

**Department of Health and Human Services**  
**Centers for Disease Control and Prevention**  
**National Center on Birth Defects and Developmental Disabilities**

**Record of the Meeting of the**  
**National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect**

**December 8-9, 2003**

**Held at the Swiss Hotel**  
**Atlanta, Georgia**

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**Department of Health and Human Services  
Centers for Disease Control and Prevention  
National Center for Birth Defects and Developmental Disorders**

**National Task Force on Alcohol Fetal Syndrome and Fetal Alcohol Effect  
December 8-9, 2003  
Meeting Summary**

The National Task Force on Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) met on December 8-9, 2003, in Atlanta, Georgia. Several new members were in attendance.

Dr. Deborah Cohen provided an update on the **30<sup>th</sup> Anniversary Conference: Truth and Consequences of FAS**, a national conference that highlighted FAS epidemiology, prevention, diagnosis, interventions, caregiver experiences, and other issues. Feedback from conference participants has been positive.

Dr. Karla Damus outlined The **March of Dimes National Prematurity Campaign**. Prematurity is the single most important cause of perinatal mortality and the second leading cause of infant mortality in the U.S. The 5-year, \$75 million MOD campaign focuses on primary prevention of preterm births. The campaign goals are to: 1) raise public awareness, 2) educate women on the signs of premature labor; 3) assist practitioners; 4) invest in identifying causes and promising interventions; and 5) seek guaranteed access to health care. The MOD also influenced the introduction of two pieces of recent legislation to prevent prematurity through research, education, and improved access to maternity care and health care coverage for special needs children. It was noted that both NIAAA and CDC are working on research that address the issue of preterm delivery.

Callie Gass presented on findings from the **SAMHSA-sponsored Town Hall Meetings** and provided an update on the accomplishments of the FASD Center for Excellence. The needs most commonly identified in the town hall meetings were diagnosis (particularly for those children without the “face” of FAS); greater understanding of FASD in all service systems (especially education); the establishment of developmental disability eligibility beyond an IQ threshold; appropriate services for individuals with FASD and their families; respite care; and financial support. Ms. Devries announced plans to establish a national family leadership council on FAS, members of which will be from established state family advocacy groups. It was agreed that the Town Hall Meetings summary report should be broadly disseminated.

**FASD Center for Excellence**'s recent activities include the Hope for Women in Recovery Summit, support of comprehensive systems of care development at the state level, and collaboration with NOFAS on a curriculum for certified substance abuse counselors. Proceedings from the Summit will be available soon and a February 2004 follow-up meeting is planned. In addition, the Center has been directed by their steering committee to work with the ICCFAS to ensure the non-redundancy of work across agencies (NIH, CDC, and SAMHSA) and compile a list of the agencies' work in the field. A cost analysis of FAS will be published in the *Journal of American Genetics* and is available at [www.fascenter.samhsa.gov](http://www.fascenter.samhsa.gov). In terms of what the Task Force can do to help the Center reach its goals, Ms. Gass indicated that the Task Force's

efforts to further clarify FAS diagnostic criteria would help. Also, the Task Force could help promote consistency of FAS information across agencies and programs, assist in information dissemination, and contribute to the Center's work on developing comprehensive systems of care.

Dr. Heather Carmichael Olson presented on **Factors That Improve Outcomes for Individuals Affected by FAS or Related Disorders**. Dr. Olson highlighted research findings related to protective factors and stressed the importance of protective factors research and intervention. Research shows that accumulation of risk is a major predictor of later problems so reducing risk is an important goal. Also, it is important to identify vulnerable children early and prevent them from experiencing excessive stress. It has also been found that there are key points in life when protective factors are especially important. Research has also examined why some children are resilient in high-risk environments and this is partly due to intrinsic attributes of the individuals and partly due to environmental factors. With that, the idea of assessing and trying to influence risk and protective factors has emerged. Protective factors are influences that help to avoid, reduce, or alter the impact of risks. Dr. Olson outlined protective factors specific to young children, adolescents, and young adults and presented findings from Ann Streissguth's seminal study of secondary disabilities of individuals with FAS.

Dr. Olson proposed recommendations for intervention based on the protective factors literature. For children aged 0-5, help parents provide appropriate caregiving, offer caregiver education specific to FAS/ARND, and coach parents on how to promote behavior regulation and child compliance. For children 5-11, help parents hone their caregiving skills (e.g., how to handle challenging behaviors, promote child's social skills). Children need positive school experiences and peer relationships. Adolescents need coping strategies, good family relations, and positive peer networks. Also, specially arranged mental health treatments and positive school experiences are helpful. For young adults, many problems are established by "negative feedback loops." They will need specialized treatments, life coaching or advocacy, specialized job settings, and protected living situations.

Some ideas for protective factors research and intervention could include examination of what protective factors occur in the typical situation and those that occur specifically with FAS/ARND individuals, provision of early intervention where reducing risks and enhancing protective factors is the focus, and, for older children, deliberately reduce risks and manipulate protective factors to change behaviors. Dr. Olson also proposed creation of regional intervention training centers (e.g., for mental health providers and educators) and establishment of places for young adults/parents to come together. Mental health and early interventions for children, adolescents, and young adults need to be studied to see if they work with the FAS/ARND population. Good natural history studies are critical, as are intervention research studies.

Dr. Deborah Morrow discussed the *Individuals with Disabilities Education Act (IDEA)*, specifically Parts C and B. Administered by state health or education departments, Part C covers infants and toddlers with disabilities, birth through age 2 and their families. Providers are trained to deliver direct services to the child in the home. Part B covers children and youth with disabilities, ages 3 through 21. A child covered under Part C should transition right into Part B if they qualify. Services can be gained through the IDEA under Part C: 1) if the state establishes

FAS as a syndrome; 2) if the FAS effects result in a developmental delay; or 3) through “informed clinical opinion.” However, state cuts are threatening service delivery under Part C.

Part B of IDEA requires a multidisciplinary evaluation (at least 90 days to 6 months before age 3) of the child. Eligibility is determined by a multidisciplinary team (includes parent). If any one of several criteria is met, services must be provided (social, educational etc.). The 14 disability categories are developmental delay, autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, or visual impairment.

Dr. Morrow described several conditions and the related IDEA requirements. These included autism, mental retardation, other health impairments (the likely category to qualify children with FAS/FAE), specific learning disabilities, traumatic brain injury, and visual impairment. For all of these conditions, the symptoms have to adversely affect educational performance. The IDEA’s list of eligible conditions and categories does not include FAS. However, FAS may manifest itself in one or more of the disability categories. The “label” for the child does not matter much. Once the school identifies a child with a disability, they must address *all* the child’s educational needs that result from the disability. Dr. Morrow suggested that Task Force members encourage practitioners to get involved in the IDEA criteria panels as these criteria are under review with the current reauthorization of the legislation.

Mr. Oscar Morgan, from the National Mental Health Association (NMHA), presented on **Understanding and Accessing the Public Mental Health System**. Mr. Morgan indicated that the current public mental health system was built and funded for adults aged >18 years and those with chronic mental health issues. Children are not a priority in this system. Since the mental health system requires a diagnosis to get services, children may be labeled “conduct disorder” to reflect underlying interpersonal difficulties. Very young children are often difficult to diagnose and a psychiatric diagnosis may follow them throughout their life, even if, in some cases, it is incorrect.

The definition of the “mental health care system” is another issue. Medicaid provides funding for mental health services. Other systems, such as the school system (under IDEA), the social services system (under Title IV and foster care), and the juvenile justice system are required to provide mental health services to children as well. The mental health system is probably the last to provide services to children, and if so, probably does so with little funding. Mr. Morgan mentioned the importance of co-occurring disorders, particularly with women who are substance abusers, and stressed the importance of screening children for mental health problems. He suggested that one opportunity that is available is through Medicaid’s Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program. EPSDT requires states to screen children and youth (aged 0-21) for a variety of health issues (one of which is alcohol/substance abuse) and to provide appropriate services. Unfortunately, this program is underutilized in many states. It was mentioned by those in attendance that better utilization of EPSDT and mental health and FAS may be issues the Task Force wants to consider.

Dr. Brenda Scafidi discussed **Mississippi’s State-Based FAS Program Initiative**. In 2002,

Mississippi formed an Interagency Coordinating Council for Children and Youth (ICCCY) with Serious Emotional Disturbance (inclusive of conduct disorders and behavioral emotional problems), which included members from a statewide organization of families with children with emotional disorders. The mental health department was named the executor of the Initiative. The state also has 15 MAP (Making a Plan) teams that meet once a month, with broad representation, to review the needs of special education children, and to find resources to keep them in the state.

The ICCCY identified gaps and limitations in the existing system for children with ED including the following: there were different definitions and ways to identify this population; the policies/plans and procedures in place to address ED differed; agencies had limited awareness of the services and grants applicable to ED; there was no inter-agency training consolidation; there was limited data collection and use relevant to this population; restricted funding categories were not easily broadened within/among agencies; and interagency matches to maximize resources (budgets, grants) were underutilized.

The ICCCY recommended that the system be available, accessible and accountable. Dr. Scafidi developed a triptych (graphical representation of existing systems) describing each agency's sections and subpart programs relevant to these children in order to make the path clearer to the parents and families needing this help. The triptych provides a schematic of the systems of care, describes the IDEA legislation, a system of care model, what to look for entering services, etc. The ICCCY also recommended: 1) development and implementation of interagency policies and procedures to correct the gaps above (plus evaluation measures of service delivery and costs); and 2) provision of a single point structure to implement and operate a system to identify targeted children and to define accessible resources.

The ICCCY will continue to work to increase the number of MAP teams across the state. They also plan to add FAS to the interagency agreement as a priority; and add FAS to the existing assessment tools and intake forms in order to determine the number of FAS-affected children. The FAS Town Hall meeting in Mississippi was instrumental in raising state officials' awareness about the specific concerns and challenges of children affected by prenatal alcohol exposure and their families.

Faye Calhoun provided an **update on NIAAA activities**. The agenda of the upcoming ICCFAS December 12th meeting includes meetings of the Education and Juvenile Justice Subcommittees. The ICCFAS will also work to map the progress made by the various agencies represented on the ICCFAS to identify overlaps and remaining areas of need. Dr. Calhoun is interested in Task Force's discussion on the ethical aspects of diagnosis, FAS recognition and service provision. She urged CDC to report on how criteria for other conditions, such as ADHD and autism, were developed to allow their listing within IDEA. The criteria of those conditions are not much clearer than FASD, and they have distinguishable but overlapping areas, similar to FASD. Discussion related to this indicated that FAS does differ from autism and ADHD. Autism has several measurement instruments validated through research and ADHD has specific behavioral tests that allow for specific diagnosis. However, Dr. Calhoun believed that we may learn something from these other groups in terms of how we address this issue.

An update on the **Surgeon General's Advisory** was given. A request has been submitted to the Surgeon General on behalf of the Task Force to recommend reissuing the advisory about alcohol use in pregnancy and the Surgeon General's response is pending. The final version of the letter to the Secretary and the advisory will be e-mailed out to the members.

Discussion on **FAS and Education Requirements** resulted in a suggestion that the Task Force draft letters to each state about including education about FAS in its education requirements. Dr. Floyd requested further deliberation on this issue, examining the advantages and disadvantages of such requirements. There are various groups not present today (e.g., juvenile justice, foster care, social services, and financing) who could provide valuable input to this topic.

