National Task Force on FAS and FAE
Conference Call Summary
Thursday, May 13, 2004 – 2:00 p.m. EST

Task Force Members Present: Charles Schad, Jocie Devries, Kristine Berry, Jean Wright, Faye Calhoun, Claire Coles, James Berner, Lisa Miller, Deb Cohen, Raul Caetano
Liaison Members Present: Robert Sokol, Karla Damus, Sharon Davis
Chair: Edward P. Riley
Acting Executive Secretary: Coleen Boyle
Designated Federal Official: R. Louise Floyd
CDC Staff Present: Jacqui Bertrand, Mary Kate Weber, Martha Alexander, James Tsai, Patricia Price-Green, Tanya Sharpe, Jackie Vowell
Guests: Amanda Schwartz (Washington, DC), Carolyn Smith (TX Office for Prevention of Developmental Disabilities, Linda Morrill (TX Office for Prevention of Developmental Disabilities), Mary Gray Rust (University of TX at Austin), Amy Elliott (South Dakota), Paul Conner (WA), Ann Streissguth (WA), Sandra Gillendo (TX Department of Child Protective Services), Wendy Gale, Rebecca Reeves (NC), Deirdra Roach (NIAAA), Amanda Starts, Lee Ann Coamonda, Rebecca Stone (University of Oklahoma), Jan Pearson (VA), Robert Schott (AZ), J.J. Smith (reporter from Substance Abuse News).

Roll Call and Welcome
A roll call of Task Force members was done. A quorum of members was present so the meeting could proceed. Liaison members and other guests also announced themselves. Dr. Riley welcomed everyone to the call and reviewed the items to be covered during the call. These included an update on and discussion of the revisions to the CNS criteria outlined in the most recent version of the FAS Guidelines Report, updates on recent Task Force motions, a discussion regarding existing Task Force working groups, and public comment.

Update on the Revisions to the CNS Diagnostic Criteria outlined in the FAS Guidelines Report
Before the update, Dr. Floyd mentioned to the group that the document being reviewed today is in draft form so the full report could not be disseminated to guests who are participating on the call. The report was received by Task Force and Liaison members for review and comment. Jackie Vowell forwarded a one-pager providing background information on the FAS Guidelines efforts to members of the public via fax and/or email who indicated their attendance prior to the call. This can be found in **Appendix A**.

Dr. Jacquelyn Bertrand, who has been the CDC lead in the development of the Report on Guidelines for Referral and Diagnosis of FAS, provided the following update on the concerns that were raised at the December 2003 Task Force meeting regarding the CNS criteria component and how these concerns were addressed in the revisions to the document:

The following concerns about the CNS criteria were raised and further discussion and resolution were requested:

- How many domains are needed to indicate functional CNS impairment so as to differentiate between environmental exposure and prenatal alcohol exposure as causes for the observed CNS impairments?
- What level of deficits is required to indicate deficit in any particular domain (although this is a constant tug-of-war requiring balance)?
- Because levels of deficits were not specified, this gave the impression that the Guidelines were not endorsing strongly enough the use of psychometric testing during the evaluation process.
- At this point in the state of the science, defining ARND simply as the CNS criteria without dysmorphia or growth impairment may not be appropriate.

To address these concerns, CDC consulted with Dr. Claire Coles, one of the chairs of the ARND subcommittee, and other select members of the SWG who had been participating in the development of the CNS criteria throughout the process. The following revisions were made:

- It is now specified within the document that the limited science along with clinical information support the finding that prenatal alcohol affects multiple domains,
    - As such, significant deficits in a global IQ measure (i.e., individuals scoring 2 standard deviations below the mean) would indicate deficits in multiple domains because IQ tests inherently measure multiple domains. Thus, the criterion of scoring below the 3rd percentile on an IQ measure (or DQ measure for infants) was added as a stand-alone criterion for CNS functional abnormality. Note: percentiles are used to be consistent with face and growth parameters.
    - To address concerns about individuals who do not have mental retardation, the multiple domains issue was addressed by revising a second criterion to be deficits in three domains with performance below the 16th percentile (i.e., 1 standard deviation below the mean).
- A specific, highlighted statement was added that the Guidelines recommend that functional deficits be assessed using norm referenced, standardized measures and that domains should be assessed by appropriate professionals using reliable and validated instruments.
- To address the issue of harmonization with other diagnostic systems, similarities and differences (including where systems were more conservative or more inclusive) were described throughout the CNS criteria section (as well as other sections of the report).
- The section on diagnosing individuals who do not meet the full FAS criteria has been revised to reflect that the state of the science does not permit forming a conclusion on diagnosis for those individuals at this time, but work will continue.

