

**National Task Force on Fetal Alcohol Syndrome
and Fetal Alcohol Effect (NTFFAS/FAE) Meeting**

**December 10-11, 2001
Washington, D.C.**

Summary Report

Those present during either or both days of the December 10-11, 2002 National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (NTFFAS/FAE) Meeting were: Diouna Baker (SAMHSA), Michelle Beamer (Rapporteur, Cambridge Communications), Dr. Jacquelyn Bertrand (NCBDDD/CDC), Sarah Horton Bobo (Michigan Department of Community Health), Dr. Paul Brounstein (CSAP/SAMHSA), Dr. Faye Calhoun (NIAAA/NIH), The Honorable Susan Carlson (Minnesota Association for FAS: MOFAS), Dr. Michael Charness (Harvard Medical School), Dr. Deborah Cohen (New Jersey Office for Prevention of Mental Retardation and Developmental Disabilities), Dr. Claire Coles (Emory University School of Medicine), Dr. José Cordero (NCBDDD/CDC), Donna Cotter (CSAT/SAMHSA), Dr. Karla Damus (National March of Dimes), Dr. Nancy Day (Professor of Pyschiatry and Epidemiology, University of Pittsburgh), Jocie DeVries (FAS Family Resource Institute), Dr. Samia Noursi (Logicon/Row Sciences), Dr. Mary Dufour (NIAAA/NIS), Dr. Louis Floyd (Designated Federal Official, NCBDDD/CDC), Laurie Foudin (NIAAA/NIH), Sandi Gangell (People, Inc.), Connie Granoff (NCBDDD/CDC), Mary Lou Oster Granite (MRDD/CRMC/NICHD/WIH), Lynne Haverkos (NICHD/NIH), Melissa Hogan (NCBDDD/CDC), Joyce Holl (Minnesota Association for FAS: MOFAS), Dr. Jan Harlow (ED/OSEP), Dr. Ellen Hutchins (DPSWH/MCHB), Karen Hymbaugh (NCBDDD/CDC), Stephan Klene (Parent Representative), Dr. Teresa Maresca (Indian Health Board), Dr. Kathleen Masis (Indian Health Services), Kathleen Mitchell (National Organization on Fetal Alcohol Syndrome: NOFAS), Gaylon Morris (NCBDDD/CDC), Elizabeth Parra (NCBDDD/CDC), Dr. Edward Riley (San Diego State University), Deirdre Roach (NIAAA/NIH), Dr. Luther Robinson (State University of New York at Buffalo), Dr. Robert Schacht (Northern Arizona University), Dr. Charles Schad (Retired Educator), Dr. Jasjeet Sidhu (NCBDDD/CDC), Dr. Phillip Smith (Indian Health Services), Dr. Dixie Snider (Assistant Surgeon General, Associate Director for Science, CDC and Executive Secretary, NTFFAS/FAE), Dr. Robert Sokol (Wayne State University), Dr. Deborah Stone (CSAP/SAMHSA), Judith Thierry (Indian Health Services), Ann Waller (FAS Family Resource Institute), Dr. Kenneth Warren (NIAAA/NIH), Mary Kate Weber (NCBDDD/CDC), Georgiana Wilton, Barbara Wybrecht (Parent Representative).

**Monday, December 10, 2001
Opening Session**

Background/Progress to Date of the NTFFAS/FAE

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

Dr. Edward Riley, NTFFAS/FAE Chair, called the third meeting to order, welcoming the participants. He pointed out that following the previous meeting, concern was expressed by several members of the NTFFAS/FAE regarding the direction the Task Force was taking. After a number of telephone conversations and conference calls, he said he was pleased to report that the mission of the Task Force has been broadly defined as stated in the Charter, and that everyone is comfortable and happy with that mission. He suggested that any feelings of limitations should be put to rest in order to enable them to move forward.

The following background was shared:

The Secretary of Health and Human Services was directed by the Public Health Service Act, Section 399G, (42 U.S.C. Section 280f, as added by Public law 105-392) to establish a National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (NTFFAS/FAE). Authority to establish the Task Force was delegated to the National Center on Birth Defects and Developmental Disabilities (NCBDDD), Centers for Disease Control and Prevention (CDC). The purpose of the Task Force is to advise all governmental agencies, academic bodies, and community groups that conduct or support fetal alcohol syndrome and fetal alcohol effect research, programs, and surveillance. The Fetal Alcohol Syndrome Program within NCBDDD was given the primary responsibility of establishing the Task Force and managing its operations. The Task Force was organized as a CDC Federal Advisory Committee. Information regarding the formation of the Task Force was disseminated and nominations for membership were solicited. A preplanning meeting was held in November 1999 to gain input about priority matters for the Task Force. Committee members were appointed in Fall of 2000, and the first official meeting of the Task Force was held December 14-15, 2000. A second meeting was held April 25-26, 2001. At the Task Force meeting in April 2001, a number of issues were decided with regard to priorities, working groups, and future plans.

Identified priority areas to be addressed by the Task Force include:

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

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

2. Identifying and recommending interventions for high-risk women by:

- * Developing policy statements defining who is at risk for an alcohol-exposed pregnancy and making recommendations for screening and treatment procedures

- * Developing recommendations for improving provider education in screening, detection, and intervention with high-risk women
- * Facilitating coordination of prevention strategies among agencies, programs, professional and advocacy organizations, as well as business and trade organizations (i.e., HMOs)

1. Specifying critical services needed by persons with FAS and their families by:

- * Making recommendations for identification and evaluation of promising treatment methods for interventions across the life span
- * Identifying federal guidelines that support comprehensive treatment for individuals and their families

2. Enhancing public education and awareness of FAS/FAE by:

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

Working Groups within the Task Force formed in order to explore specific needs to be addressed with regard to:

- * Developing a national public awareness campaign
- * Increasing provider education
- * Surveying state program services for individuals with FAS/FAE and their families
- * Developing a multi-level collaboration project that would include investigating the creation of a national registry of children with FAS to address research issues requiring large sample sizes than exist in individual sites

Working groups have submitted reports and developed lists of recommendations for consideration by the Task Force. The working groups include the: Professional Education Workgroup, Visibility/Public Awareness Workgroup, Survey Workgroup, and Multi-level Collaboration Workgroup.

At the conclusion of the April 2001 meeting, future plan were delineated, including:

- * Scheduling the next meeting for December 10-11 of 2001 in Washington, D.C.
- * Including in that meeting a Joint Session with the Interagency Coordinating Committee on FAS (ICCFAS) to update the Task Force on new and ongoing efforts by participating agencies and inform ICCFAS members of the priority areas identified by the Task Force
- * Developing a framework and time line for gathering additional information in preparation of a strategic plan to address primary and secondary prevention issues in FAS/FAE

The objectives of the December 10-11, 2001 meeting were stated as being to:

- * Develop a strategic plan for meeting the directives outlined in the Charter by learning about and discussing the best practices of other advisory committees
- * Create a specific mission statement to be used by NTFFAS/FAE
- * Gain knowledge of interagency efforts within the previously identified priority areas through a joint session with ICCFAS
- * Assimilate all of the above to define the strategies, mission, priorities and workgroups

Update on Progress of the National Center on Birth Defects and Developmental Disabilities

**Dr. José Cordero, Director
National Center on Birth Defects
and Developmental Disabilities
Centers for Disease Control and Prevention**

Dr. Cordero updated the Task Force on the activities of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) over the last several months. The Center budget is \$70 million. The first few months were spent defining the mission, which should continue to evolve in the next six months. In September 2002, there will be a national meeting to showcase the Center's activities and partners along with its mission and vision. During the first six months at the new Center, in attempting to describe the Center's mission, the "Four Ps" were identified. These include: Promote optimal fetal, infant, and child development; Prevent birth defects and childhood developmental disabilities; Promoting wellness among people with disabilities; and forming effective Partnerships for achieving the mission of the Center.

Prevention: The Center is concerned with preventing those birth defects, which can be prevented such as neural tube defects (through the use of folic acid), and fetal alcohol syndrome (through avoidance of alcohol exposure during pregnancy). Part of the challenge regards effective promotion of abstinence or postponing pregnancy when alcohol is used.

Pursuing Causes of Birth Defects and Developmental Disabilities: For about 2/3 of parents who ask their physician why their child has a serious birth defect or developmental disability, the only answer is "we don't know."

Promoting Wellness Among People with Disabilities: With 54 million people living with disabilities, the challenges are great. Many barriers to access must be addressed. The challenge of ensuring even prevention services is a major one, for example, women in wheelchairs really have no access to mammograms given that all of the machines require the person to be standing. The Office of Disability and Health together with the Activities on Technology and Development at CDC have worked on developing machines that will allow the person to sit.

Partnership: Partnerships are of significant importance to CDC. It is actually at the local and state levels that prevention and promoting wellness happen. CDC works with a large group of partners including advocacy organizations, local health departments, consumer organizations, professional organizations, and many others.

The first six months of the Center were devoted to the basics of getting organized. Dr. Cordero acknowledged Barbara Holloway, Deputy Director, for her leadership and masterful job in developing the organization of the new Center, and in attracting very talented people to the new Center. During these six months, the Center also embarked on developing the programmatic organizational structure. This process involved engaging a consultant familiar with CDC activities, going through an interview process, and convening a senior staff retreat. Out of this process emerged a number of guiding principles, such as: maintaining programmatic teams, building on what works, ensuring that staff keep their ranking and grade in the federal system, and allowing for growth and expansion of public health capacities.

The process also resulted in the organization of the Center into two divisions:

The Division of Birth Defects and Developmental Disabilities: This division is devoted to primary prevention, and this is where the activities related to finding causes of birth defects and developmental disabilities are located (use of folic acid, prevention of alcohol-exposed pregnancies). Dr. Joe Mulinare serves as Acting Director of this Division.