Ms. DeVries distributed copies of FAS\*FRI's 2003 Final Report to SAMHSA FASD Center for Excellence to Task Force members. Over the past two years, FAS/FRI coordinated the SAMHSA-sponsored town hall meetings and families are awaiting the final summary report from those efforts. Ms. Gass indicated that the dissemination of the summary report from the town hall meetings was in their 2004 work plan.

Further discussion related to FAS services included:

- Beyond early identification and diagnosis, a system linking prenatal and risk reduction services is needed. Then, a system for presumed eligibility due to alcohol exposure needs to be put in place until the child is old enough for diagnosis. The real issue is how to get the prenatal and pediatric systems to talk to diagnostic and health care systems to ensure that screening is done and that there is clinical integrity among those making the diagnosis.
- Dr. Vinson proposed that with a FAS incidence of ~1/1000, an average family physician doing obstetrics will see one FAS case in a thousand babies delivered in a career; a pediatrician will see ten times that – ten FAS children. This is an insurmountable diagnostic challenge for the physician. With that incidence and a 3% positive predictive value of the Streissguth screen, only one child out of thirty screening positive will actually have FAS. Dr. Vinson felt that referring all those for services will further overload systems and unnecessarily create anxiety in parents (although other conditions may be identified). Solutions to this challenge could include asking ACOG to put more detail onto the routine prenatal form to improve communication between general and obstetric care providers and working to create one point of entry for the provider so that s/he need not have to make multiple diagnoses to match the child to all the needed services. It is important to note, as indicated by other Task Force members, that these estimates are based only on children diagnosed with FAS and do not take into account those children with other prenatal alcohol-related conditions. The estimates also assume that cases are equally distributed through all obstetric and pediatric practices.

Other Task Force activities/suggestions included:

- Have experts provide a state of the art on the hard science as opposed to the social sciences. Better articulation of the science could allow for a discussion about functional models applicable to different drugs and responses.
- A request was made to put together an "FAS 101" packet for new Task Force members.
- As new members of the task force were unfamiliar with previous Task Force recommendations, it was suggested that the Task Force revisit the 2002 recommendations,

assess their status, identify those not yet addressed, and find a mechanism to make them happen.

- A future agenda should include discussion of personal liberty issues (e.g., potential prosecution of pregnant women who drink; bartenders refusing to serve a woman).
- The Mississippi-style graphic layout of access to resources is needed by judges too, as relevant to their defendants and witnesses. Establishing the definitions and making the issue accessible at the local level (i.e., terminology) will make the topic of FAS less intimidating and attention can then be paid to what needs to be done within the system.

***Education/Teacher credentialing*** was discussed. A motion that the Task Force recommend that teachers be required to complete a 3-hour semester course on FAS prior to certification, effective as of January 1, 2006 was made. Several Task Force members' concern at not having achieved something in this regard for the affected populations was voiced. Relevant curricula are being developed and could be used in these teacher education efforts. There was also a suggestion made to form a Task Force education workgroup. There was agreement to recommend teacher education about the identification, treatment and prevention of this disorder. However, three semester hours constitutes 45 hours of lecture, which is not practical to mandate for all public school teachers. **The motion was revised to recommend that teachers complete a course on FAS as part of their certification and suggested that this be done effective as of September 1, 2006. The motion was passed: 7 (yes), 2 (no), 1(abstain).**

**A motion that the Task Force recommend that FAS be included in the reauthorization of IDEA under "other health impairments" was put forth.** It was suggested that FAS should be the term to add to IDEA, rather than as a spectrum condition such as autism disorder, to get a foot in door. **The motion passed unanimously.**

A **CDC update** was provided by Dr. Cordero. He indicated that CDC is currently undergoing an agency-wide strategic planning process. This process, known as the Futures Initiative, is being done using an "outside-in" approach, to gain input from CDC's "customers" on the directions and issues the agency should address. All CDC advisory committee Chairs will be contacted for input. Information on the Futures Initiative is available on CDC's website.

CDC's NCBDDD will hold a national conference July 25-29, 2004 in Washington, D.C. on birth defects, developmental disabilities, disability and health, and hereditary blood disorders. NCBDDD is almost fully staffed except for a position for Director of the Division of Birth Defects and Developmental Disabilities and nominations for this position were solicited.

CDC recently funded 5 state-based FAS Prevention grantees in six states (Michigan, Minnesota, Missouri, Colorado, and South Dakota/North Dakota) to monitor FAS at the state and county level and implement prevention activities. These 5-year projects will work with CDC to adapt individualized interventions (such as Project Choices) to public health settings.

Dr. Floyd updated the Task Force on the progress of the ***Scientific Workgroup on Diagnostic Guidelines for FAS/ARND***. The fourth draft of the FAS diagnostic guidelines (which were approved by the Task Force earlier in 2003) was presented. The diagnostic criteria for FAS are:

1. *Face* -- Based on racial norms, child exhibits all three characteristics of facial features:
  - smooth philtrum (lip-philtrum guide 4 or 5)
  - thin vermilion (lip-philtrum guide 4 or 5)
  - palpebral fissures (#10<sup>th</sup> percentile)
2. *Growth* -- Confirmed prenatal or postnatal height and/or weight #10<sup>th</sup> percentile, documented at any one point in time (adjusted for age, gender, gestational age, race/ethnicity.)
3. *Central Nervous System or Neurobehavioral Disorders*
  - Structural
    - Head circumference #10<sup>th</sup> percentile
    - Brain abnormalities observable through imaging
  - Neurological  
May include seizures not due to a postnatal insult or other signs such as impaired motor skills, neurosensory hearing loss, memory loss, or poor eye-hand coordination.
  - Functional
    - Deficits or developmental delay
    - Executive functioning deficits
    - Motor functioning delays or deficits
    - Problems of attention and/or hyperactivity
    - Social skills
    - Other: mental health problems, sensory problems, pragmatic language problems, memory deficits, and/or difficulty responding appropriately to common parenting practices.
4. *Maternal alcohol exposure* -- either through confirmed prenatal alcohol exposure, unknown prenatal alcohol exposure, or confirmed absence of exposure.

Dr. Bertrand briefly described how the CNS criteria were developed. Those working in the ARND working group and other experts were asked to identify five key domains (and examples of behaviors associated with each) that they see most frequently in individuals with FAS. Those domains cited most frequently are outlined above. To be inclusive rather than exclusive, “any one structural abnormality, neurological problem, or poor performance in a functional domain,” meets the criteria for a CNS problem.

In summary, diagnosis of FAS requires all of the following: documentation of all three facial abnormalities, documentation of CNS/neurobehavioral disorders (structural, functional, and/or neurological), and documentation of growth deficits. Confirmed prenatal alcohol exposure can strengthen the evidence for diagnosis but is not necessary in the presence of all of the aforementioned categories. An additional note on environmental impact was added to the revised guideline and guidelines for initiating a referral and considerations for referral and follow-up were outlined. Additional components of the Guidelines in development include a section on essential services for affected individuals and their families, a section on intervening with women at risk for an alcohol-exposed pregnancy, and appendices that include relevant assessment instruments recommended in the Guidelines report.

The Task Force was asked to review and comment on the current Guidelines report; provide input on the need to include examples of appropriate standardized psychometric tests for

assessing CNS domains affected by prenatal alcohol exposure; consider the proposed interim diagnostic criteria for ARND based on the work of the SWG, and offer insights into the use of the term “Fetal Alcohol Spectrum Disorder.”

It has been said that the SWG’s FAS diagnostic criteria do not go far enough in that they do not address the issue of children without “the face.” An addition to the Guideline criteria was proposed – have the diagnostic criteria for ARND (with or without the face/growth deficits) be the same as the CNS criteria for FAS that is currently proposed in the Guidelines. Some Task Force members recommended clarity within the Guidelines regarding the CNS criteria and also in terms of maternal alcohol use. It was agreed though that the Task Force finish its charge to develop specific clinical guidelines for FAS, and then separately define what the other disorders in the spectrum are.

A discussion regarding the use of the term Fetal Alcohol Spectrum Disorder occurred. A proposed definition was offered: *FASD is an umbrella term used to describe a group of conditions that share a common etiology (alcohol exposure) and common developmental abnormalities including adaptive functioning, attention and memory problems, distractibility, learning problems, poor judgment and fine and gross motor difficulties.* Discussion of this definition occurred but there was no official endorsement of it by the Task Force.

Drs. Jocelyn Cook and Julie Conry provided an **Update from Health Canada’s National Advisory Committee on FASD.** In Canada, FASD is an umbrella term for the spectrum of caused disabilities. Their guidelines go from the screening through the follow-up process, and discuss partial ARND as well as FAS. They based FAS diagnosis on growth at #10<sup>th</sup> percentile and the three facial features; for ARND, only brain outcomes but no facial features; and for partial FAS, one or more facial feature. They used the IOM wording and four-digit diagnostic codes to translate some empirical measurements into the IOM guidance. Similarities and difference of the Canadian guidelines to the U.S. guidelines were outlined and are detailed in the minutes.

**Public comment** was solicited twice during the meeting. Dr. Heather Carmichael offered several comments pertinent to the development of the diagnostic guidelines. These are detailed in the minutes and include: 1) required multiple deficits could occur across domains, and should be taken as an indication of FAS rather than environmental impacts; 2) the current Guideline requirement of only one functional domain below expectations could make the definition clinically unreliable, especially for those children with ARND; 3) provide clear notice that the Guidelines are still under review, and state that a continued review of ARND is underway; 4) review of data from several databases to assess how many children would be identified using proposed cutoffs to assess how the CNS guidelines would perform (as they relate to children with and without the mental health problems, head circumference); 5) allow opportunities for input Guidelines publication; and 6) give more attention to the environmental impact statement (and harmonize it with the IOM’s approach).

It was agreed that several databases could quickly enlighten how accurately the low/average numerical cutoff relates to exposure measures. Dr. Coles emphasized that any criteria issued should state that diagnostic standards lack adequate norms for the measurements discussed (e.g.,

palpebral fissures for African Americans aged 11 years). Emphasis is also needed for good diagnoses for those over age 4 years and adolescents, and for standards of care. Also, it would be important to acknowledge that these criteria are not useful for adults and adolescents and that research and development of standards for these populations is needed.

**Closing comments** included the following:

Work will continue on the Guidelines report. The issuance of the revised draft report will not wait until the next Task Force meeting (June 2004). The report will be refined with the input received from the Task Force via e-mail and conference call, and once approved, plans will be made to publish in an *MMWR* report. The report will also be sent to ACOG and AAP for dissemination, and perhaps submitted to professional journals.

A recommendation was proposed for a discussion at the next Task Force meeting on how to advance the research and democratic processes on how to change the educational systems, social welfare, juvenile justice, etc., to integrate them and make access to FAS diagnosis/intervention easier. Additional issues suggested for future Task Force deliberations include involvement of the judicial system and focused efforts on prevention.

A summary of Action Items & Future Agenda Suggestions can be found in **Attachment 1**.

The next Task Force meeting will be held on **Wednesday/Thursday, June 16-17, 2004**.