Dr. Bertrand indicated that the goal was to achieve a balance between conservative approaches to diagnosis (i.e., those that minimize false positives) and more inclusive approaches (i.e., those that minimize false negatives) while still producing criteria and a document that is helpful to clinicians, service providers, caregivers and anyone else who work with individuals with FAS. These Guidelines are a step forward, reflecting current scientific information. They are not the ultimate endpoint. CDC will continue to refine, update, and/or expand the diagnostic guidelines as scientific information becomes available.

Discussion

- Dr. Sokol indicated that these criteria will be too difficult to use in practice without being able to specify the psychometric tests and he does not believe that the CNS criteria as presented here can be applied in practice. He said that that science in this area is not yet to this point and more research is needed.
- Dr. Caetano indicated that there will be a challenge implementing these criteria and asked if they have been tested for usability in the field? This is what has been done with the DSM4 criteria, for example.
- Dr. Bertrand said that testing will be part of an ongoing process. If we wait, it will be years before we get any guidelines out there.
- Dr. Boyle mentioned that the FAS Guidelines report provides the evidence base for the proposed criteria outlining the up-to-date empirical and clinical evidence for each of the criteria elements. Using the DSM4 criteria as a comparison is not a fair comparison. These guidelines are a starting point. We can use these, developing and revising them as we learn more over time.
- Ms. Devries indicated that her organization, FAS*FRI, worked with Senator Daschle's office in getting specific legislation to set up the Task Force and Congress wanted representation from scientists and research but also from parents. FAS*FRI is the oldest FAS advocacy organization in the U.S. Much discussion has occurred regarding these guidelines by researchers and others, but families also have a stake in this process. Dr. Bertrand has done an excellent job with the guidelines report. Last year, Ms. Devries expressed concern that families were not included in these discussions. Dr. Bertrand worked with Ms. Devries and other advocacy group members to review the document from a family perspective and incorporated family feedback and input into the document. The document is an excellent step forward and families have a deep interest in it.
- Dr. Schad indicated that he reviewed the document and while parts of it are not perfect, we have come a long way. The guidelines will evolve and it is now time that we agree, move forward, and approve this.
- In response to Dr. Sokol's comment about the using these criteria for the purpose of determining a case definition for use in epidemiology and surveillance, Dr. Miller said that was not the intent; rather, the guidelines were developed for use in clinical practice.
- Dr. Bertrand agreed that this report is a clinical document. It offers guidelines for referral and for making the FAS diagnosis.
- Dr. Sokol indicated that his original comments were misunderstood and that he feels that it is difficult to assess psychometrics in a clinical setting. Dr. Riley agreed that this is a good point.
- Dr. Bertrand clarified that the descriptors that fall under the domains cannot be determined through psychometrics. They are there to provide examples of what behaviors the child may present with. The key is for clinicians to identify the domains affected which can then be measured using standardized psychometric instruments.
- Dr. Floyd indicated that there was some discussion about naming specific psychometric tests but the decision was made not to do so. Canada does provide specific tests in their guidelines; however, here the decision would be left to clinician or specialist judgment to decide which tests to administer.
- Dr. Riley asked about the inclusion of standard deviation in the CNS component of the Guidelines. Dr. Bertrand responded that this has been a challenge since the initial

discussions on this topic and the compromise was to provide a more conservative cutpoint for IQ tests and developmental tests and more inclusive cutpoints for the individual domains so as to accommodate individuals who do not have mental retardation or significant developmental delay. This offers a balance between the conservative and overly inclusive criteria that currently exist.

- Dr. Streissguth did not have the document being discussed and asked what the domains in the guidelines were. Dr. Bertrand provided them: cognitive problems, executive functioning, motor problems, attention problems, social skills, and an "other" category. These areas were chosen because they incorporated the behaviors most likely to be demonstrated by children with FAS.

Motion Called and Seconded

- Dr. Devries made a motion that the Task Force vote to approve the document. Dr. Schad seconded the motion.

Dr. Riley asked the group if there is any additional discussion on the motion put forth?

- Dr. Damus asked if changes can still be made once the document was approved. She indicated that she had some comments that could be considered unsubstantial.
- Dr. Riley also said that the document needed editorial work and that he had an issue in one section regarding ADHD.
- Dr. Bertrand indicated that Task Force members can email their changes to her or send her changes on a hard copy through the mail.