The Division of Human Development and Disabilities: This division is devoted to promoting health and wellness in individuals with disabilities, and helping individuals with specific conditions (i.e., metabolic screening program). They are not trying to prevent phenylketonuria (PKU), but they are trying to assure that individuals who have PKU have the appropriate diet and health services in order to prevent mental retardation. Disability and health activities and the Legacy Project (a program looking at preventing mild mental retardation) are located within this division. Dr. Ed Brann serves as Acting Director of this Division.

In addition to these two divisions, the Center has established an Office of Science and Public Health Policy for which Dr. Coleen Boyle serves as Director and Associate Director for Science. This Office is crosscutting and will focus on areas including health services research, health economics, prevention effectiveness, and biostatistics. The Center's organizational structure provides an opportunity for growth. The selection of permanent Division Directors, by a national search committee is currently underway.

New Executive Secretary for NTFFAS/FAE

**Dr. Dixie Snider
Assistant Surgeon General
Associate Director for Science
Centers for Disease Control and Prevention**

Dr. Snider indicated that he recently accepted the role of Executive Secretary for the Task Force at the request of Dr. Cordero and Dr. Louise Floyd. Currently, he is the Executive Secretary for the Advisory Committee on Immunization Practices (ACIP) for CDC, which does not just pertain strictly to the National Immunization Program at CDC. It also includes components like the National Center for Infectious Diseases, the National Center for HIV, STD and TB Prevention, the National Center for Chronic Disease Prevention and Health Promotion, as well as people and organizations outside of CDC such as the Federal Drug Administration (FDA) and the National Institutes of Health (NIH).

One of his roles as ACIP Executive Secretary is to act as a liaison between the Director of CDC, with other agencies and bodies, both outside and inside of federal and state government, to synthesize agendas and work together to prevent vaccine preventable diseases. Prior to that, he served as Executive Secretary for the Advisory Committee for the Elimination of Tuberculosis, and was involved in the creation of that committee. He currently works on a number of other advisory committees as a consultant or regular member including the Vaccine and Related Biological Products Advisory Committee and the Lead Screening Program Advisory Committee.

In speaking with Dr. Cordero, Dr. Snider felt that as the NTFFAS/FAE Executive Secretary, there were many opportunities, including an opportunity for the Office of the Director at CDC, to engage with this Task Force on the issues of FAS/FAE. He stressed that he is eager to be of assistance in seeing that the agenda designed by the Task Force is carried out, as well as in opening the lines of communication with other agencies to coordinate this endeavor.

Dr. Riley officially welcomed Dr. Snider, noting that his position as Executive Secretary on the Task Force elevates the status of the advisory committee, particularly given that they now have someone from the Office of the Director involved with the Task Force. Dr. Louise Floyd, former Executive Secretary, will still be closely associated with the Task Force, and will continue the role she has played in the last few meetings because she is critical to this committee.

Introductions and Model Strategic Planning Approaches

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

Dr. Riley pointed out that by taking into consideration strategic ways this Task Force can focus its goals, by having a plan, the Task Force will be able to better focus their attention on those domains with which they really need to deal. He stressed that, specifically, the following needed to be accomplished during this meeting:

- * Devise strategic ways to focus goals
- * Draw up a plan to focus attention on specific things

- * Prioritize the issues to be accomplished over the next 2 to 3 years, and also consider longer range plans
- * Create a mission statement

Dr. Riley hopes to get as much input as possible during this meeting into what the group thinks the mission and strategic plans are. He stressed that the Task Force did not need to end up with a final document or mission statement. He assured the group that they will have time to conduct conference calls, send e-mails, and have other discussions before finalizing the statement and plan. He then requested that everyone, including those in the audience, partake in the discussions in order to guarantee as much input into the process as possible.

Dr. Riley then led the Task Force members and other attendees in a round of introductions. The list of attendees appears at the beginning of this document. Further information, including contact information, may be found in the participant roster.

Changing the Conversation: National Treatment Plan Overview

Ms. Donna Cotter
Coordinator, National Treatment Plan
Center for Substance Abuse Treatment
Substance Abuse and Mental Health
Services Administration

A strategic plan was recently completed by the Center for Substance Abuse Treatment (CSAT), of the Substance Abuse and Mental Health Services Administration (SAMHSA), called Changing the Conversation: The National Treatment Plan Initiative to Improve Substance Abuse Treatment. Ms. Cotter was the Coordinator of the National Treatment Plan Initiative (NTPI). The purpose of this presentation was to shed light on a complex endeavor and give the NTFFAS/FAE ideas to use to move forward in their own planning. Ms. Cotter noted that the development of the NTPI strategic plan was quite daunting, and that the foresight of a handful of people was critical. She stressed that there must be a desire to move forward at all times, and that there is a goal worth achieving despite the multiple obstacles. She reviewed the Changing the Conversation report, stressing that while she was describing the NTPI process, the Task Force should be thinking about in terms of how they would work through their own process.

NTPI leaders worked through a number of steps in order to create their plan. First, they established a locus of management, a small core group to make the day-to-day decisions required to keep the process moving forward. A steering group was then established, along with expert panels, which met 4 times for 1-2 days each time over a period of one year. In order to gain legitimacy and solicit insight from the public, hearings took place. Once the information was collected, the panels began the process of developing the plan. The panelists themselves created the vision.

In terms of the locus of management, Ms. Cotter stressed that at least one staff member must be full-time, dedicated to dealing with every issue that arises in the process. She stressed the importance of having people in place who are authorized to make decisions and control logistics. The significant thing about this effort is that they held the first meeting of the first panel on April 21, 1999. One year and 3 days later, they had a product. This is critical because such reports age. She pointed out that they could not expect to fly large numbers of people around the country to make decisions, because sometimes decisions must be made daily. The CSAT management group guided their full process and controlled all of the logistics.

The steering group is critical because outside input must be obtained. Ms. Cotter suggested that the Task Force serve as the steering group, and then decide what their locus of management would be. The steering group serves a number of purposes, one of which is to identify the problems facing the field. The NTPI group developed 5 broad domains and then formulated activities and goals for the expert panels. The 5 domains that were considered significant problems or issues in substance abuse treatment included:

- * Closing the Treatment Gap
- * Reducing Stigma and Changing Attitudes
- * Improving and Strengthening Treatment Systems
- * Connecting Services and Research
- * Addressing Workforce Issues

A great deal of discussion occurred under each of these broad categories. There were 6 people in the steering group and two to three staff members who began this process by laying out the specific issues that needed to be addressed.

The panels of experts were made up not only of researchers and service providers, but also included consumers, family members, policy makers (federal and state), provider associations, and people interested in doing this work. Ms. Cotter stressed that the expert panels must be extremely inclusive, although panels should not become so large that they are unwieldy. Each of the NTPI panels was made up of approximately 30 people and were open to anyone who wished to attend and participate as part of the group. Thoughts and ideas of others outside of the panel were included in the panel minutes of each meeting. Each panel was assigned its own domain. CSAT placed a 10-recommendation limit on each panel, for a maximum of 50 recommendations for the entire document. They also stressed to each panel that offering no more than 3 recommendations is probably more effective given that the product is not a how to manual, but a national strategic plan. This also provides a great deal of flexibility at the state and local levels; which is critical, due to different requirements in different parts of the country.

Another aspect of the project was to keep the field equally involved in this process by shining the light away from CSAT, which was merely the steward of the project using funds to facilitate the process and travel participants. Key to the process was that CSAT also hired a contractor. The project manager selected was someone renowned in the mental health field who carried out a similar effort for the federal government in the mental health

area 25 years previously. Therefore, she understood how to make this happen in a way that it would be valuable. She became a part of the core team of 4 people who managed the process. In the selection of panel chairs, CSAT was very deliberate in not choosing federal employees to assure input from everyone not just CSAT. This way, the document was written by the field and was cast as for the field. All of the panel member chairs represent highly regarded organizations in the field, or were themselves highly regarded as experts.

Another critical piece of the process was going to the larger public. In order to attract the interest of the nation at large, a pageant atmosphere was created around the project. It could not be a process that suggested that the government was writing another book to go on the shelf." This process included media coverage, high visibility, and the conduct of 6 public hearings around the country. They targeted the media in the 6 sites where they held hearings (Arlington, VA; Hartford, CT; Chicago, IL; Washington, D.C.; Portland, OR; and Tampa, FL). They arranged for local Senators and Congressman to testify. The more legitimacy they could add to the process, and the more they could demonstrate that the process was truly inclusive and nationwide, the more validity it had. They held 1-day, structured meetings. Ms. Cotter stressed that a large staff was not necessarily needed. While the logistics of the process were daunting, she basically carried them out by herself with occasional help around the hearings of 5 to 6 additional staff. Public hearing participants were asked to sign up in advance to testify. They were able to get 90 to 100 testimonies into each 8-hour period by limiting participants to 3 minutes each. People were extremely grateful for the opportunity to testify. For example, many in Portland, OR, thanked the federal government for traveling all the way out there to hear their issues.

Ultimately, each panel was required to develop a final report, which was then synthesized into the final plan. Volume 1 of the final report presents a concise 50-page document, which outlines a set of guidelines and recommendations drawn from the panel reports and public hearing summaries. This is the document sent to Congress and mass-mailed all over the country. Volume 2 includes the individual panel reports and summaries from the 6 public hearings. This provides information for those interested in a more detailed account of the NTPI findings. Volume 2 also includes an acknowledgment section listing the many people who participated in the process. This section helps to demonstrate that this report was by and for the field.

