

**Department of Health and Human Services (DHHS)
Centers for Disease Control and Prevention (CDC)
National Center on Birth Defects and Developmental Disabilities (NCBDDD)**

National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect

**March 13-14, 2003
Atlanta, Georgia**

Summary Report

The National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect convened at the Doubletree Hotel in Atlanta/Buckhead, Georgia on March 13-14, 2003. The following members were present at the National Task Force on FAS/FAE meeting:

Task Force Members Present: Edward P. Riley, PhD, Chair (Director, Center for Behavioral Teratology, San Diego State University); Michael E. Charness, MD (Chief, Neurology Services, Harvard Medical School); Claire D. Coles, PhD (Department of Psychiatry and Behavioral Sciences, Emory University); Nancy L. Day, PhD (Professor of Psychiatry and Epidemiology, University of Pittsburgh); Jocie C. Devries (Founder and Executive Director FAS Family Resource Institute, Lynnwood Washington); Fred W. Garcia (Chief, Program Services, Washington State Division of Alcohol and Substance Abuse); Kathleen T. Mitchell (Program Director and National Spokesperson, National Organization on Fetal Alcohol Syndrome); Luther K. Robinson, Jr., MD (Associate Professor of Pediatrics, State University of New York at Buffalo); Charles M. Schad, EdD (Educator, Retired); Faye B. Calhoun, DPA, MS (Associate Director for Collaborative Research Activities, National Institute for Alcohol Abuse and Alcoholism, NIH); Louise Floyd, DSN, RN (Acting Chief, FAS Prevention Office, National Center on Birth Defects and Developmental Disabilities, CDC). **Liaison Representatives Present:** Deborah E. Cohen, PhD (Director, Office for Prevention of Mental Retardation and Developmental Disabilities, Department of Human Services); Fredericka Wolman for Karla Damus, RN, PhD (March of Dimes); George A. Hacker, JD (Director, Alcohol Policies Project, Center for Science in the Public Interest). **Executive Secretary:** José F. Cordero, MD, MPH (Director, National Center on Birth Defects and Developmental Disabilities, CDC). **Designated Federal Officer:** Louise Floyd, DSN, RN (Team Leader, FAS Prevention Team, National Center on Birth Defects and Developmental Disabilities, CDC). **Committee Management Specialist:** Jacqueline Vowell (FAS Prevention Team, National Center on Birth Defects and Developmental Disabilities, CDC). **Other Participants:** Connie Granoff, Elizabeth Parra, MPH, Tanya Sharpe, PhD, MS Jasjeet Sidhu, MD, MPH, Jorge Rosenthal, PhD, Martha Alexander, MPH, Jacquelyn Bertrand, PhD, Melissa Hogan, Mary Kate Weber, MPH (FAS Prevention Team, National Center on Birth Defects and Developmental Disabilities, CDC); Robert Levine, MD (Meharry Medical College); Ben Wheat (Federal Bureau of Prisons, U.S. Department of Justice); Beth Weinman (Federal Bureau of Prisons, U.S. Department of Justice); Susan Aduato, PhD (University of Medicine and Dentistry of New Jersey); Jocelynn Cook (Health Canada); Judith Thierry (Indian Health Service); Callie B. Gass (FAS Center for Excellence, SAMHSA); Maggie Ulione (St. Louis University); Georgia A. Gore (FAS Family Resource Institute); Ken Warren (NIAAA, NIH); Yvonne W. Fry, MD (Morehouse School of Medicine); Mari Stephens (March of Dimes, Georgia Chapter); Sarah Horton Bobo (Michigan FAS Workgroup); Kristin Clark Jones (Cambridge Communications).

March 13, 2003

Call to Order: Introductions, Announcements, and Opening Remarks

*Dr. Edward P. Riley, Chair
Director, Center for Behavioral Teratology
San Diego State University*

*Dr. José F. Cordero, Executive Secretary
Director, National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention (CDC)*

Dr. Riley called the meeting to order at 8:38 a.m. on Thursday, March 13, 2003. He welcomed everyone in attendance. Introductions were made by Task Force members, liaisons, and members of the audience. Those present are noted on page 1 of this document.

Dr. Cordero thanked Dr. Dixie Snider who served as Executive Secretary since September of 2001. CDC is going through some major changes in the Office of the Director, and Dr. Snider, Associate Director for Science, has become involved in a number of key issues and committees. There has been a tremendous amount of progress made in the area of Fetal Alcohol Syndrome (FAS). This year marks the 30th anniversary of the recognition of FAS in North America. It is time to put forth a major effort to prevent FAS. Dr. Cordero stressed that there has been a 30% reduction rate in spina bifida cases in the U.S., and now it is time to measure the impact of the reduction in FAS.

Dr. Cordero stated that all of the elements are present to develop effective prevention programs for FAS. The research indicates that alcohol use during pregnancy can result in FAS, and there is also quite a bit of research related to prevention and intervention. Great progress has been made in the past 30 years, and there is now an infrastructure for education. Similarly, one of the challenges is the importance of access to care and services. There also needs to be a way of monitoring the progress that is being made. The right policies and financing are also essential and the level of financing that is available today for FAS, compared to 10 years ago, is substantial. The combination of research, training and education, prevention services, monitoring, policy development, and financing will lead to health and wellness for both women of childbearing age and individuals affected by prenatal alcohol exposure. Fitting the pieces of the puzzle together is the challenge facing us.

**Update from the NCBDDD Scientific Working
Group on Diagnostic Guidelines for FAS and ARND**

***Louise Floyd, D.S.N., R.N.
Behavioral Scientist
Acting Chief, FAS Prevention Office***

Dr. Floyd outlined the events that led up to development of the screening and diagnostic criteria for FAS, which include the following:

- CDC received a Congressional mandate to develop guidelines for the diagnosis of FAS and other negative birth outcomes resulting from prenatal exposure to alcohol; to incorporate these guidelines into curricula for medical and allied health students and practitioners, and seek to have them fully recognized by professional organizations and accrediting boards; to disseminate curricula to and provide training for medical and allied health students and practitioners regarding guidelines; and to coordinate these efforts with the National Task Force on FAS and with existing federally funded FAS prevention programs and appropriate non-governmental organizations.
- An internal working group was convened at CDC on May 29, 2002 to develop a preliminary plan for responding to the mandate. CDC identified and invited external partners to join the Scientific Working Group (SWG) and the first meeting of SWG was on July 12, 2002 in Atlanta.
- At that meeting, four sub-groups were created: FAS Screening and Diagnosis; ARND Screening and Diagnosis; Essential Services for Children with FAS/ARND; and Identifying and Intervening with Women at Risk for an Alcohol-Exposed Pregnancy. The sub-groups met in the afternoon and began deliberations related to the guidelines in the respective topic areas.
- A second meeting of two of the SWG sub-groups occurred September 20, 2002 in conjunction with the National Task Force meeting. The FAS Screening and Diagnostic Sub-group and the Essential Services Sub-group met to further deliberate on their recommendations. The recommendations from these two sub-groups were presented to the Task Force for review and input. The component of the criteria for FAS screening and diagnosis that presented the most difficulty to the FAS Screening and Diagnosis Sub-group was the Central Nervous System/Neurobehavioral component. This group felt that the ARND Screening and Diagnosis Sub-group were most qualified to develop that particular component of the criteria.