**Department of Health and Human Services  
National Task Force on Alcohol Fetal Syndrome and Fetal Alcohol Effect**

**Meeting Minutes  
December 8-9, 2003**

**DECEMBER 8, 2003**

**Task Force Members and Attendees**

The National Task Force on Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE) met on December 8-9, 2003, in Atlanta, Georgia. The following people were in attendance:

**Task Force Chair:** Edward P. Riley, PhD, Director, Center for Behavioral Teratology, San Diego State University  
**Executive Secretary:** José Cordero, MD, MPH, Director, NCBDDD, CDC  
**Designated Federal Official:** Louise R. Floyd, DSN, RN, Team Leader, CDC FAS Prevention Team

**Task Force Members** present were:

Kristen L. Barry, PhD, Department of Veterans Affairs, Ann Arbor, MI  
 Raul Caetano, MD, PhD, MPH, University of Texas School of Public Health, Dallas, TX  
 Deborah E. Cohen, PhD, New Jersey Department of Human Services, Trenton, NJ  
 Claire D. Coles, PhD, Emory University School of Medicine, Atlanta, GA  
 Jocie C. DeVries, FAS Family Resource Institute, Seattle, WA  
 Mark B. Mengel, MD, MPH, Saint Louis University School of Medicine, St. Louis, MO  
 Raquelle Myers, JD, National Indian Justice Center, Santa Rosa, CA  
 Charles M. Schad, EdD, retired academician, Spearfish, SD  
 Jean A. Wright, MD, Backus Children's Hospital, Savannah, GA

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

**Absent:** James E. Berner, MD, Alaska Native Tribal Health Consortium  
 Lisa A. Miller, MD, Colorado Department of Public Health and Environment

**Liaison Members** present were:

American Academy of Pediatrics: George Brenneman, MD, for Christopher Cunniff, MD  
 March of Dimes: Karla Damus, RN, PhD, Senior Research Associate  
 Center for Science in the Public Interest: George A. Hacker, JD, Director, Alcohol Policies Project  
 National Organization on Fetal Alcohol Syndrome, Kathleen T. Mitchell, Program Director and National Spokesperson  
 American Academy of Family Practitioners: Daniel C. Vinson, MD, MSPH, Professor, University of Missouri-Columbia  
**Absent:** Robert J. Sokol, MD (American College of Obstetrics and Gynecology)

**Federal agency staff** present were:

CDC: Martha Alexander, Jacqueline Bertrand, Connie Granoff, Elizabeth Parra Dang, Yvette Dominique, Connie Granoff, Claudette Grant-Joseph, Melissa Hogan, Barbara Holloway, Cathie Ramadie, Sonya Rasmussen, Reneé Ross, Tanya Sharp, Jasjeet Sidhu, Esther Sumantojo, Jacqueline Vowell, Mary Kate Weber

Department of Education: Deborah Morrow, PhD, U.S. Department of Education, Office of Special Education Programs

Substance Abuse Treatment and Mental Health Services Administration (SAMHSA): Callie Gass, Project Director, FASD Center for Excellence

**Others in attendance** included:

Julie Conry, MD, Health Canada, Vancouver, British Columbia  
 Jocelyn L. Cook, PhD, Health Canada  
 Leslie Evans, Organization of Teratology and Information Services  
 Oscar Morgan, National Mental Health Association  
 Marie Murray, Meeting Reporter, Atlanta, GA  
 Heather Carmichael Olson, PhD, Fetal Alcohol Syndrome Diagnostic Clinic, FAS Diagnostic and Prevention Network  
 Brenda Scafidi, EdD, Director, Division of Children and Youth Services, Mississippi Department of Mental Health

Several new Task Force members are on the committee and are beginning their terms today. Introductions of Task Force members, Liaison members, and those in the audience were made. Drs. Cordero, Riley, and Floyd offered welcoming remarks. This Task Force, requested by the Secretary of Health and Human Services, advises the CDC and other federal agencies working in this field.

**New Member Orientation**

The first item on the agenda included orientation of new members to the **Federal Advisory Committee Act (FACA)**. Ms. Reneé Ross from CDC's Committee Management Office provided background information on FACA and requirements of these types of committees. This Task Force is a FACA committee. FACA dictates the Task Force's structure and outlines members' and officers' responsibilities. New members also received information regarding **ethics and financial disclosure** and a video was shown which provided examples of situations where ethics issues may arise for FACA committee members. Ms. Cathy Ramadei from CDC's Committee Management Office discussed ethics and financial disclosure and answered questions related to these issues.

**Updates:**

**Update on the 30<sup>th</sup> Anniversary Conference: Truth and Consequences of FAS**  
**Deborah Cohen, PhD, NJ Department of Human Services**

This national conference included presentations and workshops on FAS epidemiology,

prevention, diagnosis, interventions, research needs, caregiver testimony, and other issues (e.g., criminal justice, psychiatry, needs of birth and foster/adoptive parents). Preliminary conference evaluation results are very positive.

### **March of Dimes National Prematurity Campaign**

#### **Karla Damus, PhD, March of Dimes**

Between 1981-2001, the rate of premature births rose from 9.4% to 11.9%, an increase of over 27%. Awareness of this problem is lacking both among the general public and health care providers. Prematurity is the single most important cause of perinatal mortality and the second leading cause of infant mortality in the U.S. The economic costs of preterm delivery on women, infants, families, and the health care system are staggering.

In response to this serious problem, the March of Dimes has implemented a 5-year, \$75 million campaign focused on primary prevention of preterm births. Pregnant women are seen multiple times by health care providers, and at a time when they are probably more likely to change their behavior. Optimal advantage of those opportunities must be taken. The campaign goals are to: 1) raise public awareness, 2) educate women on the signs of premature labor; 3) assist practitioners; 4) invest in identifying causes and promising interventions; and 5) seek guaranteed access to health care.

The campaign, focused on risk reduction and evidence-based prevention strategies, builds on preconceptional health and seeks to improve reproductive health in general and to prevent preterm labor. The MOD is also sponsoring trials to see if the use of fish oils (omega 3) may be helpful. The MOD also influenced the introduction of the “Preemie Act” (expands prematurity research, education and support services) and the “Prevent Prematurity and Improve Child Health Act of 2003” (expands access to maternity care and health coverage for special needs infants/children).

#### ***Discussion:***

- Dr. Calhoun reported on a related NIAAA/NICHD partnership where researchers are exploring a variety of adverse health outcomes due to alcohol exposure. These include preterm births, SIDS, and FAS.
- Dr. Cordero commented that we have a great opportunity to impact many different health issues if we focus on preconceptional health. He also mentioned that NCBDDD is working with ACOG to see how preconceptional care can be improved as part of prenatal care. In addition, Dr. Cordero indicated that NCBDDD’s new Division of Hereditary Blood Disorders will be looking at the impact of preterm birth in some of their work. Dr. Cordero also offered to share with the March of Dimes new data on dysmenorrhagia.
- A question was asked regarding the impact of preterm births in younger women. Dr. Damus indicated that young women only contribute to 20% of unintended pregnancy. Older women are more likely to have an unintended pregnancy, have higher risk pregnancies, and have higher rates of addiction.

## **Summary of Service Needs Identified at the SAMHSA Town Hall Meetings and FASD Center for Excellence Update**

### **Callie Gass, Project Director, FASD Center for Excellence**

SAMHSA's FASD Center for Excellence works to identify best practices in prevention and interventions for women, identify comprehensive systems of care, assist to develop these systems of care where they do not exist, and respond to directions from this Task Force. The Center aims to identify, develop, and promote best practices in FASD prevention and treatment, in exemplary systems of care, and through innovative techniques for preventing alcohol use by women of childbearing age. The Center also fosters collaboration among various groups to develop prevention and treatment partnerships; and provides and evaluates training for professionals, families, women at risk, community members, and individuals with FASD.

The accomplishments of the Center's second year were outlined. These included completion of the town hall meetings (done in partnership with the FAS Family Resource Institute - FAS/FRI), and a summit for women in recovery (which included legislative representation). The needs most commonly identified in the town hall meetings were diagnosis (particularly for those children without the "face" of FAS); greater understanding of FASD in all service systems (especially education); the establishment of developmental disability eligibility beyond an IQ threshold; appropriate services for individuals with FASD and their families; respite care; and financial support (e.g., estate planning for young adults/adults who will not be self-supporting). The proceedings of the Hope for Women in Recovery summit will be available soon and a February 2004 follow-up meeting is planned. Development of a comprehensive systems of care model continues, although how it will be implemented is up to each state. The Center is also collaborating with NOFAS to develop a curriculum for certified substance abuse counselors. To date, core competencies for substance abuse treatment providers have been developed.

The Center's Steering Committee directed the Center to work with the ICCFAS to ensure the non-redundancy of work across agencies (NIH, CDC, and SAMHSA), to compile a list of the agencies' work in this field, and to broadly disseminate federally-funded project results. The ICCFAS has also discussed the importance of identifying the key components of a good curriculum. Ms. Gass also reported that a cost analysis of FAS will be published in the *Journal of American Genetics* and then posted on the Center's website ([www.fascenter.samhsa.gov](http://www.fascenter.samhsa.gov)). Ms. Gass emphasized to the Task Force that the importance of diagnosis and systems of care development cannot be underestimated.

### ***Discussion:***

- Ms. Devries announced FAS/FRI's plan to establish a national family leadership council on FAS. Members of the council will be from established state family advocacy groups. Ms. Devries also recommended that the town hall meeting report should be disseminated beyond physicians and nurses, to others providing services to families.
- Dr. Coles mentioned that we need to move beyond training medical students and physicians and should consider training other service providers.
- Dr. Riley asked what the Task Force can do to help the Center reach its goals. Ms. Gass indicated that the Task Force's efforts to further clarify FAS diagnostic criteria would be very helpful. Also, the Task Force could help promote consistency of FAS information across agencies and programs, assist in the dissemination of information, and contribute to

the Center's work on developing comprehensive systems of care.

- Dr. Damus suggested that national organizations (e.g., AAP, ACOG) could also be tapped to help disseminate new information. These groups have newsletters and other communication mechanisms for getting the word out.

### **Factors that Improve Outcomes for Individuals Affected by FAS or Related Disorders Heather Carmichael Olson, PhD, FAS Diagnostic Clinic, University of Washington**

Research on protective factors has examined why certain individuals develop severe psychopathology, and why some children living in high-risk environments develop problems. Findings show that accumulation of risk is a major predictor of later problems so reducing risk is an important goal. Also, it is important to identify vulnerable children early and prevent them from experiencing excessive stress. It has also been found that there are key points in life when protective factors are especially important. Research has also examined why some children are resilient in high-risk environments and this is partly due to intrinsic attributes of the individuals and partly due to environmental factors. With that, the idea of assessing and trying to influence risk and protective factors has emerged. Protective factors are influences that help to avoid, reduce, or alter the impact of risks.

Some ideas for protective factors research and intervention could include examination of what protective factors occur in the typical situation and those that occur specifically with FAS/ARND individuals, provision of early intervention where reducing risks and enhancing protective factors is the focus, and, for older children, deliberately reduce risks and manipulate protective factors to change behaviors.