Ms. Cotter cautioned the Task Force not to repeat one of the CSAT's errors which was to take 5 domains and turn out 5 guidelines because people are still struggling with the difference between what they heard in the panels and the final product. For example, a panel might have discussed Connecting Services and Research, but this does not specifically appear in the guidelines. However, the domains represent the problems, the tough issues that have to be fixed. Positive statements around how to proceed with the guidelines were outlined as follows:

- * Invest for Results
- * Commit to Quality
- * "No Wrong Door" to Treatment
- * Change Attitudes
- * Build Partnerships

Within those 5 guidelines, they separated out the top 3 and the bottom 2 because the bottom 2 are overarching and process oriented. Attitudes must be changed and partnerships must be built to make a significant improvement in substance abuse treatment across the nation. This is done by investing for results, having a nation with no wrong doors to treatment, and committing to quality in the process. There is nothing new in these two documents, but for the first time, the substance abuse treatment field and its stakeholders came together and agreed upon a consensus document --consensus around priorities for changing substance abuse treatment in the nation. The power that this gives, especially when one needs to testify on the Hill for more funding, is that CSAT did not write this alone. The nation wrote it, and it is a consensus document of what the issues are and what resources are needed to implement the recommendations, which gives it more credibility.

Specific, doable action steps are given at various levels and have been assigned to various organizations. Some of the recommendations are CSAT's responsibility to commence, while other recommendations have to be carried out in the field either by the states or a combination of partnerships (e.g., states, providers, accrediting organizations, etc.). The steps are not necessarily linear. The report outlines a laundry list from which steps can be chosen to match what an area needs to improve substance abuse treatment.

In terms of the vision, the Reducing Stigma and Changing Attitudes Panel created a vision for their own panel, which resonated so beautifully with every other panel that they unanimously chose to adopt it as the vision of the National Treatment Plan. They have found it to be powerful in the way it evokes reactions from the people in the field as they have traveled around the country. The vision reads as follows:

"We envision a society where people who are addicted to alcohol or other drugs, people in recovery from addiction, and people at risk for addiction are valued and treated with dignity; and where stigma, accompanying attitudes, discrimination, and other barriers to recovery are eliminated. We envision a society where addiction is recognized as a public health issue - a treatable disease for which individuals should seek and receive treatment - and where treatment is recognized as a specialized field of expertise."

The report was released on November 28, 2000. Unfortunately, with the change in Administration, they had to wait for things to settle. During that year, they went into the field to disseminate the message throughout the country. CSAT's Director, Dr. Wesley Clark, highlighted the National Treatment Plan recommendations in presentations made across the country. Anyone who spoke for him also used the plan. Ms. Cotter began receiving calls directly from the people who received it. She traveled to 10 or more statewide or provider association-wide conferences to make a presentations about the National Treatment Plan. She stressed that they must ignite the field with interest in order to keep the product from sitting on the shelf. A great campaign is a must. States and communities must "own" the plan.

One state opened a major door for CSAT. In late October, the State Provider Association made the decision to devote their entire annual conference to advancing the National Treatment Plan. People resonate with the phrase, Changing the Conversation. The State Provider Association decided to "change the conversation" from the national to the state level. CSAT supported the conference by supplying presenters. This effort energized the

State of New York. Following this, she will meet with 4 additional states to create conferences around the issue of the National Treatment Plan across the country. Thus, it is beginning to "snowball." She stressed that once people signed on, they were hooked. She now has a team of about 25 people who are anxious to travel anywhere to give presentations and make this happen.

In conclusion, Ms. Cotter pointed out that clearly nothing helps to energize people more than funding to spend on these processes. Thus, CSAT is in the process of developing a grant program to stimulate states and/or national organizations to take on a part of the National Treatment Plan to develop a process in their local areas to advance the Changing the Conversation recommendations in order to improve substance abuse treatment. Grant funding will soon be available to the public. Ms. Cotter wished the Task Force great success in their endeavors, indicating that she would be happy to consult with and advise them as needed.

Discussion Summary:

* An inquiry was posed regarding the budget. Ms. Cotter responded that the NTPI did not start with a budget at all. The people heading up the program had a desire to see this project through and "found" funding by having the Director ask for money from various sources, and by receiving overflow from Division Directors and others. CSAT had no targeted line item for this program. They wound up with 6 logistics and other types of contracts. This was a nightmare from a budget management standpoint, but they were able to access what was needed to get the project off the ground. The panelists' travel, lodging, and food expenses were paid, but they did not receive honorariums. The approximate cost was probably \$3-5 million over the entire program. Now that there is a grant program, that amount will increase significantly because substance abuse treatment in the rest of the nation needs funding support. They are in the process of meeting with states, foundations, etc. across the country to leverage more funding in order to keep this process alive.

* Dr. Snider parallels the NTPI with the development of the TB strategic plan. At the time, there was no money budgeted, and virtually no research. A small foundation with some funding was found and various other resources joined, which eventually made the TB plan a success. It is possible to start with very little money and resources and create something large if creativity is used to find resources that share the same values, goals, and objectives.

* Dr. Floyd asked for CSAT's partnership with the Task Force with regard to reducing stigmas and supporting substance abuse treatment for women. She also requested that Ms. Cotter expand on the issue of bringing professionals into the public hearings and as well as getting updates on the state of the science on substance abuse. Ms. Cotter responded that they would be happy to partner with the Task Force. She said that the CSAT contractor's task was to protect the integrity of the document wording. The process began with a literature search on the five domains identified, and copies were provided for each participant. Then the participants were asked to give their recommendations based on all of the work that had been done prior to NTP. An editorial board, made up of panel representatives, reviewed the draft documents to make final decisions on the entire document. This maintained process legitimacy in order to avoid things being edited or altered during the course of government clearance. After the document was finished, they sent the synthesis document for clearance and held the panel

reports sacred. When the synthesis document was cleared, the panel report was cleared de facto. While government representatives did not necessarily believe in every word in the document, they were true to and believed in the process, and they respected what the country said.

* An inquiry was posed from the audience regarding whether the five domains were created by CSAT or the steering committee. Ms. Cotter said the six members of the steering committee provided the list of five domains on which the panel groups worked.

* Dr. Snider inquired about the issues overlapping between NTPI and NTFFAS/FAE and the possibility of the two entities working together. Ms. Cotter suggested that they form a partnership and create a network of partnerships with which to interface.

* Dr. Cordero asked about closing treatment gaps and measuring impact and results. Ms. Cotter responded that the NTPI has not designed a measurement program as of yet, but they are aware that they must do that. In the grant program they are setting up, they hope to create a coordinating center outside of the federal government. Her desire is to move the entire process to the field, and to have the field take complete ownership. Once a coordinating center is in place, they will be asked to develop measuring tools for use all over the country. The next phase is larger than the process, which was daunting enough. Now they must figure out how to keep the process moving forward despite changing administrations.

CDC Examples of Successful Strategic Planning Models

The Measles White Paper

**Dr. José Cordero, Director
National Center on Birth Defects
and Developmental Disabilities
Centers for Disease Control and Prevention**

Dr. Cordero described the Measles White Paper, an example of successful planning that translated into significant impact and change in that there has not been a significant transmission of indigenous measles in 4 or 5 years. Most current cases are linked to importation. He pointed out that a parallel can be drawn between the measles and FAS/FAE processes, and he began with a brief summary of the landmarks in the study of FAS/FAE as they relate to prevention. There was a paper published in 1973 on FAS that made a difference and instigated action. FAS is one of a handful of birth defects and developmental disabilities for which the cause is known. Since 1973, much has been learned about the teratology of alcohol exposure and pregnancy, its neural/ behavioral effects, who the high-risk groups are, approaches to surveillance, and methods to reduce alcohol exposure during pregnancy. The need for treatment centers is widely recognized, especially those for pregnant women. FAS is preventable, but the implementation of prevention programs is challenging. As they prepare to address the central issue of prevention, they must be clear that prevention is difficult, but possible. Other prevention programs

have been successful. When the issue of measles in the United States was first addressed, there were approximately 50,000 cases. Clearly with the vaccine, measles could be prevented, but the challenge was to reduce 50,000 cases to zero. Similarly, this group must consider how to achieve zero cases of FAS. They must not forget that when the polio vaccine was developed, few people thought that zero cases, or eradication, could be achieved. Yet, the world is on the verge of global eradication of polio. Certainly, they could develop the political will to accomplish the same with FAS/FAE.

In terms of measles, the National Vaccine Advisory Committee developed a process similar to CSAT's NTPI. They determined the key steps and addressed them in an effort to ensure control of measles in the United States. For measles, the recommendations were grouped into five areas:

Access to Immunization Services: While a vaccine must be available, there must also be assurance that it gets to every child who needs it.

Importance of Education Regarding Immunization: This meant education of physicians as well as parents about the importance of immunizations.

Surveillance: If a program is to be successful, there must be a measurement component. The program must know where it is and where it is going. This program needed to monitor the rate of measles, and the same is true of FAS. This is an important tool, or compass, to know whether a program is moving in the right direction.

Assessment of the Systems: There must be an evaluation of how well the system of prevention is working. This was a key component of the measles program.

Improving Vaccines and Number of Vaccines: Vaccines had to improve and the number of vaccines had to increase. In FAS/FAE, this translates into the improvement of treatment and prevention approaches.

There are similarities in many examples where the Task Force can look for guidance in the issues of FAS/FAE. Key to success in any program is political will. They must not forget this. For immunizations, there has been a major political push, which was followed with funds to ensure that the goals were achieved. Immunizations have been a sustained, positive effort since 1996, in which the goals for 2000, were met and/or have been exceeded, and the goals are expected to continue to be met or exceeded through 2010.

The Tuberculosis Strategic Plan

Dr. Dixie Snider
Assistant Surgeon General
Associate Director for Science
Centers for Disease Control and Prevention

Dr. Snider has been involved in a number of strategic planning exercises at CDC around emerging infections, syphilis elimination, and the prevention of neural tube defects. He is most familiar with the Strategic Plan for Elimination of Tuberculosis and its counterpart, the Strategic Plan for Combating Multi-Drug Resistant Tuberculosis. The stimulus for the development of the Strategic Plan for Elimination of Tuberculosis occurred at a national tuberculosis conference in 1985. Dr. James Mason, the Director of CDC at the time, was in attendance. One of the things he said during that conference, which had a profound effect, was that he was not sure CDC should even have a Division of Tuberculosis Control since there was no strategic plan in place to control eliminate the disease. Dr. Mason's view was that tuberculosis should have been a disease of the past. Instead, there was a holding pattern of treating clinical cases and making some efforts to prevent tuberculosis, but there was no serious effort to eliminate the disease. He thought that was unacceptable.

