup document's content; if not, a conference call could be held at the beginning of April. The workgroup's findings will be presented at the meeting.

Further subgroup:

RSA Conference Workgroup. Time being of the essence, with February deadlines, this workgroup was endorsed by the committee. The development time frame is by the end of December. Coordinator: Day. Members: Charness, DeVries, Calhoun. Consultant: Sokol, Damus (regarding March of Dimes funding). Dr. Damus will also work with the subgroup to consider activity for the next APHA conference, which may issue a resolution on FAS at the next meeting.

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Survey Workgroup (focusing on the child, with treatment services for women to be addressed subsequently. Ms. Baker volunteered as a consultant for the latter group when it is formed. The time line calls for a draft survey/plan to be submitted at the April meeting. Between the second and third meeting, a workgroup on mothers at risk will be formed. Coordinator: Riley. Members: Floyd, DeVries, Garcia. Consultants: Wigren, Bertrand, Cohen, McKinney

Further Subgroup:

Special Needs/Populations, Native Populations: Members: Maresca, Schad. §

Potential Sub-group: Managed Care Workgroup

Multi-level Collaborations Workgroup: Recommendations will be presented to the Task Force in April on potential formats for these collaborations, and their estimated cost. Coordinator: Charness. Members: Schad, Calhoun, Riley, Cohen, Mitchell, Day Coles, DeVries. Consultants: Damus, Boyle, Roach

Dr. Riley asked the workgroup coordinators to keep him and Dr. Floyd informed of their activity.

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New Business: The members listed other areas which the Task Force might address:

- DeVries: investigate adoption and foster care, the sites of many children with FAS. · Mitchell: develop a mission statement; discuss investigating stigma more deeply than just in education, public awareness, etc.
- Garcia: primary prevention. · Coles: involvement of other agencies in FAS work (DoE, DoJ, Administration on Developmental Disabilities, etc.) to collaborate with this Task Force; very early identification to prevent family breakup, or FAS itself, as well as intervening with the children).
- Wybrecht: Antonia Rathbun has a project related to the services needed by families with children with FAS.
- DeVries: explore generational FAS (looking up line from a baby with FAS, since a woman who has FAS is at highest risk of producing children with FAS).
- Day: discuss the name "FAS" in view of the need to address adults with FAS. Explore a diagnostic code for FAS.

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Closing Comments

Discussion of FAS as a Category. Dr. Riley anticipated that, in addition to reviewing what was accomplished at this meeting, the Task Force mission will be discussed at the next meeting. While each workgroup will have to address FAE as well as FAS, as required by the law, he expected there would likely be greater acceptance of recommendations regarding FAS than for FAE. He requested input on how to address the issue, when even professional groups are hard to convince that FAE effects may exist independent of FAS. Early identification should be not only for children but also for adults that were exposed as children. This could be a topic for the National Visibility/Public Awareness Workgroup.

General discussion questioned whether FAS/FAE are the appropriate categories. FAS is listed in ICD-9 under "exposures to noxious substances and alcohol;" but is not in the DSM, and causality has never been established for FAE. It was commented further that FAE diagnosis is moot for a child exposed to alcohol in pregnancy, only becoming an issue at age 4-5 when IQ and other disabilities become clear. But that fact invites reporting of each child exposed in pregnancy, which then invites the establishment of a threshold, which then truly invades privacy. Stigmatizing a person who drank a little should be avoided. Ms. DeVries commented that it has taken ten years of work to get the media to use the acronym; changing it would be difficult. Although many still do not know what it is, Dr. Schad thought that having convinced people that FAS/FAE is important mandated sticking with that name.

Dr. Robinson paralleled this with the situation of neuro fibromatosis, which John Merrick (the "Elephant Man") was thought to have, and brought it to the general public's attention. The names FAE, ARND, etc., dignify a group of conditions without much associated data, a situation grappled with by the research community as well as families. While he blessed Congress for trying to address it by mandating funding to address those with "FAE," which has no diagnosis, he affirmed that the functional relationships of these conditions must be delineated. Ms. DeVries hoped to do that by proposing a DSM code, but Dr. Floyd reported that such categorizations take years to accomplish. Congress attempted to acknowledge that there are other aspects that are · attributable to alcohol exposure. The IOM report itself cites alcohol exposure effects, ARND and ARBD.

DSM Implications. Dr. Coles advised caution and a good look at the ramifications of a DSM code before proceeding, warning that the worst diagnosis for insurance reimbursement is still a mental health code. She preferred sticking with an ICD code if data indicate FAS/FAE to be neurologically based. Nonetheless, despite the complexity of addressing DSM, Dr. Day urged that this be kept on the Task Force's list. Something must be done on the adult level to make this condition diagnosable and therefore reimbursable.

FAS/FAE Interventions. Ms. Wybrecht asked if any data exist to demonstrate successful FAS/FAE prevention programs. Members responded that this depends on the outcomes; for example, it is proven that adolescent awareness can be raised, but not that behavior is necessarily changed. Older studies exist as well as 10-15 projects underway. She was referred to the Technology Transfer Center Website, which lists potentially helpful programs and technology.

Dr. Floyd thanked the attendees for their work, which was impressive, at this inaugural meeting of the FAS/FAE Task Force, and with no further comment, the meeting adjourned at 12:32 p.m.

Photo of signatures from FAS National Task Force Meeting

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Attachments:

Identified Priorities for the National Task Force on Fetal Alcohol Syndrome/Fetal Alcohol Effect

1. Develop recommendations and strategies for improving the diagnosis of FAS/FAE by:

- Specifying the full clinical spectrum of FAS and FAE including the neurocognitive phenotype
- proposing research methodologies to enhance FAS diagnosis · endorsing and supporting continued surveillance of FAS/FAE
- enhancing education of professionals who will impact families and individuals dealing with fetal alcohol exposure

2. Identify and recommend interventions for high risk women by:

- developing policy statements defining who is at risk for an alcohol-exposed pregnancy and making recommendations for screening and treatment procedures
- developing recommendations for improving provider education in screening, detection and intervention with high-risk women
- facilitating coordination of prevention strategies among agencies, programs, professional and advocacy organizations, as well as business and trade organizations (i.e. HMOs)

3. Specify Critical Services Needed by Persons with FAS and their Families by:

- making recommendations for identifying and evaluation promising treatment methods for interventions across the life span
- identifying federal guidelines that support comprehensive treatment for individuals and their families

4. Enhance Public Education and Awareness of FAS/FAE by:

- making recommendations for developing consistent public health messages to be used in public awareness efforts aimed at reducing prenatal alcohol exposure (including needed resources)
- promoting coordination between all federal, state, local, nonprofit, tribal, professional, and business partners to endorse consensus regarding supporting science and appropriate messages

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This page was last reviewed on Friday October 02, 2009.