- The ARND Screening and Diagnosis Sub-group was unable to arrange a meeting but a poll of the experts was conducted to identify the CNS/neurobehavioral domains most affected by prenatal alcohol exposure. Results were incorporated into the FAS Screening and Diagnosis Guideline within the Central Nervous System and Neurobehavioral Disorders component. These will be presented at the Task Force meeting today for review and input.
- The third meeting of the FAS Screening and Diagnosis Sub-group was teleconferenced on March 11, 2003 and the FAS Screening/Referral and Diagnostic Guidelines were reviewed and revised.
- The third draft of the FAS Screening/Referral and Diagnostic Guidelines will be presented this morning for Task Force review and recommendations.
- In the initial pre-planning for the SWG, it was recommended that CDC engage a few consultants to assist in this process. A technical writer will work with CDC staff to prepare a full report which will include the guidelines, the process used to develop the guidelines, the scientific basis for the guidelines and criteria, the essential services needed by those diagnosed, identifying and intervening with high risk women, and a section on the ongoing work needed to establish additional criteria for conditions that are part of the spectrum of disorders resulting from prenatal alcohol exposure. Another consultant, a pediatrician from the National Initiative for Children's Healthcare Quality, will assist in the development of a toolkit and in the dissemination of the materials to medical students and health practitioners.

Next steps include the following:

- Incorporate Task Force recommendations into the FAS Screening/Referral and Diagnostic Guidelines.
- Assess the need for additional meetings of any of the Sub-groups in order to prepare recommendations for the final report.
- Prepare the full report as described above.
- Prepare a tool kit to accompany the screening/referral and diagnostic guidelines that includes checklists and resource guides that identify diagnostic referral options.
- Secure endorsement of the report and recommendations from Task Force and major partners in the endeavor.
- Provide the report and recommendations to the FAS Regional Training Centers for implementation and dissemination.

Review of the Guidelines

***Dr. Edward P. Riley and Dr. Luther K. Robinson, Jr. with
Drs. Jacquelyn Bertrand, Claire Coles, Louise Floyd, and Kenneth Warren***

**Note: The guidelines discussed are in draft form for Review - Not Citation (rev. 3/12/03).
Portions of the actual text of the draft guidelines are designated below in *Italics*.**

Dr. Riley indicated that the process referred to in the Guidelines is a two-stage process; a referral process and a diagnostic process. These stages should not be confused with each other, which occasionally happens.

Dr. Robinson stated that in terms of referral, what is important is capturing the concern of the primary care providers as it relates to recognizing the person who is at risk of having FAS. FAS is a disorder that is characterized by alterations in morphology after a baby has been exposed to substantial amounts of alcohol before birth. Maternal alcohol exposure is a significant part of that; however, the guidelines focus on morphology. The child who has a phenotype that is reminiscent of FAS should be referred for evaluation by someone with the requisite training and experience in diagnosis of FAS. The FAS phenotype is characterized by facial differences that include the eyes, nose, upper lip, and if a child displays any type of growth deficit.

Dr. Robinson reviewed criteria numbers one (face), two (growth), and four (maternal alcohol use) for **initiating a referral for FAS diagnostic evaluation**. Drs. Bertrand and Coles presented the CNS/Neurobehavioral criteria.

1) Face:

Based on racial norms, presence of one or more characteristic facial features:

- *Smooth philtrum (lip-philtrum guide)*
- *Thin vermilion (lip-philtrum guide)*
- *Short palpebral fissures (\leq 10th percentile)**

*Note: * It is very difficult to measure palpebral fissures length (PFL) accurately. See Recommended Method in Appendix X.*

2) Growth:

Prenatal or postnatal height and/or weight \leq 10th percentile documented at any one point in time (adjusted for age, gender, gestational age, and race/ethnicity).

Note: examiner should make sure point in time of growth deficit does not correlate with a point in time when the child was nutritionally deprived.

3) Central Nervous System or Neurobehavioral Disorders:

Prenatal and early brain damage is usually very generalized, rather than specific, to individual regions of the brain and their functions. Therefore, the functional abilities affected by prenatal exposure to alcohol vary greatly across children, depending on amount of alcohol exposure, timing of exposure, and pattern of exposure (e.g., chronic exposure versus binge episodes). Central Nervous System abnormalities may result in structural and/or functional problems. Structural problems include diminished overall head circumferences (OFC) \leq 10th percentile or brain abnormalities observable through imaging techniques (generally not available at initial appointments). Functional problems include cognitive deficits or developmental delay, deficits in fine and gross motor functioning, attention and hyperactivity problems, social skills deficits, poor organization and planning, academic performance problems in school-age children, and mental health issues.

The referral criteria for the CNS/Neurobehavioral component represent a very broad description of problems and deficits a clinician is likely to see. It is laid out in a very general way and takes into account parental report. The basic framework outlined in the Institute of Medicine (IOM) report was maintained by the ARND Working Group. In July, the ARND Working Group felt that a more thorough discussion of the issues related to CNS/neurobehavior was needed. The Working Group decided to conduct a survey of clinicians and researchers who specialize in neurobehavioral issues, and who have contact with families and children with FAS. They were polled to find out what behavioral domains they encountered most frequently. Twenty-two clinicians were surveyed, and their responses were synthesized. The clinicians were asked to list the five areas of deficit they considered most important for diagnosis of FAS or related disorders. In addition, the clinicians were also asked to list 3-5 specific behaviors that could be used as examples of each of the five areas of deficit.

Although there are many areas of vulnerability, there were five domains that were consistently identified by clinicians and clinical researchers. Examples within each domain are not exclusive:

- *Cognitive deficits or developmental delay:* includes delay of milestones, low I.Q. scores, learning disabilities, math deficits, discrepancies between verbal and non-verbal skills, uneven profile of cognitive abilities, and poor academic achievement.
- *Executive functioning deficits:* includes poor organization or planning, poor strategy use, lack of inhibition, difficulty following multi-step directions, difficulty changing strategies, difficulty thinking of things in a different way.
- *Motor functioning delays or deficits:* includes difficulty writing or drawing, clumsiness, tremors, and poor dexterity.
- *Attention and hyperactivity problems:* includes inattentiveness, easily distracted, difficulty calming down, overly active, overly reactive, and difficulty completing tasks or staying on task.