Dr. Snider said they took Dr. Mason's advice seriously and embarked upon a strategic planning exercise that followed reasonably well with the CSAT effort. The first step was an overall evaluation of programs to find out why treatment compliance objectives were not being achieved. At the time, about 70% of people were complying with treatment, though in some parts of the country (New York City, for example), compliance was at 40%. They recognized that one thing they needed to do was to better apply what was already known with regard to prevention, detection, treatment, and compliance. Most of the tools in place for tuberculosis were developed 30 to 100 years previously, thus researching new tools was a major priority. The group also realized that widespread education and communication were needed.

The group established a steering committee and a locus of management, and expert panels were convened. While public hearings were not held, primarily because the general public had little interest in the problem at the time, they had a lot of involvement from external partners at the outset, and throughout the process (e.g., state and local health departments, constituency organizations like the American Thoracic Society and the Infectious Disease Society of America, other federal agencies such as the FDA and NIH, etc.). Within a few years, many external partners came together to form the National Coalition for the Elimination of Tuberculosis that had approximately 60 member organizations.

From a historical perspective, the TB strategic plan was very useful. When TB spiked in the mid 1980s, not a lot of response was evoked on the part of Congress or others. However, multi-drug resistance, which emerged in the early 1990's, raised concern. Having a strategic plan already in place, which was only slightly modified to deal with the multi-drug resistance aspect, enabled quick dialogue with various policymakers about this public health issue, and garnered the necessary funding to respond. The budget has grown exponentially over the years (from \$5 million to \$103 million with the development of the plan, and even more since then). NIH had \$300,000 invested in TB research in the early 1980's, which within a few years after the release of the plan increased to \$25 million. The two plans had a global impact as well. In the early 1980's, the World Health Organization (WHO) had a global TB program consisting of one statistician, but it grew to more than 30 individuals in multi-disciplines, including behavioral and social scientists, after the release of the plan. The private sector (e.g., non-governmental organizations, pharmaceutical companies, and private foundations) got involved as well. This clearly demonstrates that solid strategic planning can result in great success.

Dr. Snider stressed that persistence is key. Putting together panels and leveraging funding will not happen all at once. It can take many years and a lot of searching. Friends and interested partners can be found in many places. For example, the National Institute for Occupational Safety and Health (NIOSH) is not typically focused on infectious diseases; it is more oriented toward chemical and other types of exposures. However, they recognized that infectious diseases were a problem in the work environment and became a partner in the TB plan. NIOSH advocates, unions, and employee associations became concerned with tuberculosis as a result. The point is, strategic planning efforts, if done well, can have a tremendous positive impact.

Identifying Strategic Planning Elements for the Task Force

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

Having heard background information and taking into consideration model approaches, Dr. Riley explained that the group's task was now to embark upon the development of their own strategic planning elements. He acknowledged that the NTFFAS/FAE challenges were similar to those faced by other groups, such as low starting budgets, placing emphasis on the importance of partnerships, and setting clear goals.

Gaylon Morris, a facilitator from CDC, then led the panel in their deliberations to:

- * Establish the priorities and goals of NTFFAS/FAE;
- * Determine how to get services to families; and
- * Enhance the prevention of FAS/FAE.

Initially, the group expressed confusion about the process for creating a strategy; some felt this had already been done and/or that it was necessary to set goals first and then create a strategy. A suggestion was made that the panel think of themselves as a steering committee or expert panel and start making recommendations. Some members stated recommendations had already been made. Dr. Floyd suggested that, at this point, the Task Force establish consensus on the broad priority domains, and then outline specific goals under each domain. Dr. Riley added that, while the panel had an idea of certain goals, knowledge about how those affected feel and their day-to-day experiences is somewhat limited. He said he liked the "town meeting" approach to obtain input on such issues.

Discussion Summary:

Discussion has been grouped according to topic areas. In the case of overlapping topics, the input has been placed with the topic under which it arose. The main categories discussed included: (1) Existing Information/Models, (2) Information Dissemination, (3) Research/Surveillance Issues, (4) Affected Groups and Other Stakeholders, and (5) Town Halls/Other Mechanisms for Obtaining Input.

Existing Information/Models

* A suggestion was made that they needed to review activity reports from other committees while creating their own strategy (i.e., the process used to generate once the strategic plan and track its implementation).

Information Dissemination/Education

* Dr. Cohen pointed out that FAS is not even a recognized public health problem. It is not contagious, there is no knowledge of a process for eradication, and there is no perception that this is a serious issue in the medical community. There is a lot of disbelief in the broader community that FAS exists, so the work needs to start two steps back behind the research for measles or even drug and alcohol addiction.

* Dr. Riley pointed out that various "white papers" on impediments to diagnosis, impediments to treatment, etc., could be contracted out.

* Dr. Schad emphasized the need for the Task Force to address awareness and education of individual groups (e.g., parents, children, judicial and psychological professionals, physicians, etc.) and the need for addressing the cost of FAS children to society. A broad approach needs to be considered. He has received calls from judges who were concerned about how to handle FAS/FAE children in the courts. The president of the South Dakota State Mental Health program is also interested in the subject.

* Dr. Riley pointed out that town hall meetings were not only a way to obtain input, but also could serve as forums for educating communities.

* Dr. Sidhu suggested putting the document in the Federal Registry.

Research/Surveillance Issues

* Dr. Charness pointed out that, unlike FAS/FAE, the science around measles was more advanced; that is, there was effective immunization for measles at the time a plan for elimination was conceived. Thus, armed with knowledge of a successful measles treatment, the challenge for the public health professionals was to communicate the importance of universal immunization to policymakers. In comparison, the study of FAS/FAE with regard to measurement, prevention, treatment and intervention is much further behind. Currently, there is no systematic way to prevent, treat, intervene, and measure for FAS/FAE. He stressed that access to treatment is crucial in this nascent stage of this field. Any venture undertaken must have measurement and research as part of the goals in order to allow testing for proposed interventions and testing additional treatments. He cautioned them to be careful to keep expectations in line with what is possible, and to match what policymakers are able to do. Many agreed.

* Dr. Robinson pointed out that since FAS is the result of the overriding problem of maternal substance abuse and/or alcoholism, many families report difficulty in obtaining a diagnosis. In order to improve prevention,

diagnosis, and treatment there must be: a case definition and more comprehensive surveillance of FAS incidents and prevalence.

* Dr. Snider reminded the group to keep the full spectrum of research in mind. While prevention and treatment are critical, there is also behavioral science, communication, and education. Multi-disciplinary research is needed. FAS is a social problem, not just a bio-medical one. As this develops, he suggested that they seek input from professionals who could suggest the types of research needed.

* Ms. DeVries raised the issue of multi-site research. Dr. Riley indicated that this topic had been tabled, but assured her that it would be revisited.

* Dr. Floyd was not convinced that previous literature searches had been thorough enough. She wondered whether the group needed to conduct a more conscientious, systematic review of research-to-date dealing with intervening with women at-risk and affected individuals. The panel agreed that a more thorough literature search should be conducted, particularly since much more had been published since the last search used for the Institute of Medicine Report on FAS.

Affected Groups and other Stakeholders

* Ms. Mitchell suggested (and others agreed) separating each affected group into categories: prevention/intervention for substance users, prevention/intervention for affected individuals, those who have addictive disease or are in recovery, and parents/groups that deal with affected individuals.

* Dr. Calhoun stressed that the approach to solving problems will evolve with on-going communication with stakeholders, families, and affected children. There are also confidentiality and ethics issues. Those issues can only be identified by communicating with the field about real-life problems they confront every day. It is difficult to plan the correct approach and make recommendations without this.

* Ms. DeVries, speaking as a family member, pointed out that with the ocean of problems involved with FAS/FAE, the family, not treatment programs, makes the best intervention. She stressed that early intervention and keeping families together will work.

* Dr. Riley talked about being mindful of special populations that may be particularly affected, especially those from low-income and various minority groups.

Town Halls/Other Mechanisms for Obtaining Input

* Dr. Floyd suggested that the group consider the National Treatment Program's use of town meetings, taking into consideration as many venues as possible by which to gain public comment. She cited CSAT's use of the Internet for posting comments and asked that the group think about approaches for how special communities could give their input, making it as expansive as possible. Others agreed that there must be alternative

mechanisms for input for those who lacked the ability and/or the resources to attend a town hall meeting in person.

* There was agreement that while the Task Force might believe they know what their goals should be, they should seek broad input to ensure that they are on the correct course. Although the working groups have given their recommendations, once input is obtained through town meetings and other sources, the Task Force will need to determine whether their working groups and recommendations are, indeed, appropriate.

* Dr. Calhoun wondered whether gathering comments via the Internet or Federal Registry would be a good way for the Task Force to obtain information. She pointed out that the people she knows to be affected by FAS/FAE do not read the Federal Registry, nor would they search the web for an opportunity to comment. She thought they had to set up other ways of obtaining input. Dr. Floyd pointed out that since FAS is such a broad issue involving many different groups of varying socio-economic levels, utilizing various communication mechanisms would be beneficial. Others suggested that if there was a decision to have a website for public comment, it must be well publicized. However, Dr. Coles stressed that many people do not have access to computers or the Internet.

* Dr. Cohen said that the town hall meeting approach could be similar to a disabilities conference held in the early 1990s. It addressed both prevention and treatment, and papers from experts were solicited and published in book format by CDC. These papers laid out prevention strategies and the procedures for handling the disabilities, as well as encouraging wellness and health. That led to a much fuller program and additional funding. It was an excellent conference because it resulted in a document and somewhat of a strategic plan. Dr. Cohen wondered whether the Task Force's town hall meetings would be small, or whether they should convene conferences to bring about 100 people together in order to obtain the input they desire.