Protective factor findings are more robust for younger children. For older children, these are more difficult to capture. Findings from the developmental literature indicate that *young children* need sensitive and responsive caregiving, secure attachment in infancy/preschool years, appropriate parental warmth and control and a positive parent-child relationship, developmentally stimulating home environments, positive peer relations, and support of parent from partners and communities. *Older children, adolescents, and young adults* need continued appropriate parental warmth and control (allowing gradual independence as the child can handle it), positive effective family communication, positive peer networks and social support, self-esteem and self efficacy, and opportunities for planning life events.

Dr. Olson presented findings from Ann Streissguth's secondary disabilities study. The intent of this study was to describe secondary disabilities among those with FAS/ARND and identify factors associated with negative and positive outcomes. Over 400 caregivers were interviewed on the natural "life history" of the individual with FAS/ARND. While there were some limitations in this study (e.g., no comparison group, mixed clinical sample, diagnoses over many years), many of the study recommendations are being implemented.

In the study, universal "protective factors" that reduce the odds of these secondary disabilities correlated to those in the developmental literature. Protective factors that reduced secondary disabilities included: living in a stable, nurturing environment, being diagnosed before age 6, never having experience violence against oneself, staying in each living situation for an average of > 2.8 years, experiencing a "good quality home" from age 8-12 years, having applied for and

found eligible for developmental disabilities services, having a diagnosis of FAS rather than fetal alcohol effect, and having basic needs met.

Other Study Highlights -- Early diagnosis is critical. In the study, diagnosis had a strong association with all risk factors with the exception of mental health problems. The availability of social services is also essential (developmental disability services were associated with reducing the risk of troubles with the law.) Females in the study had lower rates of secondary disabilities. The odds of confinement experiences were reduced by living in a stable, nurturing environment and by early diagnosis. Not living with an alcohol abuse reduced the risk of later alcohol and drug problems. The odds of problems with employment were increased by intrinsic factors (having FAS, low IQ, low adaptive function), and decreased by some universal factors such as, early diagnosis, longer time in good home, more stable placement, and not experiencing violence. The odds of independent living were also increased by intrinsic factors (low IQ, being male, high problem behavior score). Only early diagnosis reduced the odds of this secondary disability.

The study also found that higher rates of disrupted school experiences were related to more trouble with the law. Reasons cited by individuals with FAS/ARND who abstained from alcohol use were: no access to alcohol, drinking was against individual's belief, and family does not drink. Individuals with FAS/ARND who had not become parents had less often experienced abuse or domestic violence, been homeless, and had non-nurturing homes. This study did not reveal if protective factors differ for different family structures, cultures, or other variables. Also, it is not known if these protective processes operate differently for those with FAS compared to those with ARND. Most importantly, we don't know if these factors will actually improve outcomes. To accomplish this, we need systematic treatment research.

Dr. Olson proposed recommendations for intervention based on the protective factors literature. For children aged 0-5, we need to help parents provide appropriate caregiving (teach how to foster secure attachments, caregiver education specific to FAS/ARND, coach parents on how to promote behavior regulation and child compliance. Children must be identified early. Positive peer relations for children and supports for parents are also needed. For children 5-11, parents need help in honing their caregiving skills (how to handle challenging behaviors, promote child's social skills) and maintaining placements. Children need positive school experiences and peer relationships. Adolescents need coping strategies, good family relations and positive peer networks as the adolescent transition may be especially difficult. Also, specially arranged mental health treatments and positive school experiences are helpful. For young adults, many problems are established by "negative feedback loops." They will need specialized treatments, life coaching or advocacy, specialized job settings, and protected living situations.

Dr. Olson also proposed creation of regional intervention training centers (e.g., for mental health providers and educators) and establishment of places for young adults/parents to come together. Established mental health and early interventions for ages 0-5, 5-11, adolescents and young adults need to be studied to see if they work in the FAS/ARND population. Good natural history studies are critical, as are intervention research studies in order to show what works. Finally, good diagnosis is vital so that we can find the people who need finding.

**Discussion:**

- Dr. Olson commented that Washington state has a database of 2,000 cases which could support studies like these. Medication studies could also be considered. “Early” FAS diagnosis in Streissguth’s secondary disability study was by age 6 years, but that could be influenced by the fact that this was a sample of clinical cases with critical problems and parents looking for help. Study of whether these children have more secondary conditions, or poorer outcomes, relative to when they were diagnosed, and comparison of that to the developmental disability data for the general population, is desirable.
- Ms. DeVries believed that this risk and protective factor approach is very effective with families.

**Individuals with Disabilities Education Act (IDEA)****Deborah Morrow, PhD, U.S. Department of Education**

The IDEA provides for the education of children who have an impairment that adversely affects educational performance. The question for this discussion is how does FAS/ARND fit into Part C and Part B of IDEA. Part C covers infants and toddlers with disabilities, birth through age 2 and their families and is administered by state health or education departments. Providers are trained to deliver direct services to the child in the home. Part B covers children and youth with disabilities, ages 3 through 21. A child covered under Part C should transition right into Part B if they qualify. Any help the Task Force could provide to foster the relationship between local providers and the state departments of health and education was requested.

The IDEA’s list of eligible conditions and categories does not include FAS, so the provision of special education for the condition of FAS is not a given. However, services can be gained through the IDEA under Part C: 1) if the state establishes FAS as a syndrome; 2) if the FAS effects result in a developmental delay; or 3) an “informed clinical opinion” by a Part C provider can override everything else (e.g., the child could at some point manifest a developmental delay). However, state cuts are threatening service delivery under Part C.

Part B of IDEA requires a multidisciplinary evaluation (at least 90 days to 6 months before age 3) of the child. The parent is included on this multidisciplinary team. Eligibility is determined by this group and if any one of several criteria are met, services must be provided (social, educational etc.). The 14 disability categories are developmental delay, autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, or visual impairment. Note that developmental delay is defined by the state. When educational symptoms emerge, the child can qualify if he/she has a delay in one or more areas. The delay can be characterized as physical, communication, cognitive, social/emotional, or adaptive.

FAS may manifest itself in one or more of the disability categories. The “label” for the child does not matter much. Once the school identifies a child with a disability, they must address *all* the child’s educational needs that result from the disability.

The Department of Education would welcome this Task Force’s encouragement to practitioners to teleconference with the criteria panels as these criteria are under review with the current

reauthorization of IDEA.

Dr. Morrow described several conditions and the related IDEA requirements. For all of these conditions, the symptoms have to adversely affect educational performance.

Autism - Under the category of autism, children are IDEA-qualified with the characteristics of repetitive activities, resistance to change, stereotypic movements, and unusual response to sensory experiences.

Emotional Disturbance - One or more characteristics of emotional disturbance to a marked degree also qualify for IDEA. This includes the inability to learn not explained by intellectual, sensory or health factors; inability to build or maintain satisfactory interpersonal relationships (peers/teachers); inappropriate behavior or feelings under normal circumstances; a general pervasive mood of unhappiness or depression, and tendency to develop physical symptoms or fears associated with personal or school problems.

Mental retardation is significantly sub-average general intellectual functioning (normal IQ is 70, but that is not necessarily universal). This is concurrent with deficits in adaptive behavior manifested during the developmental period to age 18.

Other health impairment includes limited strength, vitality or alertness, OR heightened alertness to environmental stimuli resulting in limited alertness with respect to the educational environment, and chronic or acute health problems (such as asthma, ADD or ADHD, diabetes, epilepsy, heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever and sickle cell anemia). This is the area under which children with FAS, though not listed, could possibly qualify (e.g., under “limited alertness”). The considerations listed are included in the regulations. More can be added to the state requirement without being specified in the federal legislation, however, they are more likely to be added if they are in the federal legislation.

Specific learning disability is disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations, including conditions such as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. It does not include learning problems that are primarily the result of visual, hearing or motor disabilities, of mental retardation, of emotional disturbance, or of environmental, cultural or economic disadvantage.

Speech or Language Impairment - This is a communication disorder such as stuttering, impaired articulation, a language impairment, or a voice impairment that adversely affects educational performance.

Traumatic Brain Injury - FAS does not qualify under this category since it must be due to an acquired injury due to external physical force that results in total or partial functional disability or psychosocial impairment, or both, in one or more of the listed areas. It does not apply to brain injuries that are congenital or degenerative or caused by birth trauma.

*Visual impairment* includes blindness or an impairment in vision that, even with correction, adversely affects educational performance.

In summary, the state determines criteria under Part C of IDEA. FAS children (aged 0-2) could be eligible for Part C if the state has determined that FAS is an established condition (state's decision), if the child exhibits one or more developmental delays, or if the child is identified through "informed clinical opinion." Eligibility under Part B (children aged 3-21) must be in one or more of 14 disability categories (see above). Developmental delay is at the state's discretion. FAS or other prenatal alcohol-related condition may manifest itself in one or more of the disability categories. When schools identify a child with a disability, they must address all of the child's educational needs that result from the disability.

To get more information on IDEA, 34 CFR, 300(b) Part C and 300.7 Part B, go to <http://www.ed.gov/about/offices/list/osep/index.html>. Dr. Morrow also suggested visiting state department of education (or lead agency) sites as well. Visit the National Early Childhood Technical Assistant Center (NECTAC) website at [www.nectac.org](http://www.nectac.org) to locate state-specific contacts.

#### ***Discussion:***

- A comment was made that an FAS-diagnosed child who does well with an early intervention can qualify as developmentally delayed, most likely diagnosed at the age 8 transition. In fourth grade, the child has fewer pictures to reference and has to start taking notes in class. That is why there is a high referral rate at age 8 for many children, not just those with FAS.
- The current reauthorization of the IDEA has dramatically changed assessment, now examining what is known about the child and determining if anything else needs to be known. If so, more information is gathered. Finely targeted assessments can now be done, and early referral is critical. Local physicians need to work with the Part C and IDEA agencies, and they need to be educated that doing so will save them much time later. Unless a child is connected to a good child evaluation center or multidisciplinary evaluation team, FAS is not likely to be discovered. Screeners generally test aptitude and barriers to learning rather than look for a diagnosis. A record of an FAS diagnosis is helpful for later reference if the individual runs into trouble with the law. Every state Part C interagency agreement also requires a council involving parents, another way to affect the policy world and provide an opportunity for state advocacy.

#### **Understanding and Accessing the Public Mental Health System**

##### **Oscar Morgan, National Mental Health Association (NMHA)**

The NMHA is America's oldest advocacy organization for mental health and wellness. The current public mental health system was built and funded for adults aged >18 years and those with chronic (now 'severe and persistent') mental health issues. There were few services to children aged <12 years. The concept of prevention was unknown and today is still controversial since that assumes that parents could have done something different. Now, the term "early intervention" is preferred.

When the child's emotional disturbance precludes the school's responsibility to pay for the service, and it becomes the responsibility of the public health system, issues of access to services

still need to be addressed. Since the mental health system requires a diagnosis to get services, those children began to be labeled “conduct disorder” to reflect the underlying interpersonal difficulties. Very young children are often difficult to diagnose and a psychiatric diagnosis may follow them throughout their life, even if, in some cases, it is incorrect.

The definition of the “mental health care system” is another issue. Those mental health services funded by Medicaid are outside the purview and policy making of the state mental health system. Only ~3% of funds for state systems come from SAMHSA, and most of that 3% is directed to those aged 18-45. The Medicaid portion of funding is expected to grow to 60% in the next few years. Then, there is the school system (under IDEA), the social services system (under Title IV and foster care), and the juvenile justice system. The mental health system is probably the last to provide services, and if so, probably does so with little funding, since children have been a low priority in the public health system.