- *Inappropriate social skills:* includes lack of stranger fear, naiveté, often scapegoated, gullibility, easily taken advantage of, inappropriate choice of friends, preferring younger friends, superficial interactions, difficulty understanding the perspective of others, and inappropriate initiations or interactions.
- *Miscellaneous problems:* in addition to these five most often cited problem areas, deficits and problems can present in several other areas, including: sensory problems, pragmatic language problems, memory deficits, and/or difficulty responding appropriately to common parenting practices.
- *Mental health problems:* difficulty in any of these areas can lead to mental health problems with life-long consequences. The primary mental health problems include conduct disorders, anxiety disorders, adjustment disorders, and depression.

Those five criteria were then generalized and broadened. In the Guidelines, when one is in the diagnosis phase, these areas should be assessed by a qualified professional using appropriate standardized instruments. Also important is that meeting one of these criteria is not enough for diagnosis.

4) Maternal Alcohol Exposure:

- *Confirmed prenatal exposure requires documentation of the alcohol consumption patterns of the birth mother during the index pregnancy based on clinical observation, self-report, reports of heavy prenatal alcohol use by a reliable informant, or medical records documenting positive blood alcohol levels, alcohol treatment, or other social, legal, or medical problems related to drinking during the index pregnancy.*
- *Unknown prenatal alcohol exposure indicates that there is neither confirmed presence nor confirmed absence of exposure. Examples include: the child is adopted and prenatal exposure (s) are unknown; birth mother is an alcoholic, but confirmed evidence of exposure during pregnancy does not exist; conflicting reports about exposure exist that cannot be reliably resolved.*

When to Refer for Evaluation of Possible FAS Diagnosis:

Referral should be made in the following instances, with or without maternal alcohol exposure, though maternal alcohol exposure, when present, strengthens the evidence for referral:

- *When all three facial features are present.*
- *When one or more facial features are present along with growth deficits in height and/or weight.*

- *When one or more facial features are present, along with one or more central nervous system or neurobehavioral deficits.*
- *When one or more facial features are present, along with growth deficits and one or more central nervous system or neurobehavioral deficits.*

Depending on the resources in the community, referral could be made to a developmental pediatrician, a FAS clinic, a genetics clinic, or another provider specialist.

Other Considerations for Follow-up:

- *If the child has growth deficits and one or more structural or neurobehavioral deficits, and there is no information on alcohol exposure, referral may be appropriate according to clinician's judgement.*
- *If prenatal alcohol exposure in the high risk range is known (7 or more drinks per week or 4 or more drinks on one occasion) in the absence of any other positive screening criteria, the primary health care provider should document this exposure and closely monitor the child's ongoing growth and development.*

Discussion Points:

- ~ Dr. Robinson stated that the time to refer was largely based on when a clinician suspected that a child was affected, certainly if the patient had a face reminiscent of FAS, whether or not there is prenatal exposure. Concerning referral, the facial phenotype is most heavily weighted for evaluation. Certainly, other combinations such as growth and developmental disabilities are taken into consideration as well.
- ~ It was noted that it is very clear that many individuals get referred for FAS diagnosis because of their facial features. Yet other partners in this evaluation process are physicians who care for women, family care physicians, internists, and obstetricians, to name a few. Psychologists are an important part of the referral process. The referral process is an outgrowth of the IOM criteria, in which a diagnosis of FAS is made in the context of meeting the three criteria. The referral guidelines impact all physicians who care for patients who are concerned about the matter of prenatal alcohol exposure and its consequences.
- ~ Dr. Riley suggested a recommendation concerning the CNS involvement piece (criterion number three). The language needs to be changed. As it now reads, the overall circumference with less than 10% is indicative of a structural problem, or CNS damage. It was noted that 10% of the general population has an OFC abnormality. The wording should be changed to indicate that this factor *may* be indicative of some CNS involvement. Dr. Riley also stated that the clinicians involved were not going to spend a tremendous amount of time in filling out checklists. He also asked what other areas of CNS involvement were not on the list. It was suggested that the details listed under some of the headings were not inclusive, and it may be difficult for a pediatrician to

realistically examine all of the details in a 10-minute time period. This may create a sense of artificial specificity that does not really exist in this context.

- ~ Noted was that there was consistency in the responses received from the 22 clinicians surveyed in terms of the major behavioral domains seen. For screening situations, checklists and other tools are not stand-alone documents. They do require some training and exposure, and that is one issue that needs to be made clear. It was suggested that the examples within each domain could include “but are not limited to.” It was also suggested to develop age-related criterion associated with the examples given.
- ~ Dr. Cordero stated that the common denominator is early recognition of children who have either FAS or other developmental disorders that need attention. The concern is how one integrates the screening/referral guidelines in the context of a very busy pediatric practice. The pediatrician might have only 10 minutes to spend with a child. Dr. Floyd recommended that it is possible that other office staff member (such as a nurse) could be integrated into the screening/referral process.
- ~ It was suggested that studies need to be completed concerning the number of children who were being referred into the system. Dr. Wolman stated that what happens downstream is very important. Dr. Cordero stressed the importance of connecting the referral or diagnosis to available services. One without the other will not work. The feedback loop of the referring physician back to the specialist is critical.
- ~ Ms. Devries recommended incorporating developmental screening for milestones in with screening for FAS. There are certain ages at which milestones are assessed, such as certain motor skills present at a particular age. She pointed out that it does not seem as though the guidelines were created with family input. The families are frustrated that the clinicians cannot recognize FAS, and yet it appears that input was not asked for by families who are actually affected by FAS. It seems that their frustrations are not reflected.
- ~ Dr. Floyd stated that part of the charge is to educate physicians and allied health professionals, and to raise awareness about FAS. In terms of getting parental input, Kathy Mitchell was a part of the Working Group as well as Deborah Cohen. The Working Group is open to hearing additional recommendations. Dr. Cordero reinforced the idea that whatever is done will include parents. Ms. Mitchell stressed the importance of training the practitioners to include the neurobehavioral aspects and facial effects of the child along with the social affects on the family when alcoholism is present.
- ~ Dr. Cohen suggested that many high-risk women were in Medicaid managed health care, and considering implementation within the Medicaid system needs to be included. In New Jersey, there are FAS diagnostic centers, and many of the children coming to the centers are in the foster care system. In terms of service systems, many children are in the system in one way or another.