* Ms. Mitchell suggested that the Task Force take into consideration how to handle the groups (e.g., physicians, parents, children, adults, members of the judicial system, etc.) who are reluctant to diagnose or accept diagnoses when the reality is that FAS/FAE exists. While these individuals should be at the town meetings, they may not attend because they do not acknowledge FAS/FAE as a problem. Moreover, issues like sudden infant death syndrome (SIDS) are rarely raised although they should be part of these discussions.

* Dr. Cordero suggested that a process be devised to determine the key questions to be raised in a town meeting so that people could give input on them. Dr. Snider agreed, saying that the Task Force could easily design the town meetings posing a number of questions and suggesting whom the participants should be. Invitations could be sent to prominent community leaders, governors, judges, clinicians, families, etc. The panel could lay out the ground they would like covered in the discussions. This would be a successful approach even if the entire range of issues was not covered in each meeting. In fact, trying to cover too much in each meeting could be overwhelming. Dr. Charness reinforced the benefit of inviting prominent local community members; they gain ownership of the process and its outcome, and even if they are learning about the issue for the first time, they are recognized as custodians in the process and may become more active in the implementation of any programs that may result.

* Dr. Riley pointed out that town hall meetings were not only a way to obtain input, but also could serve as forums for educating communities.

* Ms. DeVries expressed her approval of the panel's adoption of having town meetings. She recalled a needs assessment retreat she attended with a group of parents. During that retreat, the parents were allowed to speak for two days and the professionals had to listen before saying anything. With that in mind, she stressed the importance of arranging town meetings properly and in such a way that would show respect for those giving input.

* Ms. Wybrecht noted that in August 2002, there will be a conference for individuals with FAS/ARND in Michigan which could be the site of the first town meeting. Participants will include 50 affected individuals and 50 support persons. She pointed out that parental anger has not been her experience. In Michigan, parents mobilized to leverage funding. She has convened 5 national conferences with very little money, and she did not think getting at least 100 people to attend would be difficult.

* In terms of topics, Dr. Masis suggested that the concepts of amount of distress and frustration that affected families experience in dealing with uninterested professionals, impediments to proper diagnosis, and denial should be addressed. Others agreed that these topics are critical.

Defining the Mission of the National Task Force on FAS/FAE

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

Upon completion of deliberations on identifying strategic planning elements for the Task Force, Dr. Riley turned the group's attention to the business of creating a mission statement for the Task Force. He prefaced the discussion by stating that the mission statement for the Task Force should be based on the Purpose outlined in the NTFFAS/FAE Charter, which reads:

"To foster coordination among all governmental agencies, academic bodies, and community groups that conduct or support fetal alcohol syndrome and fetal alcohol effects research, programs, and surveillance; and to otherwise meet the general needs of populations actually or potentially impacted by fetal alcohol syndrome and fetal alcohol effect."

The goal was to elaborate more clearly on that and create a mutually agreed-upon mission statement. In order to accomplish the mission, Dr. Riley stressed that it would also be necessary to set goals and timelines for reaching those goals, pointing out that defining the mission would be an evolving process.

Mr. Morris then facilitated the discussion, asking the Task Force for their comments and thoughts about what they perceived to be the mission and purpose of the NTFFAS/FAE.

Discussion Summary

- * Dr. Maresca proposed as a mission statement, "Facilitate the elimination of FAS/FAE as the nation's number one preventable cause of birth defects, reverse the progression of associated problems so as to reduce morbidity, not only to the individual, but also to the associated families and systems with which affected individuals are in contact."
- * Ms. DeVries recalled that when working on her group's mission statement the following verbiage was included: "Parents working with professionals to identify, understand, and care for individuals with FAS/FAE and their families, and to prevent future generations from having to live with this disability." She also liked Dr. Maresca's suggestion.
- * Ms. Mitchell suggested adding, "to increasing awareness and identification."
- * Dr. Schad stated that treatment of affected individuals was a concern for him personally. He also said that the concept of denial is critical and inhibits treatment as well.
- * Dr. Cohen said the mission statement should be broad like the one offered by Dr. Maresca. She suggested that the other pieces the group mentioned were objectives. She thought the mission statement should be the broad, "pie in the sky" (e.g., who they are, what they do). How they do it is a different discussion. Treatment and diagnosis are important, but they really represent a process to implement the mission. She suggested they look closer at Dr. Maresca's proposal. Dr. Coles agreed by saying that the statement should be a broad overview. Referring to process, she said they should focus on the barriers that prevent them from acting on what they already know in order to facilitate the elimination of FAS.
- * Dr. Maresca responded by modifying her original statement to read, "To facilitate the elimination of FAS/FAE as the nation's number one preventable cause of birth defects, and to reverse the progression of any associated conditions (morbidity, mortality, secondary conditions, individuals, and affected communities can be specified in the statement as well)."
- * Dr. Charness suggested, "To enhance the awareness, prevention, and treatment of FAS/FAE as the nation's number one..." which would encompass education, treatment, and research.
- * Ms. Mitchell thought that there should be something in the mission about reducing the stigma around FAS/FAE. Some panel members thought that this could be implied in "secondary conditions." Then Ms. Mitchell asked what they should call the problem (e.g., FAS/FAE and/or ARND?). Everyone decided that this question would be up for discussion.
- * Dr. Bertrand suggested that the mission statement be summed up in a single sentence with perhaps 2 or 3 bullets to highlight different areas.
- * Ms. Waller suggested that the suggestions of Dr. Maresca and Dr. Charness be combined. She also preferred the term "elimination" because it is stronger than "prevention." Others agreed, but Dr. Masis pointed out that care should be taken when using words like "elimination" and "prevention" because sometimes families do not feel like they are cherished. Sometimes "elimination" is heard the wrong way. They could work toward "eliminating the problems" by "preventing exposure and taking care of the people in families who have been exposed." They must take care not to suggest in any way that the people with disabilities themselves be eliminated.

- * Dr. Charness asked that "the" be after "FAE" rather than "as" to respond to Dr. Riley's dissatisfaction with the language in "as the nation's number one." He would not be satisfied if FAE became "the number two leading."
- * Dr. Sokol commented that the problem with mission statements is that most are longer than a sentence, so no one remembers them. He strongly argued that one simple statement would be most effective. They could then go on with the vision and specific goals in order to capture the other important issues. Others agreed.
- * A suggestion was made that they merely say, ". . . and to support the victims." The panel vehemently disagreed with using the word "victims."
- * Ms. Waller made a suggestion to add "and impacts" after "associated conditions" to broaden it to the families, systems, society, etc.
- * Dr. Snider asked to add "currently" before "the nation's number one preventable cause" in order to acknowledge that it is currently the nation's number one preventable cause. He agreed with the idea of a single sentence and then adding the bulleted highlights.
- * Dr. Riley asked the group to think about how the term "birth defects" is perceived in the world. When most people think of "birth defects" they look for physical abnormalities. With FAS/FAE, the biggest challenges are the behavioral and cognitive problems associated with FAS/FAE. There cannot be anything misinterpreted in the mission statement. The statement needs to be expanded to include this idea. He suggested that the clause read: ". . . preventable cause of developmental disabilities." Dr. Charness added: ". . . through research, education, diagnosis, prevention, and intervention." Some thought this might go under "to accomplish this mission by" but he pointed out that this was to see if they could put everything in a single sentence.
- * Dr. Cordero suggested that they consider how to capture Ms. Mitchell's earlier comment that they have the two issues of prevention and assisting families that have affected individuals. He suggested using the term "foster" or "facilitate" along with "promoting wellness among those affected."
- * Dr. Floyd asked if they could just have another sentence that states, "We are going to approach the problem . . ." and then enumerate 1, 2, 3, etc. Dr. Schacht suggested using one simple overarching sentence and have implementations spelled out later in subsequent documentation. Dr. Floyd agreed and said it should be a "call to arms" and repeatable.
- * Ms. Mitchell commented that a key word is "lifelong," pointing out that some people could read this as it is written and then possibly be surprised if they met an adult with this problem. Dr. Cordero suggested, "Promote lifelong interventions for those impacted by these conditions."
- * A suggestion was made that "birth defects" be cut and "developmental disabilities" be left in place.
- * Mr. Morris suggested adding "facilitate the elimination of FAS/FAE and promote lifelong interventions for those impacted by these conditions." There was substantial agreement.
- * Dr. Riley asked to state the facts about FAS/FAE at the beginning: "FAS/FAE is the number one preventable cause of lifelong developmental disabilities. Our mission is to facilitate the elimination of FAS/FAE and promote lifelong intervention to those impacted by these conditions." This states the major problem up front.
- * A suggestion was made that the statement be changed to "major cause of developmental disabilities" instead of "number one cause of." There was disagreement about this line. Ms. Mitchell thought the statement needed to include "number one preventable cause of." She thought that "major cause of" was not strong enough. Others agreed that it would become an effective, easily remembered mantra.

* A suggestion was made to delete repeating "FAS/FAE" in the second sentence and to put "prevent prenatal exposure to alcohol." Dr. Cordero clarified that people are not affected by prenatal exposure, they are affected by FAS/FAE.

* Ms. Wilton suggested including citations to prove that FAS/FAE is the "number one preventable cause." She also indicated the importance of prenatal education regarding exposure. Ms. Wilton stated she had taken many calls from women who told their doctors they had two glasses of wine before they found out they were pregnant, and after the doctors told them they had done damage to the fetus, they had abortions. She stressed the importance of education.

* Dr. Cordero suggested that they may need to look to the research regarding the use of the phrase "number one preventable" to make certain it can be supported. To assert something like that must be proven. The question should eventually be "Why are we not preventing something which is within our ability to prevent?"

The group stopped at this point to attend the Joint Session.