Task Force Member Vote

11 Yes: Caetano, Berner, Coles, Devries, Miller, Riley, Schad, Wright, Calhoun, Cohen, Berry

0 No

The Report on Guidelines for Referral and Diagnosis of FAS is approved by the Task Force.

Task Force Motion Updates

<u>IDEA Reauthorization</u>: Dr. Cohen reported that after the last meeting she spoke to legislative folks at the Arc and NOFAS and learned that reauthorization is very far down the road, and it is too late to get FAS in the IDEA legislation. NOFAS met with Representative Miller, Chair of the House Committee on Education and the Workforce, but he does not support a long list of disorders in the legislation and said that the learning and behavior problems of children with FAS are already included in the existing language. The Arc and NOFAS legislative folks suggest working with the Department of Education after the reauthorization has passed to get FAS included in the regulations that the Department will develop once the legislation is passed. As of now, the IDEA reauthorization has not yet passed. Sharon Davis indicated that it was being discussed by the Senate yesterday and is continuing today.

<u>Education Motion</u>: Dr. Schad reported that he has made preliminary contacts with some folks in the education arena and will be meeting with key folks in the weeks ahead. He hopes to have more information to present at the Task Force's June meeting.

Development of Task Force Working Groups
Dr. Riley indicated that there currently are two existing Task Force working groups (Research Working Group and Services and Public Awareness Working Group). Task Force members received descriptions of these in an email sent previously. They are also defined within the Task Force Recommendations article published in a 2002 MMWR. Dr. Floyd asked what members would like to do. Should these groups be retained or should others be created?

- Dr. Berry expressed interest in focusing on women at risk and how to intervene with them, indicating that this would most likely fall under the existing Research Working Group.
- Dr. Schad indicated that educating teachers is a critical area (this falls under Task Force recommendation #4)
- Dr. Cohen suggested retaining the two existing groups and then perhaps developing ad-hoc groups as needed.

It was decided that Task Force members would decide which group they would like to participate in at the June meeting. The groups would have the opportunity to discuss priority area and next steps at that time.

Public Comment
Ms. Mary Rust from the Texas Center for Disabilities mentioned a recent study done by Dr. Mary Nettleman in which OB/GYN textbooks were reviewed and many still condone women's drinking during pregnancy. Ms. Rust is very concerned by this and believes that provider education is a key issue that needs to be addressed.

Dr. Riley indicated that everyone on this Task Force agrees with Ms. Rust on this and there is currently work being done at CDC and through SAMHSA's FAS Center for Excellence that is addressing this issue.

Bob Schott from Northern Arizona University indicated that he understood that documents like the Guidelines Report discussed today should be discussed in a smaller forum without wide distribution. However, he suggested that there should be a place where draft documents such as this one can made accessible for public comment.

The meeting adjourned at 3:00 p.m. EST.

Minutes approved on 10/04/04
by Edward P. Riley, PhD
Chair, National Task Force on FAS/FAE

APPENDIX A

Conference Call Meeting of the
National Task Force on FAS and FAE
May 13, 2004

Background Informational Summary

In the 2002 Departments of Labor, Health and Human Services, and Education, and Related Agencies Appropriation Bill the Centers for Disease Control and Prevention received the following mandate to:

- Develop guidelines for the diagnosis of Fetal Alcohol Syndrome (FAS) and other negative birth outcomes resulting from prenatal exposure to alcohol;

- 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;

- Disseminate curricula to and provide training for medical and allied health students and practitioners regarding guidelines;

- Coordinate efforts with the National Task Force on FAS and Fetal Alcohol Effects (FAE), existing federally funded FAS prevention programs, and appropriate non-governmental organizations.

In response to this mandate CDC conducted the following activities:

- Convened a Scientific Working Group (SWG) consisting of clinicians, researchers, parent advocates, members of the National Task Force on FAS/FAE, CDC, National Institute on Alcohol Abuse and Alcoholism, and Substance Abuse and Mental Health Services Administration.

- Held three meetings of the SWG and numerous conference calls among Working Groups dealing with FAS screening, essential services for children and families, and identifying and intervening with women at risk.

- Drafted diagnostic criteria for FAS in the areas of facial dysmorphia, growth promoters (height, weight, and head circumference), neurological problems, and Central Nervous System (CNS) disorders.

- Presented drafts of the progress to date for different occasions to the National Task Force on FAS/FAE for approval. All criteria have been approved as final with the exception of the CNS diagnostic criteria. **These criteria are still in draft form; therefore, this document is not available for dissemination at this time.** This will be the first item on the agenda for the May 13, 2004 meeting conference call.