*Opportunities and challenges:* Medicaid’s Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program requires states to screen for a variety of health issues, one of which is alcohol/substance abuse early and periodically among those aged 0-21 years, and to provide appropriate services, even if these are not provided by the state in its approved Medicaid program. However, the lack of trained mental health professionals to execute the program has caused EPSDT to be underutilized. The Children’s Health Plan of 1997 expanded Medicaid eligibility for children, but state budget cuts are affecting that eligibility and those services.

At least 70%, probably 90%, of the women incarcerated for misdemeanor crimes are usually in prison due to early childhood trauma that led to substance use. Some very interesting programs are looking at children and how they are affected if the mother has abused alcohol or drugs. The concept of co-occurring disorders supports that substance abuse cannot be separated from other problems; all need to be treated. That concept needs to be applied to children, at least for screening, either through state Medicaid, CHIPS, the IDEA, or other programs. If the Task Force has or knows of an appropriate screen for children, Mr. Morgan asked that they supply it. Finally, he applauded this Task Force’s work and validated the things being expressed at this meeting.

***Discussion:***

- Foster children are Medicaid-eligible. Medicaid is also responsible for children with FAS in adoptive families (within the context of the Social Security Administration). Supplemental Security Income (SSI) recipients may have their own contracted mental health providers. Even on a state level, the Department of Social Services and the mental health system may have different criteria for accredited care. And in most states, parents have to give up custody to get the child on Medicaid. Some federal legislation is being proposed to address this.
- The EPSDT program reimburses for services, except pediatrician-diagnosis of an emotional or psychiatric disorder. EPSDT screening is a state option which Dr. Scafidi hoped the Task Force would address. Even though a comparison of the costs of care in the community versus in an institution show the value of the former, it is very challenging to get a disabled child placed in an adoptive home eligible for Medicaid, using EPSDT.
- The state-mandated Medicaid Advisory Committees should have Task Force representation

to at least inform the discussion and facilitate some changes in state Medicaid plans.

**Mississippi State-Based FAS Program Initiative**  
**Brenda Scafidi, EdD, Mississippi Department of Mental Health**

In her work in the mental health field, there have been many labels. The classification of “learning disabled” was followed by relevant assessments, after which it became “brain damage” and then “minimal brain dysfunction” when the damage was not visible on an EEG. Then came IDEA, which categorized many children. But the one least identified, or under-identified, was the category for “emotionally disturbed.” Today, the gap between science and practice needs to be bridged.

The number of Mississippi children identified and served rose with the inauguration of Medicaid reimbursement from 1,000 in 1988 to 20,000 children in 2002. In December 2002, Mississippi formed an Interagency Coordinating Council for Children and Youth (ICCCY) with Serious Emotional Disturbance (inclusive of conduct disorders and behavioral emotional problems). It included a statewide organization of families with children with emotional disorders. They appointed the mental health department as the executor of the Initiative.

To coordinate the multidisciplinary assessment and planning teams, a state-level team was assembled that still operates about once a month. They review the cases of children, typically in foster care, receiving severe care treatment either out of the state or in the public system because nothing appropriate was available. Since such external treatment was costing millions per year, the ICCCY was charged to identify other services. In 1997, a system was created that required the state legislature to create multidisciplinary assessment and planning teams (“making a plan [MAP] team”) to identify team responsibilities and to coordinate funding to serve the children through them. That kind of a structure is absolutely essential. The MAP teams meet once a month, with broad representation, to review the needs of special education children, and to find resources to keep them in the state.

Legislation, supported by the Mississippi Attorney General (AG), was passed that established a division in the AG’s office for children with emotional disturbance (ED) from family violence, sexual abuse, etc. Even unfunded, this would allow coordination, so Dr. Scafidi found unused funding and hired a coordinator for the division.

The ICCCY identified gaps and limitations in the existing system for children with ED including the following: there were different definitions and ways to identify this population; the policies/plans and procedures in place to address ED differed; agencies had limited awareness of the services and grants applicable to ED; there was no inter-agency training consolidation; there was limited data collection and use relevant to this population; restricted funding categories were not easily broadened within/among agencies; and interagency matches to maximize resources (budgets, grants) were underutilized.

The ICCCY recommended that the system be available, accessible and accountable. Dr. Scafidi developed a triptych (graphical representation of existing systems), describing each agency’s sections and subpart programs relevant to these children in order to make the path clearer to the parents and families needing this help. The triptych provides a schematic of the systems of care,

described the IDEA legislation, a system of care model, what to look for entering services, etc. It provides and supports a single point structure to identify the children targeted, and available resources and their function.

The ICCCY also recommended: 1) the development and implementation of interagency policies and procedures to correct the gaps above, plus evaluation measures of service delivery and costs; and 2) provision of a single point structure to implement and operate a system to identify targeted children and to define accessible resources. Dr. Scafidi added several special efforts:

- Focus on children, aged 0-5, most at risk of serious emotional disorders (SED), youth 14 and up (transition age), and adolescents with SED who are also chemically dependent or substance abusers.
- Improve the significant underutilization of EPSDT in screening/identifying children under age 6 who are most at risk for being or becoming SED (e.g., one or both parents are seriously mentally ill and/or substance abusers).
- Include children, aged 0-3, most at risk for becoming SED in the existing Early Intervention Programs of the Departments of Health and Mental Health. Federal regulations allow this; it is a state option. Mississippi approved a plan for this and are working on the legislation.

To address accountability, the as-yet unapproached category, since evaluation was never done, a \$35,000 block grant was awarded to help each of the 15 mental health MAP teams bridge the gaps. To connect the science (identify, measure, prescribe) with the outcomes of practice for children and family, the systemic steps are to: 1) increase the MAP teams, 2) add FAS to the interagency agreement as a priority; and 3) add FAS to the existing assessment tools and intake forms to determine the number of FAS-affected children. Detention centers are in shambles in this country and they hold children with prenatal alcohol exposure. The prevention of alcohol and drug use needs to be more prominent in the service model than it now is. "Prevention" to Dr. Scafidi means education across the state of Mississippi about these children and how to care for them.

***Discussion:***

- *How did the town hall meetings and implementation seminars affect this system development?* Experts were brought in to advise on the development and to motivate agency staff. Training on the use of instrument Dr. Larry Byrd developed in South Dakota was provided to 50 people from community centers, Catholic Charities, and other community groups. Now the state wants to go further, to look at dysmorphology and other issues. A state resident, who was in George Bush, Sr.'s administration, has exercised her political influence on behalf of FAS. Dr Scafidi's Initiative funding was turned over from the Division of Alcohol and Drugs when the Division's director went to the town hall meeting. Now, a mental health population can at last be definitively identified through personal history, dysmorphology, etc. FAS' close relationship to conduct disorder could pose implications that would make a difference in the lives of juvenile court judges desperate for some resolution to the cases they try.
- *How would you summarize the unique challenges of providing mental health services to children with FAS?* First, find them and find a way to make them visible. Concurrently, look at the state resources accessible across all nonprofits, CBOs, academia, etc. to find a way to create a vehicle to move people into services in an unfragmented way, and work

to combine processes of the many agencies to identify and serve these children, modifying policies and procedures accordingly. Also, involve someone from epidemiology and research from the beginning and be an advocate to other offices and agencies. A few thousand dollars and a donated office began the Mississippi System of Care for Children and Youth Research and Training Institute. They facilitate discussions by all agencies about anything they would like to do better, invite groups to the Center, which is a room, and then assemble people with pertinent knowledge to discuss the issues.

### **NIAAA Update**

#### **Faye Calhoun, PhD, Deputy Director, NIAAA**

The agenda of the Interagency Coordinating Committee on FAS (ICCFAS) December 12th meeting includes meetings of the Education and Juvenile Justice Subcommittees. Judge Linda Chisholm will work with the Juvenile Justice subcommittee and do other work related to alcohol issues in the legal/justice systems. That hopefully will generate information that could be disseminated to probation officers and others in the juvenile justice system. The ICCFAS will also work to map the progress made by the various agencies represented on the ICCFAS to identify overlaps and remaining areas of need. Appropriations language specifying the agencies' work occasionally will be redundant (e.g., between SAMHSA/CDC and CDC/NIAAA). However, the prevention efforts do not necessarily overlap, due to the different populations involved and methods used. For example, NIAAA is studying how to train bartenders on how best to recognize a pregnant woman and offer a soft drink rather than alcohol while CDC is testing a brief intervention strategy for women in high-risk settings. The agencies just need to better coordinate the research being done and the ICCFAS will work to achieve this.

Dr. Calhoun is interested in Task Force's discussion on the ethical aspects of diagnosis, FAS recognition and service provision. How can we reduce the requirements for identification and service provision to under-performing children in the educational system to allow research on and progress in addressing those issues. She also suggested a report from CDC on how criteria for other conditions, such as ADHD and autism, were developed to allow their listing within IDEA. The criteria of those conditions are not much clearer than FASD, and they have distinguishable but overlapping areas, similar to FASD. A similar process for FASD would be desirable. She urged the Task Force to get this information and to work with other groups for potential application to FAS.

### **Discussion:**

- Dr. Cordero indicated that autism has several measurement instruments validated by research, so in that regard it is in a different category than FAS diagnosis. Dr. Cordero welcomed the Task Force's development of FAS diagnostic guidelines and further development of criteria as another important related step. ADD/ADHD diagnosis is less specific; rather than one condition, they are a behavior set coming from approximately 6-7 underlying disorders dictating how the brain reacts (shown by brain imaging). Dr. Brenneman added that the science is clear and ADHD has specific behavioral tests not yet available to the FAS field for a specific diagnosis. Dr. Calhoun agreed, but persisted that the field has to decide how specific those will have to be and then focus on getting that done. She maintained that this should not be more difficult than for categories of ADHD.

**Public comment** was solicited with no response from the audience.

**Discussion of Task Force Involvement in Policy Issues Regarding FAS Services:**

*Surgeon General Statement.* A request has been submitted to the Surgeon General on behalf of the Task Force to recommend reissuing the advisory about alcohol use in pregnancy, especially on this 30<sup>th</sup> anniversary of Ken Jones' publication on FAS. A response from the Surgeon General's office is pending. Dr. Cohen expressed appreciation to Ken Warren for writing the multiple drafts of the advisory, which involved extensive research. The final version of the letter to the Secretary and the advisory will be e-mailed out to the members.

*FAS and Education Requirements.* Dr. Riley asked, since this Task Force is supposed to offer recommendations to agencies at the federal, state and local levels, if the members wished to draft letters to each state about including FAS in its education requirements. Dr. Floyd requested further deliberation on this issue, examining the advantages and disadvantages of such requirements. There are various relevant players not present today; representatives from juvenile justice, foster care and social services, and financing who could provide valuable input to this topic. She suggested that a workgroup study explore this issue in depth and then report back to the Task Force. Dr. Schad favored that idea, having seen the success of the Western South Dakota Task Force's inclusive approach.