- ~ Dr. Schad commended the accuracy of the screening/referral guidelines. However, in South Dakota, there are nine Indian reservations. One community is 350 miles from the closest facility where an individual can actually get a diagnosis, which includes three or four days of travel. These youngsters need to be reached. Dr. Floyd stated that the FAS Regional Training Centers have been funded to provide training to prepare people to recognize and diagnose, and until they are trained, there are not a lot of people able to do it.
- ~ Dr. Floyd stated that CDC would be happy to convene a teleconference for parents to give their input. Ms. Devries stated that she was still reserving the right to push for a meeting on this issue. If members of family advocacy groups are going to be behind this, they need to be included in the input. Dr. Riley stated that some mechanism to allow input from parents on the CNS component would be arranged.
- ~ There were no comments made concerning the maternal alcohol exposure section.
- ~ Ms. Mitchell pointed out that families who are in crisis and have been affected by alcoholism, oftentimes show signs that are observable by clinicians. The clinician notices that something is just not right in the family. Dr. Riley asked the committee if a third category should be added to cover the “unknown” in the screening/referral section of the Guideline. Many panel members did not agree to adding a third category. Dr. Floyd stated that at the referral level, referrals can be made “with or without maternal alcohol exposure.”
- ~ Noted was that CDC has been working with consultants to develop checklists that will mirror the referral and diagnostic guidelines. These are works in progress and are not ready for dissemination.
- ~ Dr. Day inquired as to why all three of the facial characteristics must be present for diagnosis. Requiring that a child has all three is not very logical, and the CNS deficits are so generic, they are not useful as a diagnostic tool. Dr. Robinson stated that the facial characteristics are present in 90% of all FAS cases, and it is a good starting point, although it is true that some children are only mildly affected. Some questions to raise are: What are the most minimal manifestations of FAS? What are the boundaries of FASD? There are patients that do have milder manifestations and are considered to have partial FAS. They still fall within the spectrum of FAS, and the phenotype is different. There is a tight phenotype and functional relationship. However, if FAS is diagnosed there will be neurobehavioral issues present as well. Dr. Calhoun added that this is why there is FASD. FASD goes from two of those criteria to no facial characteristics, and is a spectrum of disorders. The criteria for FAS should be left the way it is, and diagnosis should be restricted.
- ~ Dr. Riley asked the group if there was agreement that all three characteristics must be present. All agreed, although Dr. Day stated that this is not how it is done in practice.

- ~ Dr. Robinson pointed out that clinicians are reluctant to recognize FAS, because the diagnosis is charged with identifying a woman's behavior that clinicians do not want to confront. Surveillance data in Dr. Robinson's state suggests that the prevalence rates are very different in two closely located counties. One county has a categorical program and the neighboring county chooses to treat the symptoms.
- ~ A comment was raised about the FAS diagnosis relating to services. Services are directly related to the diagnosis. Currently, to receive services, a child must have a full FAS diagnosis.
- ~ Dr. Schad expressed concern that the focus was shifting, and that it will take years to change the way people think about FAS. The terms of diagnostic criteria for FAS have been relaxed. Until it is known what the behavioral phenotype looks like, which is related to diagnosing FAS, services must be provided specific to FAS. Noted was that a clinician may feel very strongly that a child has been exposed to alcohol prenatally, but they may not have all of the symptoms. Without the diagnosis of FAS, a child will receive no services. This is a hard decision for a clinician to make.
- ~ Dr. Garcia recognized that part of the education is to help clinicians connect the dots. Most of the referrals will more than likely come from school psychologists, child protective workers, and from alcohol and drug treatment facilities. The primary reason for the child being there is the CNS/Neurobehavioral functional criteria outlined in the guidelines.
- ~ Dr. Robinson stated that the physicians do not recognize the phenotypical neurobehavioral characteristics in infants or small children. A child that does not have the characteristic facial abnormalities, may not present a problem to the clinician until they are failing first grade.

Motion:

Dr. Riley proposed a motion that the *Recommendations on When to Refer and Diagnostic Criteria for FAS* be voted on (with the changes noted by the Task Force above). All were in favor of the motion. The motion passed unanimously.

This concluded the Guidelines review and discussion.

Recommendation from Health Canada's FAS Advisory Committee

Dr. Jocelynn L. Cook, Ph.D., M.B.A.
Senior Program Consultant
Health Canada, FAS/FAE Team
Division of Childhood and Adolescence

Dr. Cook provided an update on the progress of Canada's National Advisory Committee on screening and diagnosis of FAS. The Committee is comprised of clinicians, psychologists, physicians, community workers, occupational therapists, birth moms, and foster moms. There are three Subcommittees. Dr. Cook is a Sub-chair of the Screening, Diagnosis, and Surveillance Subcommittee. The National Advisory Committee has met six times, and has decided to enlist the help of experts in the field from the diagnostic centers across Canada to participate in and offer their recommendations and advice. The Committee has made draft recommendations about terminology and the use of the term "Fetal Alcohol Spectrum Disorder (FASD)." The Committee has also discussed diagnosis as it relates to facial abnormalities and growth, the necessity of linking diagnosis to the provision of services, the need for validated screening tools for prenatal alcohol exposure, and research needs and priorities as they relate to diagnosis.

The Committee believes that there is no truly reliable screening tool with demonstrated validity and specificity to predict prenatal alcohol exposure in children, adolescents, and adults. There are well-validated screening tools to predict problem alcohol use in pregnant women. Screening for FAS is different than screening for alcohol use during pregnancy and screening for high risk exposure. Also, they acknowledge that screening cannot be equated with diagnosis. The purpose of screening is to refer to diagnostic clinics. However, there must be clinics and services available to meet the need for referral. There are presently 11 diagnostic clinics in Canada, some of which have an 8-month waiting list. Hence, Canada's capacity is not where it needs to be.

Regarding diagnosis of FAS, assessment of FAS features may be confounded by co-occurring genetic or environmental/teratogenic conditions. In some situations, there may be two or more etiologic diagnoses. Diagnosis must be linked to availability of resources and services that will improve outcome for affected individuals and their families. Diagnosis should not be avoided or denied in the absence of services. Reporting is important, and gathering maternal information about drinking is key. Situations where maternal history is unknown or is of questionable reliability must still be addressed. Diagnosis should occur as soon as the individual presents; an early diagnosis is best.