Joint Meeting of: The National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (NTFFAS/FAE) and The Interagency Coordinating Committee on FAS (ICCFAS)

During the meeting of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (NTFFAS/FAE), a joint session was convened with the Interagency Coordinating Committee on FAS (ICCFAS). Presentations were delivered in the following areas:

- * New FAS-Related Projects for FY 2001
- * Highlights of Promising "Works in Progress"
- * Reports From Agencies on What Yet Needs to be Done and How the Task Force can be of Assistance

Discussion periods were held throughout the joint meeting. For further information, please refer to the separate, detailed summary report of the joint meeting, entitled Joint Meeting of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (NTFFAS/FAE) and the Interagency Coordinating Committee on FAS (ICCFAS).

**Tuesday, December 11, 2001
Strategic Planning Input**

Dr. Edward Riley
Dr. Dixie Snider
Mr. Gaylon Morris

During the second day of the meeting, the discussion regarding the mission statement continued. Mr. Morris began the discussion by reading the draft of the mission statement as it stood at the end of the first day's deliberations:

"Fetal Alcohol Syndrome (FAS)/Fetal Alcohol Effects (FAE) is the leading preventable (OR Nation's #1) cause of (birth defects and) developmental disabilities. Our mission is to eliminate FAS/FAE and promote effective, life-long interventions of those impacted."

Discussion Summary:

* Dr. Cohen clarified previous wording on FAS from a previously published document (title of publication not cited), which states that "FAS is arguably the most common known non-genetic cause of mental retardation." A few sentences later, it says that "FAS, Alcohol-Related Birth Defects (ARBD), and Alcohol-Related Neurodevelopmental Disorder (ARND) constitute a major public health concern."

* Dr. Robinson said that FAS is the birth defect, not the cause, and he suggested that it should read ". . . nation's leading birth defect associated with developmental disabilities."

* Dr. Sokol suggested that "impacted" be replaced with "affected." Dr. Cordero pointed out that "affected" would be interpreted as affecting family members. He wanted to make sure that was implicit. The panel agreed that it would be included.

* Concern was expressed about the potential negative connotations of the word "eliminate." A suggestion was made to replace it with "prevent FAS/FAE and promote effective, life-long interventions for those impacted."

* Dr. Calhoun said she would like to see "FAS/ARND." ARND, she believes, says more than FAE. She thought that most people did not know what those effects are. If they add "neurological," people will understand what they are dealing with. Several panel members agreed. Dr. Sokol pointed out that if the panel did not want to deal with issues of congenital defects, perhaps the wording could be "alcohol-related effects," (ARE) which includes both neurodevelopmental disorders and anatomic defects. Dr. Coles agreed that "neurological" needed to be a component in the statement. Dr. Floyd suggested using the term "alcohol-related birth defects." A comment was made that "ARE" is not commonly used and people would not know what it meant. Dr. Calhoun said that "alcohol-related effects" could be construed as broadly as drunk driving. People agreed that using "ARE" confused the issue. Dr. Cordero suggested "alcohol-related neurologic effects." Dr. Coles offered "neurodevelopmental" and the group suggested consideration of Dr. Calhoun's idea of using the acronym, "ARND" after "FAS." Ms. DeVries agreed, pointing out that doing so would be in keeping with nomenclature from the Institute of Medicine report.

* At this point the statement read, "FAS/ARND is the nation's leading preventable birth defect associated with developmental disabilities . . ." Dr. Coles pointed out that there are cardiac defects and congenital anomalies

associated with this disorder, as well as physical effects. She did not feel those should be left out. The statement was then written to read, "FAS/ARND are the nation's leading preventable birth defects and developmental disabilities. Our mission is to prevent FAS/ARND and promote effective, lifelong interventions for those affected." The panel took out "associated with," and decided to spell out acronyms when first used in the statement.

Prior to the discussion of goals, strategies, and priorities, Mr. Morris presented the revised Mission Statement developed by the group. The statement reads as follows:

"FAS/ARND are the nation's leading preventable birth defects and developmental disabilities. Our mission is to prevent FAS/ARND and promote effective life-long interventions for those affected."

Goals

The group then moved onto the subject of Task Force goals. Mr. Morris began the discussion by reminding the group of the NTFFAS/FAE Functions as listed in the Charter, which are to:

- * Develop recommendations and strategies for improving the diagnosis of FAS/FAE
- * Identify and recommend interventions for high risk women
- * Specify critical services needed by persons with FAS and their families
- * Enhance the public education and awareness of FAS/FAE

The group brainstormed about Task Force goals. Their deliberations included the following points:

* Mr. Morris suggested using the mission statement to guide the discussion on Task Force goals. He suggested that they attempt to reach consensus on main categories.

* Dr. Day suggested that evaluations of goals (to measure progress) be considered. Dr. Charness said that they probably need to determine existing programs and gaps, and that evaluation is important, as well as cataloging available programs. There was general agreement on this point. Dr. Day suggested they put "evaluation and research" under the "broad functions/purposes." Then, underneath that, they could have sub-categories on how they would accomplish the various things.

* Dr. Riley suggested adding, "advise federal and state agencies based upon what is available."

* Dr. Coles pointed out that there are other main goals on which to focus. She read the second purpose in the Charter regarding meeting the general needs of populations affected by FAS/FAE.

* Dr. Floyd said that additional information needs to be collected regarding diagnostic and service needs of children with FAS/ARND, as well as what resources are available to address those needs. Mr. Morris asked how to word this. Dr. Day suggested "determining service needs and defining gaps in services." She expressed concern about the process, and suggested that they take each purpose statement one by one in order to decide how they would focus on each. In response to Dr. Day's suggestion, Dr. Snider pointed out that it is possible to modify advisory committee charters if the group agrees that something is missing.

- * There was general discussion on governmental jurisdiction versus general population in that there is nothing spelled out on how to foster coordination between government agencies services and the general population.
- * Dr. Charness pointed out that a lot of what they were debating was covered in the "Progress to Date" document, which was e-mailed to the Task Force members. He suggested reading parts of that in order to spend their time more wisely.
- * Dr. Floyd asked about how to ensure access to appropriate services for women at risk and individuals affected by prenatal alcohol exposure. She suggested verbiage to the effect of, "Advise, foster coordination, and ensure appropriate service delivery to women at risk and populations affected by this condition."
- * Ms. Waller asked if "prevention" was imbedded, pointing out that it appeared to be missing explicitly. She suggested saying, ". . . ensuring appropriate prevention and intervention service delivery . . ." could be added to make it more specific. Dr. Charness felt that staying close to the language of the Charter, which includes all of this language, would ensure that the issues of concern were covered. Others agreed.
- * Dr. Riley suggested the consolidation of the two goals to read: "To advise and foster coordination among all federal, state, and local programs and research." It was agreed that the two could be consolidated, and that five goals are reasonable.
- * There was discussion among some members about research being an explicit goal and not being merely implied by the word "advise." Most thought research should be a separate goal.
- * Dr. Coles asked the group to move beyond thinking of only government agencies as having service issues in order to encompass a wider range of society. There was general agreement.
- * Dr. Schacht said that funding of services must be explicitly stated; just authorizing services does not guarantee funding. Dr. Charness said that "meeting the needs" is broad and should encompass that, and as they go further, they may need to address the issue again later.
- * An audience member raised the issue of regulations or policy decisions with regard to the intervention of community at large versus individuals, and raising awareness by way of alcohol labels. The community at large does have a role to play. For clarity, Dr. Charness read parts of the Charter pertaining to the issue of prevention/intervention.
- * Dr. Snider wondered what the Task Force thought about the awareness issue and if it should be an important goal. He stressed that Task Force members had repeatedly pointed out that people are not aware of FAS/FAE. There is a major need for communication of the problem to the general public and professionals who need to be educated on the subject. There was general agreement from the group.

* The proposed goals are summarized as follows: (To advise and foster coordination between/among federal, state, local agencies, academics, community groups, and the population (seen as a Function of the Task Force)

* To ensure appropriate prevention and intervention service delivery to women at risk and individuals affected by FAS/ARND.

* Promote, recommend, and address research needs

* Communication and education

Strategies

* Dr. Calhoun requested that the Task Force stop discussing issues that are already written in the NTFFAS/FAE Charter and turn their attention to a discussion of the actions that the Task Force needs to take. There was general agreement.

* Mr. Morris asked the Task Force to break into subgroups for discussion. There was resistance because members felt that they had already done this. One member suggested that since the group came to consensus so easily, perhaps the time would be better spent with everyone remaining in the larger group. Others expressed concern that their discussions had been extremely structured to that point, and that they really had not had time to brainstorm.

* Dr. Floyd reminded everyone that many recommendations had been tabled at the previous meeting, and that consensus on recommendations needed to be formalized. She asked that the group be patient with this process so that they could come to consensus on the recommendations. They could decide how the recommendation list from the previous meeting fit into where the Task Force was currently going. Mr. Morris asked that the group build upon where they left off at the last meeting and add additional ideas and suggestions.

* Dr. Charness suggested reviewing the "Progress to Date" document (see Attachment 1). There was general agreement, following which the Task Force turned their attention to the priorities.

Priorities

Priorities identified from the Pre-planning meeting were read to the group (these were also outlined on the previous day).