In response to Ms. Scafidi's presentation, Ms. Devries said that she appreciated the development of state systems of care and agreed that mental health training needs to be done on many levels. The FAS/FRI advocated for support of Mississippi's efforts. Mississippi was able to identify a funding stream to help the children without having to have "FASD" attached to it.

Ms. DeVries distributed copies of FAS\*FRI's 2003 Final Report to SAMHSA FASD Center for Excellence to Task Force members. She expressed concern that the voices of families often go unheard and representatives from family advocacy groups are not able to meet due to lack of funding. FAS/FRI coordinated the SAMHSA-sponsored town hall meetings over the last two years and families are anxiously awaiting the final summary report from those efforts. Ms. Gass indicated that the summary report from the town hall meetings was in their 2004 work plan.

Dr. Riley suggested that the document distributed by Ms. Devries be reviewed overnight for discussion in the morning.

Dr. Cordero summarized the following action items for the Task Force's attention:

- Determine how to educate health care providers, beyond physicians and nurses, on the early recognition of FAS in children.
- Determine how to build on efforts in other fields that recognize the importance of early screening, to the benefit of FAS.
- Bring CMS and Medicaid to the table to learn more about financing and EPSDT in order to learn how the approaches to screening and financing of the services needed by children with FAS could be accomplished.
- All agree that early diagnosis is critical; it should be a future meeting topic.

Dr. Cohen added the perspective of the Scientific Working Group's Essential Services

Subcommittee. Beyond early identification and diagnosis, a system linking prenatal and risk reduction services is needed, and then a system for presumed eligibility due to alcohol exposure needs to be put in place until the child is old enough for diagnosis. With documented prenatal exposure, the child's eligibility is presumed and s/he can get into the service system and be followed. Trying to figure out what the cut points should be for special education and other specific service systems will just bog the discussion down. The real issue is how to get the prenatal and pediatric systems to talk to diagnostic and health care systems to ensure that screening is done and that there is clinical integrity among those making the diagnosis. It cannot be assumed that every clinician is a diagnostician.

Dr. Calhoun reiterated her conviction that whatever problems ADHD and autism had in early recognition, diagnosis and financing, must parallel those of FAS. She urged the Task Force again to find out what they did, what their (or anyone else facing such issues) successes were and what could be applied to FAS.

- Dr. Vinson pointed out that research and primary care are different arenas with different implications. With an FAS incidence of ~1/1000, an average family physician doing obstetrics will see one FAS case in a thousand babies delivered in a career; a pediatrician will see ten times that – ten FAS children. That is an insurmountable diagnostic challenge for the physician. With that incidence and a 3% positive predictive value of the Streissguth screen, only one child out of thirty screening positive will actually have FAS. Referring all those for services will further overload swamped systems and unnecessarily create anxiety in parents (although the child may have other conditions identified). Solutions suggested by Dr. Vinson included: asking ACOG to put more detail onto the routine prenatal form to improve communication between general and obstetric care providers; creating one point of entry for the provider so that s/he need not have to make multiple diagnoses to match the child to all the needed services; and perhaps, instead of adding children to existing adult services, the system should think of the child and provide a range of services from one place. It is important to note, as indicated by other Task Force members, that these estimates are based only on children diagnosed with FAS and do not take into account those children with other prenatal alcohol-related conditions. The estimates also assume that cases are equally distributed through all obstetric and pediatric practices.

Other Task Force activities suggested by members included:

- Dr. Wright suggested that at future meetings, have people provide a state of the art on the hard science as opposed to the social sciences. For example, ADHD had a huge driver, the pharmaceutical industry, which inadvertently produced a drug for another purpose that was found to benefit ADHD. Its need to defend itself and articulate the case for that use and for better drugs led to the research/education process far more than morphology or other reasons will. Better articulation of the science could allow such a discussion related to FAS and could produce functional models applicable to different drugs and responses. At least, the investigators doing that type of research could be identified, who can link the criteria to the disease (e.g., an MRI can be used to show that they meet the insurance industry's "medical necessity" for reimbursement).
- The Task Force could work with plastic surgeons or companies such as Pediatrix, which delivers 10% of all the babies born in the U.S. and ask them to photograph every baby for

- modeling in 3D (as done by computerized photos of the eye for assessment of blood vessels).
- An “FAS 101” packet should be assembled for all new members.
- It was suggested to revisit the 2002 Task Force recommendations and assess their status and also identify those not yet addressed and find a mechanism to make them happen.
- A future agenda should include discussion of related issues of personal liberty (e.g., potential prosecution of pregnant women who drink; bartenders refusing to serve a woman).
- This Task Force was formed by Congressional mandate, so someone on Capitol Hill must care what the Task Force does. Thus, this Task Force’s recommendations on research, training and services will probably therefore at least get a respectful hearing.
- The Mississippi-style graphic layout of access to resources is needed by judges too, as relevant to their defendants and witnesses. Judges can be accessed through state bar exams and through the minimum core programs required by their annual insurance. Establishing the definitions and making the issue accessible at the local level (i.e., terminology) to probations officers, social workers, lawyers, etc., will make the topic of FAS less intimidating and they could then focus on what they need to do about it. A policy at the federal level will facilitate tackling this at the local level. A uniform definition for FAS in itself will bring familiarity and perhaps the results being sought.

With no further comment, the meeting adjourned at 4:30 p.m.

### **DECEMBER 9, 2003**

Ms. Kathleen Mitchell joined the meeting on this day, and Dr. Calhoun was absent.

#### **Discussion of Task Force Involvement in Policy Issues Regarding FAS Services (cont.):**

*Education/Teacher Credentialing.* Dr. Schad recalled that parent feedback at many town hall meetings included the need for accurate diagnosis and awareness of FAS by those in the education field. **He moved that the Task Force recommend that teachers be required to complete a 3-hour semester course on FAS prior to certification, effective as of January 1, 2006.** This would be passed on to DHHS and then to the Secretary of Education for federal dissemination. Ms. DeVries stated the FAS/FRI believes that there has not been enough public awareness done at any level, and seconded his motion.

Dr. Floyd anticipated that a broader view of prevention will be addressed at a future Task Force meeting. Relevant curricula are being developed and could be used in these education efforts. CDC’s awareness and education projects are targeting school staff, as well as administrators and nurses. These projects are currently underway at the ARC, the Educational Development Center, the Double Arc, and the National Indian Justice Center (specifically focused on law enforcement personnel). Ms. Parra, the CDC technical monitor, agreed to provide more information about these curricula. Both CDC and NIAAA have funded a K-12 curriculum, which could also be reviewed for possible additions. School children, especially from age 7-11, begin to form opinions and patterns that can influence others, as demonstrated with seat belts. They are also beginning their reproductive futures, offering a good opportunity to start early with prevention efforts.

Dr. Cordero asked what processes and key steps will allow a demonstrable reduction of FAS in

about 5 years? Dr. Vinson reiterated the need to help generalists to recognize FAS and to provide a single referral point. Some Task Force members voiced their frustration at not having achieved something solid to make a difference in the affected populations. Ms. Mitchell stated that the town hall meetings' findings and the gaps identified need to be utilized and addressed, particularly those related to education (which were known even before the Task Force formed). A Task Force workgroup on education could be formed, similar to that of ICCFAS, with the Departments of Education and Justice. Dr. Riley commented that this issue was included in the Task Force recommendations of 2002 (#13 - to develop and disseminate a plan for a system-wide education on prenatal alcohol-related disabilities and #15 - teacher credentialing requirements). Dr. Cordero suggested a regular review of the Task Force's 2002 recommendations to determine what has been done and what has not, and if the latter, why not.

Dr. Damus indicated that once things are introduced to schools, it is a challenge to change them later. She urged that "prevention" be defined more broadly, with the first module stating the entire problem, and then subsequent modules focusing on specific areas. It was agreed that the SAMHSA and Mississippi presentations provided good models for establishing a system of care and the need for a single referral source.

It was noted that a Task Force recommendation for more research on systems of care for FAS children and implementation of a prevention curriculum would depend on having a standardized diagnosis of FAS. But at least, FAS-educated teachers could be enabled to identify behavioral problems and refer them to someone with training in the diagnosis. The Department of Education's authority to mandate to school districts is questionable. In general, the state or the school district makes such recommendations.

Dr. Cordero summarized that there is agreement that the Task Force would recommend educating teachers about the identification, treatment and prevention of this disorder. This could be in the format of a strong recommendation, as is done by the Advisory Committee on Immunization Practices, which is embraced by every state through their state laws.

However, three semester hours constitutes 45 hours of lecture, which is not practical to mandate for all public school teachers. Also, FAS is neither the most prevalent nor the most deadly of the many problems needing address. Three hours in health behavior education were suggested instead. Teachers just knowing of FAS and believing it is real could be sufficient when parents report that their child has FAS. Dr. Coles reported the Marcus Institute's experience that the school systems are very receptive to information on how to identify and address FAS. But implementation is complicated and needs to reflect how things really work in the system. The state board of higher education sets the curricula and examines credentialing issues. FAS should be included in teachers' health/prevention training and in special education, along with the other disorders.

**Dr. Schad revised his motion to recommend that teachers complete a course on FAS as part of their certification and suggested that this be done effective as of September 1, 2006.**

**Vote:**

In favor: Cohen, Schad, Barry, Riley, Coles, DeVries, Myers

Opposed: Mengel, Caetano

Abstained: Wright

**The motion passed.**

**Dr. Cohen moved that the Task Force recommend that FAS be included in the reauthorization of IDEA under “other health impairments.”** Dr. Schad seconded the motion and Dr. Brenneman expressed his support as well.

Dr. Cordero stated that this would name FAS specifically under “other health impairments.” Dr. Coles reported that an ICCFAS subcommittee reviewed this issue in great detail and argued that FAS should be inserted as a clean diagnosis like autism, rather than as a spectrum condition such as autism disorder, to get a foot in door.

**Vote:**

In Favor: Cohen, Schad, Barry, Caetano, Riley, Coles, Mengel, DeVries, Myers, Wright

Opposed: None

Abstained: None

**The motion passed.**

Dr. Cordero stated that the agencies would advance these recommendations and report back as an action item moves forward from the CDC director to the Assistant Secretary of Health and the Secretary of Health. Congress will consider the reauthorization of IDEA in Spring 2004, so this recommendation requires quick action.

Dr. Floyd suggested that the relevant agencies be brought to this meeting to report on how they are advancing the 2002 recommendations of the Task Force. Dr. Riley noted that the Center for Excellence is compiling each of the agencies’ work, successful or not, which should provide a matrix on what is being done.

**Update on Scientific Working Group on Diagnostic Guidelines for FAS/ARND**

**R. Louise Floyd, PhD, Team Leader, CDC FAS Prevention Team**

In the 2002 Appropriations bill, the Departments of Labor, Health and Human Services, and Education and related agencies requested that CDC: 1) develop guidelines for the diagnosis of FAS and other negative birth outcomes resulting from prenatal exposure to alcohol; 2) 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; 3) disseminate curricula to and provide training for medical and allied health students and practitioners regarding guidelines; and 4) coordinate these efforts with the National Task Force on FAS and FAE, existing federally funded FAS prevention programs, and appropriate non-governmental organizations.