Research needed includes:

- Retrospective and longitudinal studies of age-dependent changes in facial measurements (facial dysmorphology);
- Facial, growth, psychological, speech pathology, etc. data with FASD diagnoses and norms;
- Age, gender, and age-specific norms; and

- Develop, use, and validate a screening tool linking to diagnosis which is adaptable for use in different age groups and in different populations.

The Committee also recommends a multi-disciplinary team for diagnosis. The team can be geographical, regional, or even virtual. People on the team should be “value added.” The core team should consist of a coordinator or case manager (could be a nurse or social worker), a dysmorphologist (if possible), a psychiatrist, a specially trained physician (i.e., pediatrician or developmentalist), and a psychologist (speech and language should be tested).

The Committee recognized that there could be additions to the diagnostic team including mental health workers, follow-up case workers, addiction counselors, social workers, employment coaches, cultural interpreters, parole officers, and educators. In terms of the diagnosis of FAS, the Subcommittee suggests that growth should be based on the IOM criteria of ≤ 10 th percentile, using appropriate norms and taking into consideration other confounding variables including parental size/genetic potential, and medical conditions (i.e., gestational diabetes). Adults presenting with normal growth parameters should not be excluded from FASD-related diagnoses in the absence of early growth data. There is a major concern about diagnosis of adults in Canada.

In terms of facial characteristics, there are discriminating features that can readily be observed and measured. Where standards can be established are short palpebral fissures and abnormalities in the premaxillary zone (smooth/flat philtrum, and smooth upper lip). Some sentinel features (i.e., upper lip or philtrum) may be lost as discriminating features with age. Other associated physical features include abnormalities of the mid-face/maxillary area, mandible, ears, and nose. These findings should be recorded, but do not necessarily contribute directly to the diagnosis.

In terms of brain abnormalities, all tests should go from simple to complex. The findings need to be able to stand alone, and to be reproducible. Other factors must be considered such as the DSM diagnosis, life adaptations, and mood. There should also be a guideline for preschoolers. An ARND diagnosis should not be made until a child is older. It is recommended that two standard deviations below the mean should be the cut off for all tests. Three domains of impairment should be met for a diagnosis.

Particular attention is paid to receptive language, expressive language, social communication, verbal reasoning, and written language within the speech and language assessment. Concerning diagnosis of FAS and the adult/adolescent brain, secondary disabilities are very important to consider. Some could evolve to become domains used for testing for prenatal alcohol exposure (i.e., employment.) It is recommended to add a component around functional literacy and numeracy, to build quality of life issues into the assessment process, and to be aware of trends for gender differences. Abilities are often misinterpreted, so what is said must be corroborated.

Discussion Points:

- ~ Dr. Cordero commended Dr. Cook on all of Canada’s hard work to date. He asked if there were longitudinal studies of alcohol exposed children, in terms of mental

disabilities, that were not diagnosed as FAS. Dr. Cook responded that there are no studies as of yet. However, there should be more money appropriated soon. Education is key right now. There has not been a lot of talk about research given that more focus has been placed on the norms.

Dr. Floyd requested information on the list of neurobehavioral domains that are used in Canada and on the make-up of Canada's advisory group. Dr. Cook stated that under each of the suggested domains (sensory/motor/regulatory, attention, communication, intellectual, achievement, memory, executive functioning, adaptive/maladaptive/social) they will provide a list of appropriate tests. The clinicians can use the different domains to decide which one is appropriate to use to get at the impairment within that domain. It will be like a menu but not an exhaustive list, to avoid overwhelming those doing the evaluation. It needs to be doable. In terms of Committee make-up, it is comprised of experts in respected fields, and has about 20 members who were appointed by the Health Minister in Canada.

**Use of the term Fetal Alcohol Spectrum Disorders (FASD)
What is it? When is it appropriate to use it?**

The term FASD is often used to describe the continuum of conditions related to fetal exposure to alcohol. The problem appears to be that many people are using the term FASD in different ways. Some use it as an umbrella term. Others use it as a diagnostic term. It is important to understand how this term is being used to avoid confusion and misinterpretation. The Task Force deliberated on this issue.

Discussion Points:

Dr. Cordero indicated that Kieran O'Malley was the first person to use the term "FASD." In his first paper, it was used as an umbrella term to encompass FAS, recognizing that there is a range of outcomes. One must not necessarily have the face to have been exposed to alcohol prenatally.

The term "FASD" is used to acknowledge the fact that there is a wide range of disorders that result from prenatal alcohol exposure. Dr. Riley stated that the definition of this term needs to be unified. Dr. Floyd stated that there is concern about the term, and inconsistency across federal agencies regarding its definition and use. For example, it is being defined differently in printed materials. In writing, it has been defined in about three or four different ways.

Dr. Calhoun recommending keeping FAS as a separate diagnosis and giving the term FASD to all other prenatal alcohol related disorders.

Dr. Charness suggested putting FAS under FASD, along with other discreet conditions (yet to be defined) resulting from prenatal alcohol exposure.

- ~ Dr. Day stressed that it would be helpful to define FASD and stick to its correct usage. Because the diagnostic criteria are set so high, FASD needs to be defined precisely. It needs to be concluded that although some individuals only meet two of the criteria for an FAS diagnosis, they should still receive services because they have been affected by prenatal alcohol exposure. In terms of research criteria, it would also be helpful.
- ~ It was noted that “FASD” is very close to the IOM definition of “partial FAS.” Many in the field use the term “partial FAS;” however, a strict definition of FASD is in order. There is work to be done in this area, especially creating the scientific basis for use of the term. Many grantees use the term of their choice, which becomes very confusing. Most people affected do not have a textbook case of FAS. There are many determining factors such as dose and frequency that lead to different phenotypes of FASD. A partial FAS diagnosis is not as affirming to the child as an FAS diagnosis.
- ~ It was pointed out that one important issue is to assure that children who are affected get the services they need, with or without the typical FAS face. There are several arenas where these terms are used, and it would be immediately useful in the research arena. The utility of this is that researchers use a large number of definitions when they refer to effects that they produce in animals, with known exposure to alcohol. Under those controlled circumstances, it would make sense to encompass all of the terms under a single rubric. FAS is well-defined in humans, and in the clinical arena, it is not known what might have produced non-specific behavioral syndromes from other causes. FASD is used as a working definition by clinicians who encounter children when they know there has been prenatal ethanol exposure, but they are not sure what its contribution has been.
- ~ It was pointed out that from a clinical standpoint, there is another Venn diagram that would contain FAS within a broader section of FASD. Behavioral phenotypes need to be developed to go along with FASD. Dr. Cordero stated that an accurate research definition was needed, not only in the United States. There is also a need for a clinical definition. Many developmental problems are considered educational rather than medical, and the insurance companies then decide not to pay for services. The risk in producing an ICD code that describes everyone who has something that falls into the non-FAS part of FASD is that diagnostic precision is lost, and in the end, the ability to match people with different consequences of fetal alcohol exposure to appropriate treatment is difficult.
- ~ Dr. Day compared the different diagnoses in FAS and FASD and how this relates to diagnoses for autism. The diagnoses need to be linked to public health care systems, preserving the more concise diagnoses for areas where there is agreement. There are two goals, (1) how to make services available to children with disabilities due to alcohol exposure, and (2) how to most accurately diagnose the variants or the elements of FASD. Dr. Day diagramed her idea, and many in the group liked the way that she described how FAS should be a part of the umbrella term “FASD.”