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

* Specifying the full clinical spectrum of FAS and FAE including the neurocognitive phenotype

* Proposing research methodologies to enhance FAS diagnosis, endorsing and supporting continued surveillance of FAS/FAE

- * Enhancing education of professionals who will impact families and individuals dealing with fetal alcohol exposure

2. Identifying and recommending interventions for high-risk women by:

- * Developing policy statements defining who is at risk for an alcohol-exposed pregnancy and making recommendations for screening and treatment procedures

- * Developing recommendations for improving provider education in screening, detection, and intervention with high-risk women

- * Facilitating coordination of prevention strategies among agencies, programs, professional and advocacy organizations, as well as business and trade organizations (i.e., HMOs)

3. Specifying critical services needed by persons with FAS and their families by:

- * Making recommendations for identification and evaluation of promising treatment methods for interventions across the life span

- * Identifying federal guidelines that support comprehensive treatment for individuals and their families

4. Enhancing public education and awareness of FAS/FAE by:

- * Making recommendations for developing consistent public health messages to be used in public awareness efforts aimed at reducing prenatal alcohol exposure (including needed resources)

- * Promoting coordination between all federal, state, local, non-profit, Tribal, professional, and business partners to endorse consensus regarding supporting science and appropriate messages

Dr. Riley read the first priority and corresponding bulleted statements regarding diagnostic issues related to FAS/FAE. He felt this to be an important goal, and proposed commissioning a "white paper" to be written by people in the diagnostic field about what they believe to be the impediments and ways to overcome them.

- * Dr. Day suggested that the bulleted statements be put into a global framework, for example, the first bullet belongs under "develop recommendations and strategies for improving the diagnosis of FAS/FAE," the second belongs under "Research" and the third belongs in "Awareness." Everyone agreed with organizing the priorities in this manner.

* Dr. Cordero commented that perhaps one of the areas to look at would be creating working groups around different functions (e.g., Prevention, Research, and Awareness). There was agreement.

Related Business:
Working Group Breakout Session

Mr. Gaylon Morris, Facilitator
Centers for Disease Control and Prevention

The Task Force was asked to consider what the disposition of the current working groups would be, whether certain ones should be eliminated, and/or whether new ones should be developed. Mr. Morris pointed out that there appeared to be agreement during the discussion on priorities to revise the existing working groups to align them with the goals, to decide which group each member would join, and then to brainstorm within each group. The new working groups include: Research Working Group (previously known as Multi-collaborative Workgroup), Raising Awareness Working Group, and Services Working Group.

The Raising Awareness and Services Working Groups decided to meet jointly. The working groups were asked in their deliberations to:

- * Decide what actions to take;
- * Decide the gaps in decisions already made; and
- * Make recommendations regarding implementation of goals, and identify any needs associated with undertaking the tasks (e.g., additional data, etc.).

Note: Revisions of the working group sessions have been made using Michael Charness' notes and the final summary document regarding NTFAS Mission, Goals, and Priorities appears as Appendix I.

Research Working Group Presentation

Participating in this breakout group were: Dr. Calhoun, Dr. Charness (Rapporteur for the Group), Dr. Coles, Dr. Cordero, Dr. Day, Dr. Riley, Dr. Snider, Dr. Sokol, and Dr. Robinson.

This group identified two broad areas where the Task Force could focus its efforts. First, particular white papers could be written on topics where they believe there are a lot of data, that need to be collated and fully analyzed. Second, the Task Force should endorse the need for more research in deficient areas in the field.

Improvement of Diagnosis

This could be done in the form of a "white paper" or consensus panel (perhaps utilizing the NIH consensus process). The following issues were highlighted:

- * Better definitions for clinical diagnosis (particularly across time; that is, across age of the affected individual) including a better analysis of neuro-cognitive phenotype, and a better definition of ARND.
- * Better definitions would be useful for epidemiological surveys
- * Impediments to diagnosis need to be better understood (there are dysmorphology clinics in states, but pediatricians prefer recommendations to specialists)

Proposed Recommendations

- * Develop a clinical case definition for the diagnosis of FAS across time including neurocognitive phenotype and begin work aimed at establishing a clinical case definition for ARND.
- * Develop a uniform surveillance case definition of FAS and begin formative work on a uniform case definition for ARND.
- * Develop a White Paper to review and summarize relevant epidemiological research addressing the scope of the problem, prevalence, risk factors, impediments to diagnosis (i.e., dysmorphology clinics in only some states, pediatricians prefer referring to a specialist), and number of women at risk for an alcohol-exposed pregnancy.

Prevention

Proposed Recommendation

- * Develop a White Paper to review the evidence for effective prevention and treatment strategies for women at risk for or engaging in prenatal alcohol use. The paper should address identification of those at risk, barriers to implementation of effective strategies, and proscriptions against implementation for untested models or models that are not research based.

More Research Needed (topics to be addressed later)

The group felt that there were some topics for which it was not clear that "white papers" should be generated, but that they did believe to be areas that are deficient in research which need further attention, including:

1. Education

Questions should be addressed regarding whether curricula are effective for both professionals and families, and which strategies work best in the classroom.

2. Treatment (e.g., medications, behavioral therapy, family therapy, and others)

There is apparently a large amount of data on services research and treatment of pregnant women generated through federally funded research in the 1980s and 1990s that have not been fully analyzed.

3. Health Services Research (e.g., family research, legal aspects)

There was general consensus that there is a major deficiency in family research as it pertains to FAS/ARND.

Proposed Recommendation

* Develop an agenda for health services research focusing on families of individuals with FAS/ARND including, why some families do well and stay together, how birth defects affect families and how this is different for FAS, divorce rates, criminal problems, how the legal systems deals with FAS, sociology, anthropology and other issues.

4. Basic Sciences

Though the basic sciences area is well covered in NIAAA=s portfolio, it might be helpful to encourage the translation of basic findings to the clinical domain. For example, the area of imaging was discussed, which may not yet be ready for that application. As various areas of basic research become more developed, there should be some mechanism for bringing those into the clinical domain in all federal agencies involved in this area of research.

Proposed Recommendations

* Develop an agenda for basic science research including translation research, bringing basic research findings to the clinical domain (e.g., imaging), and address issues of susceptibility (is there a higher incidence of neuropsychological problems in the offspring of FAS/FAE adults who don't drink).

Discussion Summary:

* Dr. Floyd suggested an overarching "white paper" with relevance to all of the working groups that includes a systematic review and summary of the scope of problem. This would include epidemiologic studies and the best estimate of the prevalence of the conditions and the number of at-risk women. Epidemiological data that can emphasize the need to have this issue understood as a major problem.

* Ms. DeVries pointed out that there appears to be a higher incidence of anomalies in the children of people with FAS, and that they should address this topic in the area of research.

* A suggestion was made to add "continued surveillance" to track data on FAS, particularly in light of the Healthy People 2010 goal of tracking the condition.

* Dr. Coles asked to include "individuals" as well as "families" under the "Education" area.

* With regard to prevention research, a suggestion was made regarding the need for pre-conception education, with a focus on adolescents as well as men. There are some studies to suggest that even males who drink may be at high-risk for conception difficulties and/or children with birth defects. Education must start earlier for prevention, and beginning with at-risk women is too late. Moreover, women who are in abusive situations, who are incarcerated, and who have sexually transmitted infections are at much higher risk per se. Hence, primary prevention must begin early for males and females. Others agreed that education of men and their responsibilities should be addressed, and explored separately.

* With regard to the parallel between integrity of the families with and without children with other birth defects and FAS, Dr. Cohen pointed out that there is a growing body of literature about the children of people with developmental disabilities. This would allow for some ways of comparing integrity of those families and whether this is a physiological issue or a sociological issue.

* Dr. Riley thought the Research Working Group's list was complete enough and asked that they prioritize the items. Dr. Floyd suggested that since the Services/Awareness may have areas that overlap with research, it would be a good idea to hear their presentation before prioritizing the

Research Working Group's suggestions. Her suggestion was adopted.

Services Working Group Presentation

The Service Working Group and the Raising Awareness Working Group decided to meet together. Participating in this combined breakout group were: Dr. Cohen, Ms. Devries, Dr. Damus, Dr. Floyd, Mr. Klene, Dr. Maresca (Rapporteur for the Group), Ms. Mitchell, Dr. Riley, Dr. Schad, Ms. Waller, Ms. Weber, and Ms. Wybrecht.

With regard to services, the workgroup made the following recommendations to the Task Force:

Complete State/Tribal Profiles of Existing Services

Profiles should be completed, specifically of state and tribal entities, regarding existing services in order to identify the gaps. Specific questions to be asked in these profiles include:

- * What kinds of services are available to individuals with FAS/ARND?
- * What are the current eligibility criteria?
- * How are women at-risk defined?
- * What services are available to identified women at risk?

* What is the availability of professional education? "Professional education" was broadly defined as not just being related to health professionals, but also related to juvenile justice professionals, educational professionals, and those involved in other disciplines as well.

Services identified by the public and affected families could also be gathered through town meetings.

Proposed Recommendation

* Complete a profile of state, tribal, and private entities regarding existing services for individuals with FAS/ARND and women at risk for an alcohol-exposed pregnancy, including current eligibility criteria and ongoing educational efforts for professionals about FAS and ARND.

Report Card

Report cards could highlight the profile findings with regard to the availability of current services as well as identification of the gaps, with specific recommendations on closing the gaps.

Proposed Recommendation

* Develop a "report card" for essential state services needed to prevent FAS and ARND, treating individuals with FAS and ARND and their families, and women at risk for having an alcohol-exposed pregnancy.

Define a National Standard of Care for FAS/ARND

Proposed Recommendation

* Develop an agenda that will lead to the definition of a national standard of care for individuals with FAS/ARND across the lifespan, including best practices and a plan for disseminating this broadly and educating professionals who will be implementing it.

System-wide Education on the Disability

The group considered how they would be able to get information on the disability, services, and prevention to a variety of disciplines.

Proposed Recommendation

* Develop a plan for system-wide education regarding prenatal alcohol-related disabilities and disseminate to health services, judicial, education, child welfare, vocational rehabilitation, juvenile justice, and public health systems (e.g., STD, maternal child health, pregnancy testing).

Increasing Awareness Working Group Presentation

With regard to increasing awareness, the group made the following recommendations to the Task Force:

Launch a National, Coordinated Media Campaign on FAS/ARND

There was agreement in the group to move forward with a national, coordinated media campaign on FAS/ARND, and to endorse the Surgeon General's "Zero Tolerance" statements. The suggestions for components of a campaign were:

- * It should be broad-based and coordinated
- * There should be public service announcements, posters, website, TV/Radio, transportation
- * The messages should be culturally appropriate
- * It should target families, partners, special populations, youth, elders, the alcohol industry, and faith-based initiatives
- * It should be evaluated

Proposed Recommendation

- * Endorse a national coordinated media campaign (SAMHSA Center of Excellence is working on this and CDC is working on targeted campaigns) and request ICCFAS recommend how this effort can best be coordinated among all federal agencies.