In response, the NCBDDD convened a scientific workgroup (SWG) with representation of clinicians, researchers, parent advocates, Task Force members, CDC, NIAAA, and SAMHSA. Three meetings and numerous conference calls were held to discuss FAS screening and diagnosis, essential services for children and families, and identifying/intervening with women at risk. The criteria presented on this day are in their fourth draft, and these were approved by the

Task Force earlier this year. Its text also incorporated recommendations and input from parents.

The diagnostic criteria for FAS are:

1. Face: Based on racial norms, the child exhibits all three characteristic facial features: a smooth philtrum and thin vermilion (measured at 4 or 5 on the University of Washington lip-philtrum guide), and palpebral fissures measured at # 10<sup>th</sup> percentile).
2. Growth: Prenatal/postnatal height and/or weight # 10<sup>th</sup> percentile, documented at any one point in time (as long as the child is not nutritionally deprived at that point). This is adjusted for age, gender, gestational age, race and ethnicity.
3. CNS or neurobehavioral disorders: These include an array of structural and functional problems and/or neurological abnormalities of the CNS:
  - CNS/structural: a) head circumference # 10<sup>th</sup> percentile, adjusted for age and gender (including head circumference at birth), b) brain abnormalities observable through imaging techniques (e.g. reduction in size and/or change in shape of the corpus callosum, cerebellum or basal ganglia).
  - CNS/neurological outcomes may include seizures not due to a postnatal insult or other signs such as impaired motor skills, neurosensory hearing loss, memory loss, or poor eye-hand coordination.
  - CNS/functional outcomes: The domains most often cited for individuals with FAS are cognitive deficits or developmental delay, executive functioning deficits, motor functioning delays or deficits, attention and hyperactivity problems, and social skills. Deficits can also include sensory problems, pragmatic language problems, memory deficits, and difficulty responding appropriately to common parenting practices. Difficulty in any of these areas can lead to maladaptive behaviors and mental health problems.
4. Maternal alcohol exposure can fall into one of three categories: confirmed prenatal alcohol exposure, unknown prenatal alcohol exposure, and confirmed absence of exposure.

An additional note on environmental impact was added to the Guidelines: “When evaluating an individual (especially children) for the CNS deficits of FAS, it is important to keep in mind that many individuals with this disorder experience significantly disrupted home environments. They may be raised in a substance abusing family, spend time in the foster care system (usually with multiple placements), and/or be adopted (including international adoptions). Such environmental factors also affect children’s CNS functioning. Thus, environmental contributions should be considered for both inclusive and exclusive purposes when evaluating a person for the FAS diagnosis.”

Dr. Bertrand briefly discussed how the SWG ARND work group addressed the CNS criteria for FAS. Since the scientific evidence and professional consensus on CNS criteria was not at the level of specificity equal to that available for physical features, the group decided that the best approach at this point was to offer general guidelines to the clinician in identifying areas of deficit most likely to be founded with individuals with FAS. Those working in the SWG ARND working group and other experts (clinicians and researchers with extensive knowledge and experience with individuals with FAS or related conditions) were asked to select 5 key domains (and examples of behaviors associated with each) that they see most frequently in individuals

with FAS. Those described above were the domains identified. Additionally, information from the scientific literature further supported the presence of the domains and behaviors identified by the group.

Thus, diagnosis of FAS requires all of the following: documentation of all three facial abnormalities, documentation of CNS/neurobehavioral disorders (structural, functional, and/or neurological), and documentation of growth deficits. Confirmed prenatal alcohol exposure can strengthen the evidence for diagnosis but it is not necessary in the presence of all of the aforementioned categories. In terms of CNS, there was consensus that the domains should be inclusive rather than exclusive. The Guidelines specifically state that “Any one structural abnormality, neurological problem, or poor performance in a functional domain, meets the criteria for a CNS problem.”

The criteria for initiating a referral for a FAS diagnostic evaluation mirror the diagnostic guidelines. Referral for FAS diagnosis should be made:

- 1.) With confirmed heavy prenatal alcohol exposure
- 2.) In the following instances (with or without maternal alcohol exposure – although this strengthens evidence for referral):
  - Any report of concern by a parent or caregiver (foster or adoptive parent) that his/her child has or may possibly have FAS.
  - All three facial features are present.
  - One or more facial features are present, along with growth deficits in height and/or weight.
  - One or more facial features are present, along with one or more central nervous system or neurobehavioral deficits.
  - 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 pediatric specialist, an FAS clinic, a genetics clinic, a dysmorphologist, or another provider specialist. Two other considerations for referral and follow-up are: 1) if the child has growth deficits and one or more structural or neurological deficit and there is no information on alcohol exposure, referral may be appropriate according to the clinician’s judgment, and 2) 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.

Additional components of the Guidelines currently in development are sections on essential services for affected individuals and their families (a draft is in review) and another on identifying/intervening with women at risk for an alcohol-exposed pregnancy. Also, appendices that include relevant assessment instruments (e.g., for anthropometric measures) referred to in the Guidelines report will be added.

Action items for the Task Force were to review and comment on the current report; provide input on the need to include in the report examples of appropriate standardized psychometric tests for

assessing CNS domains affected by prenatal alcohol exposure, consider proposed interim diagnostic criteria for ARND based on the work of the SWG, and offer insights on the use of the term “Fetal Alcohol Spectrum Disorder.”

Included in the Task Force members’ packets, and summarized by Dr. Floyd, were two articles (by Streissguth & O’Malley, Barr & Streissguth) that were among the first to use the term “FASD.” It was proposed to define FASD as an umbrella term used to describe a group of conditions that share a common etiology (alcohol exposure) and common developmental abnormalities including adaptive functioning, attention and memory problems, distractibility, learning problems, poor judgment and fine and gross motor difficulties. Also, the Task Force’s consideration was requested of the often-heard comment that the FAS diagnostic criteria do not go far enough. Children without “the face” have all the same CNS problems, just as or even more severe, as those who have the characteristic facial features of FAS. A proposed addition to the Guideline criteria could be to have the diagnostic criteria for ARND (with or without the face/growth deficits) be the same as the CNS criteria for FAS that is currently proposed in the Guidelines. Dr. Bertrand added that this would also include children with the three facial features but no growth.

Until scientific evidence is available to move beyond what the SWG developed over two years, this addition was proposed. CDC has addressed its mandate to set criteria for FAS. It was now up to the Task Force to discuss if CDC should continue to explore the issues around “other prenatal alcohol-related conditions.”

#### **Discussion:**

- *Does this abandon the IOM criterion of documented alcohol use in pregnancy?* No, documented exposure strengthens these criteria, but for many foster or adopted children, there is no confirmed information. Also, the IOM report includes FAS criteria with and without documented alcohol exposure similar to the Guidelines.
- Dr. Riley advocated for use of the term Fetal Alcohol Spectrum Disorders. However, it is important to note that this is not a diagnostic category. He also indicated that the definition proposed for ARND could be interpreted as any child who stumbles or has a behavioral problem and whose mother admits using any alcohol use during pregnancy. Dr. Floyd agreed that some statement should be included indicating a risk-level of prenatal alcohol exposure rather than any level of drinking, which could include low-level drinking.
- Related to the proposed definition for FASD, Dr. Damus noted that the actual etiology probably will be unknown. It may possibly come from a genetic as well environmental interaction.
- Dr. Damus noted that the Royal College of Obstetricians still allows up to 7 drinks a week since they had not found an excess of birth defects below that level of exposure. She wished the document would broadly endorse no alcohol intake at all during pregnancy, in view of other likely adverse outcomes including FAS (e.g., fetal death, preterm birth, low birth weight, the likelihood of poly-substance abuse).
- These guidelines were not intended to be a monographic review of all data on alcohol use and pregnancy and not to define FASD. The intent is to define diagnostic criteria for FAS and other prenatal alcohol-related conditions. They were to help physicians identify children with FAS.

- Dr. Damus thought that FASD should be the umbrella term for all of the outcomes of alcohol use in pregnancy, including preterm delivery. The FASD definition should not change with each document. The field is already confused enough. On the other hand, Dr. Floyd wished to avoid a definition so broad as to be meaningless.
- Dr. Vinson suggested greater clarity on page 14 of the Guideline document that “confirmed absence of alcohol exposure” absolutely prevents the child’s diagnosis with FAS, even if s/he has all the facial features. Such denials are both credible and not credible.
- Dr. Coles strongly emphasized that the state of the art is not such as to yet allow any diagnostic guidelines based only on behavior. Dr. Caetano added that if the diagnosis can only be made with confirmed heavy drinking by the mother, “heavy” needs to be defined; and if that is required, it needs to be a criterion. The criteria should be facial abnormalities, growth deficits, CNS abnormalities, and alcohol use. Dr. Riley said that any suspicion of heavy drinking prompts referral; anyone would refer a child potentially heavily exposed to alcohol. But for an FAS diagnosis, the exposure is either confirmed, not confirmed, or unknown. However, it was noted that there is often little information to be confirmed. Having any documentation at all is rare, except perhaps for woman in treatment. That is why there is a threshold of exposure at the diagnostic level.
- The Streissguth group’s articles discuss affected individuals. The Canadian guidelines discuss individuals affected by FASD. The Sokol article in *JAMA* discusses how a common term such as “FASD” “... will allow researchers and physicians working with affected individuals to better understand and describe them.” At the APHA, a CSAT representative stated that “FASD” is a non-diagnostic term to describe the broad array of abnormalities or anomalies that can happen to a fetus or a child because of the mother’s use of alcohol.” There needs to be some consensus across agencies and within the field on how this term is used.
- There was further discussion of the paragraphs on ARND and FASD, which had been added only in the last week and was not yet integrated throughout the document. Dr. Cordero suggested to general agreement that the Task Force finish its charge to develop specific guidelines for clinical use for FAS, and then separately define what “spectrum disorders” are. Ms. DeVries thanked Dr. Cordero, Dr. Floyd, and Dr. Bertrand for a wonderful document. Dr. Cohen also commended CDC for their work on the diagnostic guidelines for FAS.

### **Update from Health Canada’s National Advisory Committee on FASD**

#### **Jocelyn Cook, PhD and Julie Conry, MD**

Dr. Cook explained that the Canadian Health Ministry is comparable to the U.S. DHHS. It issues all documents through the Departments of Health and Health Canada. They have an 18-member, multidisciplinary national advisory committee, which meets several times a year to advise the Health Minister on FAS, its effects on families and ways to improve quality of life. The provinces execute the services and education; the committee only advises the Health Minister and Health Canada on the federal role. They have developed a brochure in English and French (“Framework for Action for FASD”), which has the same outcome measures as discussed at this meeting.

The draft Canadian Consensus Guidelines for FASD uses FASD as an umbrella term covering the spectrum of caused disabilities. The Guidelines were developed over 18 months and were reviewed for feedback (not endorsements) among multiple groups (e.g., the Canadian Medical Association journal, health professional associations, etc.) and the provincial health ministries.

They held ten meetings, which included American representatives and Health Canada diagnosticians.