- ~ At the end of the discussion period, there was no consensus on what the definition of FASD should be. Ms. Mitchell stated that using it as an umbrella term could be problematic because it would inevitably start being used as a diagnosis.
- ~ Dr. Riley suggested putting a working group together to address this issue and report back to the Task Force at the next meeting. Dr. Schad agreed to head this group and indicated that he would bring the findings back to the group.
- ~ It was suggested again to have a Medicaid representative present at the next meeting given that there are many relevant policy issues that need to be addressed.

FASD Definition and Recommendation Usage from Health Canada

Dr. Jocelynn Cook, Ph.D.
Senior Program Consultant
Health Canada, FAS/FAE Team
Division of Childhood and Adolescence

Dr. Cook reviewed Canada's use of the term "FASD." Presently there is a person on the Committee who would like to pluralize the term from "FASD" to "FASD(s)." Many parallels are being drawn to the autism evolution:

- "FASD" is an umbrella term that suggests that alcohol is a factor in a child's development and it should not be used as a diagnostic term. Clinicians may use the term FASD for the purposes of screening and referral that should lead to a more formal interdisciplinary diagnostic process using established definitions of FAS and related conditions.
- "FASD" cannot be used when it is known for sure that the mother did not drink alcohol during pregnancy. Parameters for use of the term outside the medical or clinical community also need to be developed. In the medical community, only people with a broader knowledge of FAS diagnostic terminology should use the term.

Thus far, these are the only recommendations in Canada that have been developed concerning the use of the term "FASD." This issue is still being discussed by the Committee. Dr. Cook recommended having a joint Working Group made up of representatives from Canada and the United States given that the groups are working on many of the same issues. Noted was that the Canadian Diagnosis Committee will be meeting again on May 25, 2003, in Ottawa.

**Discussion of the Request to the Surgeon General's Office to
Reissue the Federal Advisory Against Drinking During Pregnancy**

Dr. Kenneth Warren
National Institutes of Health (NIH)

A recommendation was made at the last Task Force meeting to propose that the Surgeon General reissue the original health advisory on FAS that was issued in May 1981. Dr. Warren presented a draft letter to the Surgeon General and updated advisory on the risks of drinking during pregnancy to the Task Force for comment. Prior to 1977, there were no public statements from any authority that alcohol was a risk factor in pregnancy. The Smith and Jones reports appeared in 1973 indicating the risk alcohol has on the developing fetus, but abstaining from alcohol during pregnancy clearly was not a common, medically-accepted practice at that time. When the first health advisory was issued in 1977, a lot of careful wording went into it to minimize what would be an adverse response from medical practitioners, particularly in the field of obstetrics and gynecology. Note that the alcohol drip was still being used predominantly during that time.

The first health advisory was very conservative, recommending drinking no more than two drinks per day, but warned against drinking more than six drinks a day. The events that followed the first health advisory led to hearings in Congress pertaining to the jurisdictional dispute over the labeling of alcoholic beverages between the Food and Drug Administration (FDA) and the Bureau of Alcohol Tobacco and Firearms (ATF). The outcome of that particular hearing was a recommendation to the Department of Treasury and the Department of Health and Human Services (DHHS) to prepare a joint report on the health hazards associated with alcohol use, with a special emphasis on pregnancy, and also the methods that should be used to inform the public of those risks. The report was written over the proceeding year and a half, and it was a state-of-the-art report on a host of adverse outcomes resulting from alcohol use and its use during pregnancy. Half of the document was specifically devoted to alcohol and pregnancy. The recommendation from that particular joint government committee was to have the Surgeon General issue a health advisory. The question to Congress from the committee was to raise the issue of bottle labeling, and whether it was appropriate. The report came out at the end of 1980, and in 1981, the Surgeon General issued a health advisory recommending abstinence from alcohol use during pregnancy. This was the first government recommendation from any nation in the world that promoted not drinking alcohol if pregnant or planning a pregnancy. This advisory was placed on alcoholic beverage labels in November 1989.

In terms of updating the advisory, Dr. Warren pointed out that the science has moved forward. In preparing the updated advisory, Dr. Warren used the 1981 advisory as a model. The advisory needs to be conveyed to the Surgeon General, and an appropriate method to do this is through the National Task Force. The Task Force is chartered by the DHHS Secretary to inform the Secretary and by doing so it also informs the Surgeon General. Using that approach, Dr. Warren prepared a draft letter, the intent of which was to convey information on the importance of reissuing the advisory. Dr. Warren requested input from the group on the draft letter and the updated advisory and reminded the group that this would be a Task Force document.

Discussion Points:

- ~ Dr. Floyd said it would be appropriate to call attention to the continued high levels of alcohol use by pregnant women despite progress made and recommended using recent CDC findings as support. Dr. Warren stated that this support was in the advisory as well as the letter.
- ~ Dr. Calhoun noted the importance of making a statement at the beginning of the document recognizing the magnitude of the problem and the economic cost to the nation as a result of it. That would be a good starting point. She also suggested flipping the paragraph stating that women were continuing to drink at adverse levels regardless of a warning label, and inserting a statement about FAS as a public health problem.
- ~ It was noted that in recent years, there has been an increase in binge drinking among teenage girls, and this could be presented as strong rationale for making this advisory even louder today. Heavy consumption of alcohol is now starting in earlier for many young people.
- ~ It might be helpful to tie this in with SIDS, learning disabilities, and still births. Dr. Riley was concerned with the fact that three paragraphs deal with the issue of lower levels of exposure. Outcomes that result from high levels of exposure are well-documented and should be included as well. This is a public health issue whether children are exposed to low or high levels of alcohol. There is an enormous amount of literature available on high dose exposure.
- ~ Dr. Warren indicated that he would draft another version of the advisory, and e-mail it to the members on the Task Force. Dr. Riley requested that the members send their comments and suggestions to Dr. Warren within the week. Following the recommendations, another draft will be written. Recommendations can be e-mailed to kwarren@mail.nih.gov.