The guidelines go from screening through the follow-up process, and discuss partial FAS, ARND, and FAS. They based FAS diagnosis on growth at #10<sup>th</sup> percentile and the three facial features; for ARND, only brain outcomes but no facial features; and for partial FAS, one or more facial features. They used the IOM wording and four-digit diagnostic code to relate the empirical measurements to the IOM guidance. Dr. Cook presented a table that compared and harmonized the IOM criteria with the 4-digit approach. The only difference in dysmorphology was with palpebral fissures; where CDC used #10<sup>th</sup> percentile, Canada used #3<sup>rd</sup> percentile (minus 2 standard deviations from the mean). The diagnosticians felt that using #10<sup>th</sup> percentile would produce too many false positives. Canada wishes to have as similar a definition to the Americans' as possible, but also take into account the two countries' differences (i.e., demographics, populations).

Dr. Conry summarized that the main areas of difference were that Canada did not distinguish between brain assessment (according to neuropsychological markers) for full FAS and ARND, and the number of areas or domains needed to determine whether a child shows brain damage or dysfunction as result of exposure. They were concerned about using only one criterion to indicate FAS. Developmental and language delay may be environmental, although not apparent until the environment changes. In addition, a heavy genetic background factor such as ADD or learning disabilities are important factors that might be erroneously identified as an alcohol-related problem. They decided that the three domains of impairment should be met for an FAS diagnosis. They also set the cutoff for all tests to be 2 standard deviations below the mean to increase the confidence that the problem is actually brain damage rather than some environmental conditions.

In terms of the CNS criteria, the Canadian guidelines are not divided by functional, structural or neurological domains as are CDC's, but rather include a list of deficits with evidence of impairment in three areas leading to a diagnosis. The head circumference is set at #3<sup>rd</sup> percentile; the IQ is specified; and they provide a little more specification for communication disorders (receptive and expressive), memory, executive functioning and other areas. They specifically included social skills in adaptive behavior. The clinicians also requested that assessment of both simple and complex tasks within domains be included. Younger children perhaps can do simple tasks, but not complex ones. The group recognized that domains overlap, which provides for the use of judgment by the multidisciplinary diagnostic team to determine brain damage rather than environmental effects. They also specified sub-domains (e.g., 1 standard deviation between verbal and non-verbal, or greater discrepancy with subsets). In the cases where some at-risk children who were exposed to alcohol but were not yet old enough to demonstrate differences in the brain domains (or to be tested in all domains), deferral of diagnosis was advised. The guidelines also discouraged the use of hearsay about the mother's alcohol use and advised great care with the documentation.

In making the FAS diagnosis, the Canadian guidelines are slightly more specific about brain function, but in general they harmonized their objective 4-digit code assessment with the IOM terminology. The IOM also referenced ARBD (Alcohol-Related *Birth* Defects), which their

experts felt not overly helpful, but they referenced that as well since they are not using FASD. They encouraged their clinics to use the 4-digit code to objectively describe the manifestations of FASD (to facilitate surveillance and research) as well as the IOM's criteria, description of the diagnosis and wording. Emerging issues of concern included biomarkers, remote (e.g., rural) diagnosis, and adult diagnosis.

### **CDC Agency Update**

Dr. Cordero reported on CDC's Futures Initiative. This CDC-wide strategic planning process is being done using an "outside-in" approach, to gain input from CDC's "customers" on the directions and issues the agency should address. NCBDDD has received responses from different organizations such as the March of Dimes, AAP, AAFP, etc., and this will be an ongoing process. All CDC advisory committee Chairs will be contacted for input. Information on the Futures Initiative is available on CDC's website.

NCBDDD will hold a national conference July 25-29, 2004 in Washington, D.C. on birth defects, developmental disabilities, disability and health, and hereditary blood disorders.

NCBDDD is almost fully staffed except for a position for Director of the Division of Birth Defects and Developmental Disabilities. The Task Force members' nominations for this position were solicited. Dr. Steve Thacker is the Chair of the Search Committee for this position.

Dr. Floyd reported that CDC funded 5 state-based FAS Prevention grantees in six states to monitor FAS at the state and county level and implement prevention activities. CDC is adapting individualized interventions, such as Project Choices for public health settings (e.g., family planning and STD clinics, as well as in clinics in university-based settings). Grantees are funded for a term of 5 years and include Michigan, Minnesota, Missouri, Colorado, and South Dakota (the University of South Dakota acting as a bona fide state representative and working in collaboration with the University of North Dakota).

### **Public Comment**

Dr. Heather Carmichael Olson offered several comments, as a member of the public and psychologist, for the consideration of the Task Force and CDC as the diagnostic guidelines are developed. FAS must be case defined to be reliably counted, well described and taken seriously by service systems. The guidelines are a genuine effort to advance the diagnostic field, and to include data-based, wide-ranging thinking on the diagnostic issues. She also acknowledged the CDC's scientifically driven process, which should continue. However, after reviewing the guidelines, she had some questions about head circumference cutoffs and CNS dysfunction criteria.

The CNS dysfunction criteria are in line with current data on alcohol teratogenesis and the structural, neurological and functional deficits that could occur. Excellent information is given on the types of deficits possible. But the criteria did not respond to the concept that alcohol teratogenesis generally has diffuse effects that often emerge as functional deficits in multiple domain areas. The guidelines should be clear that required multiple deficits could occur across domains, and should be taken as an indication of FAS rather than environmental impacts. Since the current guidelines only require one domain of function to be below expectations, the

definition could become clinically unreliable and of little clinical utility. This is important in regards to FAS, but crucial to ARND, where the CNS criteria are the only identifiers.

Further concerns were that:

- The numerical cutoff for IQ, now at low-average at the highest (generally interpreted as <85), includes a large population at risk. This should be checked against available clinical data.
- Clinical meaning is generally defined psychometrically, or as a clinical decision by a multidisciplinary team, or by consensus of individuals familiar with that kind of data and qualified to interpret it. Dr. Olson advised further focused consideration of the guidelines, providing clear notice that they are still under review, and stating that a continued review of ARND is underway. It is too early to publish a statement on ARND.
- Before finalizing the guidelines, CDC should send the document to SWG members with data from several databases to assess how many children would be identified. For example, if low/below average is used (-1, -0.5, -2 standard deviations), what proportion of the population would be so identified using the current FAS and ARND definitions, using one functional domain, and how many using two or three domains? These data would advance an understanding of how the guidelines would perform.
- Domains defined with psychiatric conditions: Generate these data with and without the mental health problems. They are defined differently, according to psychiatric conditions. For the ARND criteria, any individual with any one of those definitions would be labeled as ARND, making the alcohol-related disability diagnosis synonymous to the psychiatric definitions, a path Dr. Olson considered unwise to follow.
- In addition, examine the data on head circumference at different cutoffs to see how they would perform. Ask CDC and scientific consultants to provide input before the guidelines are finalized.
- The Scientific Working Group should offer input before publication.
- The environmental impact statement is so important as to deserve more attention than currently assigned. It somewhat differs, and should be harmonized with, the IOM's approach of ruling out people based on environmental considerations. (Dr. Bertrand said that this would be done).

Responses were:

- Dr. Coles commented that the examination of several databases could quickly enlighten how accurately the low/average numerical cutoff relates to exposure measures. Existing scientific information that could advise the guidelines should be used.
- Dr. Caetano thought that operational definitions would be needed before assessing the validity and reliability of the established criteria. However, Dr. Carmichael Olsen indicated that moving the guidelines forward is an important first step, so as not to stall the process by first operationalizing.

### **Closing Comments**

Work on the Guidelines will continue. Moving from the science to practical application requires further work. The issuance of the revised draft report will not wait until the next Task Force meeting (June 2004). The report will be refined with the input received from the Task Force via e-mail and conference call, and once approved, plans will be made to publish in an *MMWR* report. The report will also be sent to ACOG and AAP for dissemination, and perhaps submitted

to professional journals.

Also suggested:

- C Dr. Vinson – The following issue was not on the 15 Task Force recommendations put forth in 2002. He recommended a discussion for the next Task Force meeting of how to advance the research and democratic processes on how to change the educational systems, social welfare, juvenile justice, etc., to integrate them and make access to FAS diagnosis/intervention easier (e.g., recommend to Congress to support improved services for women/ children).
- C Dr. Riley – The FASD Center for Excellence will fund twelve \$100,000 grants that might fit be able to address the issue raised by Dr. Vinson if the SAMHSA and Labor/DHHS appropriations setting those funds aside are passed.
- C Dr. Coles – Diagnostic standards do not have adequate norms for the measurements discussed. Establishment of those norms should be a huge component of the criteria issued (e.g., palpebral fissures for African Americans aged 11 years). A major push is also needed for good diagnoses for those over age 4 years and adolescents, and for standards of care (Recommendation #8). Those undiagnosed before age 11 tend to remain so. At least acknowledge that these criteria are not useful for adults and adolescents, indicate that standards are needed, and support research to gather existing data to rectify that.
- C Ms. Myers – Do not wait for the ideal situation, especially where issues dovetail with the courts. Judges will start setting their own standards, once a consensus is reached on the diagnosis document. DOJ can send out a letter to state Boards of Justice and Examiners and the state Attorney General offices, telling them to begin referring people and building up the data. One solution may be to have the judges look at pictures of those before them when they were younger.
- C Drs. Caetano and Barry identified the need for more work on prevention issues. They suggested that future Task Force efforts could focus more intently on this area.

Dr. Cohen moved to adjourn the meeting, was seconded, and the motion was unanimously approved. **The next meeting will be held on Wednesday/Thursday, June 16-17, 2004.**

Minutes approved on 4/13/2004  
by Edward P. Riley, PhD  
Chair, National Task Force on FAS/FAE

## **Attachment 1: Summary of Action Items and Agenda Suggestions**

### **December 2003 Meeting Action Items:**

- Email the final version of the letter to the Surgeon General and the Advisory to Task Force members.
- Assemble an "FAS 101" packet for the new members.
- Revisit the Task Force's 2002 recommendations, assess their status, and identify those that have and have not been addressed. Take action on those items not yet addressed.
- Ms. Parra Dang agreed to provide more information about currently piloted curricula from CDC's awareness and education project targeting school staff, parents, and other groups.
- Develop a plan on how to proceed with the two motions that were passed by the Task Force (teacher education on FAS, inclusion of FAS in IDEA category "other health impairments").
- The FAS Guidelines report will be revised based on Task Force feedback offered at this meeting, revisions will be sent to Task Force for review via email, and a Task Force conference call will be scheduled to address the revisions.

### **Future Agenda Suggestions:**

- Invite representatives from the Centers for Medicare and Medicaid Services (CMS) to learn more about financing and EPSDT and how to better utilize these services to identify children with disabilities.
- Determine how to build on efforts in other fields that recognize the importance of early screening and intervention to help inform how to move forward with individuals with FAS.
- Discuss early diagnosis in general.
- Determine how to educate health care providers, beyond physicians and nurses, to recognize FAS and other prenatal alcohol-related conditions in children.
- Present the hard science related to prenatal alcohol exposure as opposed to the social sciences (i.e., identify researchers studying drugs and responses to them to explore possibilities of linking drugs to the condition).
- Discuss the related issues of personal liberty (e.g., potential prosecution of pregnant women who drink; bartenders refusing to serve a woman).
- Invite representatives from relevant agencies to report on how they are advancing the Task Force's 2002 Recommendations.
- Discuss how to advance the research and democratic processes and determine how to change the educational systems, social welfare, juvenile justice, etc., to integrate them and make access to FAS diagnosis/intervention easier (e.g., recommend to Congress to support improved services for women/ children).