Letter to the President of the Teratology Society

***Dr. Edward P. Riley, Chair
Director, Center for Behavioral Teratology
San Diego State University***

Dr. Riley read the letter that he drafted to the president of the Teratology Society. He did not have copies available for dissemination, but requested comments from the Task Force. The Task Force decided to table the endorsement (or lack thereof) until the next day when Dr. Riley could provide the group with a copy of the letter.

Discussion Points:

- ~ Dr. Calhoun shared her reservations concerning the Task Force's endorsement of this statement. Once there are a few drafts with the Teratology Society, it becomes the Task Force's document not theirs. Other groups should be endorsing the Task Force's recommendations rather than the Task Force endorsing other groups.
- ~ Dr. Cordero stated that there may be some miscommunication. There are not a lot of people paying attention to FAS. It is welcomed news that other groups are paying attention. It is important that all groups that are involved and have something to say about FAS, speak with the same voice. It should not be an issue of ownership, but an opportunity to raise awareness about the problem. These efforts need to be harmonized.

With no further business posed, the meeting was adjourned for the day.

March 14, 2003

Call to Order

***Dr. Edward P. Riley, Chair
Director, Center for Behavioral Teratology
San Diego State University***

Dr. Riley called the meeting to order at 8:40 a.m. on Friday March 14, 2003. He noted that the two items on the agenda were placed there by a member who was not present at the meeting. These items are:

- Provider Education and FAS Prevention. Who should be targeted? Who should be screening? Who should be diagnosing? What kind of screening instruments are needed?
- Development of a clear message for pediatricians, nurses and other providers: how the FAS diagnosis will benefit the child and the family-should the Task Force do this?

Given that the member was not present, these issues were tabled to be addressed at another meeting.

Dr. Riley reminded the Task Force that if anyone was interested in making comments regarding the Public Affairs Committee for recommendations on the statement from the Teratology Society, to please e-mail their responses to Tina Chambers.

Federal Agency Updates on FAS and FASD

Interagency Coordinating Committee on FAS (ICCFAS)

Dr. Faye B. Calhoun, D.P.A., M.S.
Associate Director for Collaborative Research Activities
National Institute for Alcohol Abuse and Alcoholism
National Institutes of Health

Dr. Calhoun reported on the activities of the Interagency Coordinating Committee on FAS (ICCFAS). The ICCFAS includes representatives from the various federal government agencies that are involved in FAS activities. There are currently 11 agencies involved in the membership. The Department of Justice (DOJ) Bureau of Prisons recently joined the group. The 11 organizations represent three departments: The Department of Health and Human Services (DHHS), the Department of Education (DOE), and the Department of Justice. There are two Subcommittees. One is led by the Department of Education (DOE), which deals with education issues as they relate to children with FAS and other related conditions. The other Subcommittee, the Juvenile Justice Work Group, is chaired by the Justice Department, which is concerned with issues as they pertain to individuals with FAS in the criminal justice system.

The ICCFAS meeting, held December 3, 2002, began with presentations by two people who were very much involved in looking at FAS and criminal anti-social behavior. The first was Fred Bookstein, from the Institute of Gerontology at the University of Michigan. He discussed the endophrenology of fetal alcohol damage. He has a theory that extends Dr. Riley's groundbreaking work in terms of looking at the shape of the corpus callosum, and the lack thereof in persons with FAS. He proposes that one can look at the morphological features in the brain, and relate that to the likelihood for anti-social behavior and recommends more studies in this area. The other person was Katherine Page who is with the FASD Task Force in Santa Clara county, CA. Her presentation was on fetal alcohol spectrum disorders: a hidden epidemic in the courts. She reported statistics from the foster care agency in her county indicating that at least 80% of all foster care children have been exposed to alcohol in utero. The majority of these children had problems in self-regulation and issues of sustaining attention. Most of the children in the system are diagnosed with ADHD and impulsive behavior. They are managed based on assessments by people who feel that they have bad morals and should take responsibility for their actions. She discussed speech and communication patterns observed among alcohol-affected persons in the justice system who exhibit executive functioning deficits. For example, their expressive language is intact but their receptive language is often impaired.

There was also a report by the ICCFAS Juvenile Justice Work Group. They have outlined their priorities, devised a work plan and next steps, and are ready to take action and request support from government agencies in making a difference in that domain. The Substance Abuse and Mental Health Services Administration (SAMHSA) will be working with this Work Group as well.

Ellen Hutchins, from the Maternal Child Health Bureau, Health Resources Services Administration (HRSA), discussed her presentation at the Secretary's DHHS Advisory Committee on Infant Mortality. She explained that this is the first time that the Committee expressed interest in alcohol use during pregnancy. She also conducted a three-hour workshop at the National Perinatal Association meeting in Savannah, Georgia on FAS. MCHB has funded a three-year demonstration program focused on how to motivate prenatal providers to screen for alcohol use during pregnancy. This phase of the project has concluded. A great deal of information was obtained about how to screen and the instruments used.

Dr. Bobby Statner Eaton, representing the Department of Education, explained the Federal Interagency Coordinating Council (FICC). The FICC was established to help integrate the work done across federal agencies that deals with services for young children (age 0-8) and their families. This particular council cosponsors the ICCFAS Education Work Group. The group met in December and will expand their discussion to include autism, FAE, FAS, and ARND.

The Individual Disabilities Education Act (IDEA) was also discussed. IDEA is charged with promoting statewide Early Intervention Campaigns. There was also discussion of the No Child Left Behind Act of 2001. Representatives from the DOJ Bureau of Prisons stated that there are 164,000 inmates in the penal system. It is estimated that 2,000-3,000 might have FAS-related disabilities. There is a great interest at the Bureau to initiate work with states through the National Institute of Corrections or the American Correctional Association, to educate all corrections personnel about FAS.

NIAAA continues to fund about 120 projects ranging from activities ranging from molecular biology to intervention and prevention efforts. The Institute spends about \$34 million to support these projects. NIAAA has published a request for applications to support one or more consortia to conduct collaborative research on FASD. The purpose of this initiative is to develop and inform effective interventions and treatment approaches for FASD through a highly integrated, multi-disciplinary, multi-site research approach involving basic behavioral and clinical investigators and projects. The objective is to integrate existing resources within the alcohol research community.

Substance Abuse and Mental Health Services Administration (SAMHSA)

Callie B. Gass

Project Director

FAS Center for Excellence, SAMHSA

It was noted that there are currently two large meetings coming up. The first is "Building State FASD Systems," which is a FAS state coordinators' meeting to be held May 18-20, 2003. People within the state government have been invited. There will also be a large meeting in Baltimore on September 9-10, 2003, an initiative to start working with women who have had babies with FAS, or who are in recovery. It is a women's summit.

SAMHSA has also been convening Town Hall Meetings, and the draft results were disseminated

to the Task Force. The Town Hall summaries include comments that have been made at the various Town Hall Meetings across the country. A main point of the Town Hall summary is that parents spoke quite frequently about the inability to obtain an accurate diagnosis easily. Once a diagnosis has been made, the systems that are in place sometimes do not work very well.

There will be a section on the FAS Center for Excellence website entitled “Canned Goods,” because one of SAMHSA’s mandates is to make material available to all of the service sectors in the public domain. The plan is going through the clearance process currently. Fact sheets will be in pdf format and a phone number is provided for people to get more information about the spectrum disorders and behavior management among other things. The FAS hotline is accessible in Spanish and English and is available 24 hours a day.

Other

Dr. Garcia referred to a news release from the state of Washington. It describes a study that looks at a treatment program that treats women with children and women who are pregnant. Dr. Garcia stressed that it was tools like this press release that enable state legislators to obtain funding for the subject of FAS.

Centers for Disease Control and Prevention (CDC)

Louise Floyd, D.S.N., R.N.
Behavioral Scientist
Leader, FAS Prevention Team

Dr. Floyd requested updates from her team. Dr. Tanya Sharpe provided an overview on the Regional Training Centers initiative, which began in October 2002. These Centers will survey physicians and other providers, as well as medical students, to identify gaps in knowledge about FAS and gaps in provider behavior. Comprehensive FAS curricula will also be developed. The curricula will be disseminated through multi-media strategies, train-the-trainer workshops, and other mechanisms, and the Centers will work to get FAS questions included in credentialing board exams. The first grantee meeting was in December 2002, during which two working groups were formed: 1) Survey Working Group; and 2) Curricula Working Group. The Survey Working Group is partnering with an existing CDC/AAP cooperative agreement to disseminate the survey to over 6,000 pediatricians. The Curriculum Working Group has drafted a core competencies matrix to assess and evaluate training outcomes.

Ms. Elizabeth Parra delivered an update on the FAS Awareness and Education project which began in Fall 2001. There are four nonprofit organizations funded: 1) Education Development Center in Massachusetts; 2) The Arc of the United States in Maryland; 3) Double Arc in Toledo, Ohio; and 4) National Indian Justice Center in Northern California. Each is developing, implementing, and evaluating educational curricula for various audiences including parents, teachers, and criminal justice personnel. All have conducted formative research and focus groups, and have developed pieces of the curricula, which they are currently piloting.

Jasjeet Sidju provided an update on Project Choices. Project Choices, which targets high-risk

women of childbearing age, uses motivational interviewing techniques and prevention counseling. The randomized control trial began in September 2002 and data are currently being collected. There are approximately 150 participants enrolled in the trial at this time. Mary Kate Weber described CDC's Targeted Media Campaign Projects, which are developing, implementing, and evaluating media campaigns focused on women of childbearing age, informing them about the risks of drinking during pregnancy. The group is currently funding three university-based projects: 1) St. Louis University; 2) UCLA; and 3) University of Iowa. The projects are all very different in terms of the strategies used to reach their target populations. All three projects have engaged in formative work in the first year and implementation is currently underway.

Public Comment Period

Ms. Georgia Gore
Board Member, FAS*FRI

Ms. Georgia Gore, a Board Member of FAS*FRI, suggested that perhaps CDC and NIAAA could consider researching various non-clinical interventions being used by parents throughout the country. She has seen tremendous stabilization and success with neuro-feedback and vitamin supplements that her children have received. Non-traditional medicine combined with traditional medicine might prove to be more effective than each one alone. Ms. Gore requested that clinical studies be conducted on other issues that are affecting children such as rages, seizures, cerebral palsy, etc. that might be related to FAS. Many parents are seeing the same things. She also recommended addressing mental health issues of affected individuals.

Discussion of Next Steps/Meeting Adjournment

Dr. Edward P. Riley, Chair
Director, Center for Behavioral Teratology
San Diego State University

Dr. Riley pointed out that when items are solicited for the agenda, he receives very little feedback from Task Force members. He reminded the group of the importance of identifying issues for the Task Force to address.

Discussion Points:

One complaint that Dr. Riley received was that there was never enough time to discuss all of the items on the agenda. Rather than present an item or a statement, some written background material needs to be provided prior to the meeting. It would help everyone follow along while the presentations are being made. If the Task Force is going to make any progress, those items need to be on the table. What the issue is and why it is important needs to be sent out to the Task Force members ahead of the scheduled

meeting.

- ~ Ms. Devries stressed that a diagnosis is extremely important to families. Concerning the agenda, she asked Dr. Riley what issues could be brought to the Task Force. Dr. Cordero responded that the Task Force is an Advisory Committee to the Secretary. It provides the best advice to the Secretary in terms of the actions of the Department of Health and Human Services (HHS), and what the Executive Branch should take on regarding issues about FAS. It is important to decipher the important messages that come from the Town Hall Meetings and translate those into recommendations. Dr. Cordero also mentioned the importance of Medicaid's involvement with this Task Force.
- ~ A comment was made to also include some third party payer representatives rather than just including Medicaid. Medicaid is not a federal entitlement, rather it is state-based. In almost every state, there is a budget shortfall. For example, in Georgia, there is a \$100 million deficit.
- ~ Ms. Devries briefly reported on the Town Hall Meeting held in Mississippi and mentioned that an interesting project was also conducted in conjunction with the meeting. Dr. Floyd asked that the findings from that project be presented at the next Task Force meeting. Dr. Calhoun stated that the state coordinators are working on a Medicaid piece, and will be available at the next meeting. Dr. Cordero suggested looking at the comments made at the Town Hall Meetings and the recommendations that were made within that draft document. Parental involvement is very important. Concerning the *Town Hall Summary Report*, it was noted that there was substantial participation from providers at some of the sessions. There is a listing of testimony summaries and providers in the back of the report. There are also recommendations contained therein as well.
- ~ Some of the agenda items for the next meeting include: the public affairs commentary from the Teratology Society, a report from the Work Group addressing the issue of FASD, and a report on findings from the project in Mississippi.
- ~ The next Task Force Meeting will take place November 6-7, 2003.

With no further business posed, the meeting was officially adjourned.

Minutes approved on 05/09/03
by Edward P. Riley, Ph.D.
Chair, National Task Force on FAS/FAE

End of Summary Report
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