Public Policy Issues

The group briefly discussed the following issues:

- * How to address the alcohol industry in their delivery of messages related to AZero Tolerance@ and how that might work from a public health and policy standpoint
- * Have the Office of National Drug Control Policy (ONDCP) include risks of alcohol in their public messages [Ask Fred Garcia to pursue this]
- * Re-issuance of the Surgeon General's Report of warnings regarding drinking during pregnancy
- * Consider credentialing requirements for professionals with regard to continuing education on the condition. This may include issues related to licensure and education/certification of teachers and other health and justice professionals.

Proposed Recommendations

- * Contact the Office of National Drug Control Policy (ONDCP) to determine if they are able to include information on FAS/ARND in their resource materials.
- * Endorse the Surgeon General's Advisory statement regarding drinking during pregnancy, and urge the statement be re-issued as part of the coordinated national media campaign.
- * Investigate incorporating information about prevention and treatment of FAS/ARND into the credentialing requirements for teachers, justice, lawmakers, health care professionals (i.e., questions on the state board exams).

Develop Standard Curricula

Proposed Recommendation

- * Recommend the development of a K-12 curricula component to address FAS/ARND and prenatal alcohol use.

Discussion Summary:

With regard to the Services Working Group presentation, Ms. Mitchell suggested that prevention along with education is needed.

* Dr. Floyd stated that media campaign activities need to be assigned to specific groups/agencies. Dr. Maresca agreed, and said that they are currently parceled out to a number of different agencies.

* With regard to the message of "Zero Tolerance," an inquiry was posed as to whether the group intended to try to convince the alcohol industry to put forth this message. This was of concern because the industry does not believe that low levels of alcohol consumption during pregnancy have any effects on offspring. Dr. Riley cautioned that, given that the alcohol industry represents an extremely powerful lobby, the Task Force could be in jeopardy if they attempt to take them on. While they might need to be bold, they must also be prudent in whatever actions are taken. Ms. DeVries pointed out that it did not seem logical to have a Task Force on FAS/FAE and not have something to say to the alcohol industry.

* Ms. Mitchell added that from past experience with the industry, they are cooperative, but have a tendency to expect creative control. There are other groups that will respond positively. A member of the audience pointed out that originally the alcohol industry strongly resisted working with Mothers Against Drunk Drivers (MADD), but now they do. She thought that even if the Task Force was dissolved because of a powerful industry, at least they would have tried everything they could to force the alcohol industry to change their messages. Dr. Cordero agreed, saying that he was not worried about the risks to the Task Force if they chose to put pressure on the alcohol industry. He felt that there was a good chance of being able to work with the industry.

* Dr. Snider suggested working with others like the entertainment industry. He described an episode of the sitcom "Friends" where a character is pregnant. At a party, she took a sip of champagne, realized what she was doing, and spit out the champagne. He thought that was a powerful message that would reach many people, probably more powerful than a warning on a bottle. Ms. Mitchell added that the following week, that same character went out and bought champagne, and NOFAS received e-mails from many people.

* Dr. Coles cautioned that the "Zero Tolerance" message was getting a bad reputation. It has been applied in a bizarre manner and been used to arrest and jail women. Therefore, she cautioned the group to be careful in their use of terminology and the way they frame the issues. There was discussion among the group members regarding the efficacy of using the Surgeon General's "Zero Tolerance" stance. Most thought that there should be an effective way of taking a firm stand that women should not drink during pregnancy.

* There was discussion about the ONDCP which consults with television sitcom writers in order to get the facts right. The same could be done with alcohol. CDC has a partnership with the entertainment industry, particularly with soap operas which reach a particular segment of women and other adults. For example, "Days of Our Lives" had a storyline around a child born with FAS for which they earned an award from CDC. They consulted ONDCP

about the facts, and most of it was correctly portrayed, except when they started talking about how "maybe the child would get better." The soap opera industry will take up issues and are interested in accurate information.

* With regard to education, a comment was made that policymakers need to be educated as well.

* Dr. Day suggested the need to discuss the issue of bottle labeling. Many agreed that the labels were not strong or as eye-catching as they need to be. There is no statewide consensus on putting larger labels in stores. Dr. Riley indicated that there are no data to support that such warnings have any effect. Dr. Floyd pointed out that currently, labeling on bottles is directed toward pregnant women. To create awareness of a global health issue, the message must reach a wider audience.

* A suggestion was made to research labeling to find out what is and is not effective. Dr. Riley requested that this be put on the Research Working Group's agenda.

* Dr. Floyd stated that Prenatal Smoking Cessation research supports the notion of multiple cues (different places an individual sees a message) as effective as increasing cessation notes. Dr. Charness pointed out that there was some research to suggest that when there was a message for teens to stop smoking, it actually encouraged them to do so. Ms. DeVries and others said that they did not believe this to be true. She said she would not support discussion of removing warning labels, but it was clarified that there was no suggestion on the table to remove labels.

* There was some discussion that further research of labeling needs to be conducted. There was some agreement that labeling should be moved under "research."

* A suggestion was made to reorganize the research topics into the categories of primary, secondary, and tertiary.

Closing Session

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

Dr. Riley led the group in a closing session during which the Task Force deliberated on what issues were raised that would have significant impact on FAS/FAE, what their priorities should be for the coming year that could most reasonably be accomplished, operations of future meetings, and the date and logistics of the next meeting. The items agreed to which would have the greatest impact over the next year in the research area, and the operation/date of the next meeting are followed by the discussion which led to these decisions.

Greatest Impact Over the Next Year

Research Area:

- * Convene Consensus Panels or Develop White Papers on Diagnostic Issues:
 - o Surveillance definition (CDC/CSTE)
 - o Case definition (NIH model)
 - o Impediments to getting diagnosis

- * Prevention and Treatment "White Papers"
 - o Review of effective strategies, barriers, and epidemiology aspects

Education/Awareness Area:

- * Town Hall Meetings

Operations for Future Meetings

* Meetings should deal with only one or two topics. Experts should be brought into meetings to help debate various issues to assist the Task Force in their work. There should be some concentration on business/decision making.

* Information sharing should occur prior to the meeting. The Task Force must work with CDC to help facilitate this process. Email and conference calls should be utilized to conduct Task Force business prior to Task Force meetings. A Task Force listserv will be established to facilitate ongoing discussions related to Task Force reports and proposals.

Future Meetings

The next meeting was tentatively set for May 16-17, or 15-16, 2002. It was suggested that the Task Force consider adding their meetings to the end of larger conferences that some Task Force members may already be attending.

Discussion Summary:

Discussion has been grouped according to topic area. In the case of overlapping topics, the input has been placed with the topic under which it arose. The main categories discussed include: Education/Information Dissemination/Media Campaign, National Standard of Care, Recommendations, Research Issues, Town Hall Meetings/Hearings, and Uniform Definitions.

Education/Information Dissemination/Media Campaign

* Dr. Riley stressed the importance of public education/policy. The two recommendations that were endorsed were to have the Surgeon General re-issue the warning statement, and that there be a national coordinated media campaign that took into account different populations.

* With regard to a national media campaign, Dr. Floyd wondered if the Task Force could take responsibility for bringing agencies together to coordinate campaign efforts. She also suggested a recommendation about integrating alcohol messages into the education effort, and inquired as to whether anyone had information on FAS curricula in medical schools. Ms. Mitchell said it was difficult to get that adopted, and that she could provide data regarding the issue.

* Working with Hollywood/Entertainment Industry was tabled until other issues can be addressed.

* It was noted that a number of curricula are being developed, and will likely be evaluated. Thus, it was agreed that this was a long-term issue that could be tabled.

National Standard of Care

* Ms. DeVries thought that defining the "standard of care" was a long-term task. There is much that has to be done before then such as town meetings, state profiles, and the development of different types of professional education programs (i.e., core disability education, intervention education).

* Dr. Riley asked the workgroup to decide what they want the "standard of care" defined as in an ideal environment.

* There was general agreement that the "standard of care" should be a high priority. A discussion on the "standard of care" could be initiated at the town meetings.

* The reauthorization of the Individuals with Disabilities Education Act (IDEA) will occur in 2002. FAS is not on the radar screen. Getting FAS included in the reauthorization would have an enormous impact.

* Dr. Snider said that it was appropriate and important for the Task Force to define a "national standard of care." However, beyond figuring out standards, implementation must happen. Care must be taken when designing the process so that there is optimal buy-in from professionals. It is critical to think about exactly who to involve, because if the Task Force develops something and just hands it to people, it may have no credibility. Dr. Snider was in favor of addressing the "standard of care" issue at a later date.

* Dr. Riley thought that the "standard of care" issue should be a workgroup function. Dr. Snider thought that they should engage professionals in deciding the "standard of care."

* Dr. Coles agreed, suggesting that they should engage the professionals in the "standard of care" discussion and integrate that into practice. The State/Tribal Profiles need to reflect actual care. She cited an example of professionals saying they were providing care to people with FAS, although none of them actually were.

* Dr. Cohen suggested that the "standard of care" issue could be addressed through a white paper, comprising broad, complex areas (e.g., legal, medicare, policies).

* There was general agreement that they could begin work on defining a national "standard of care," although it probably would not be completed within 6 months to a year. The Services Working Group will develop a process to outline how the Task Force can begin to formulate a national "standard of care."

* Ms. Mitchell raised the issue of credentialing requirements for professionals. Dr. Cordero said that should be part of the "standard of care" issue.

Recommendations

* Dr. Cordero suggested that the Task Force prioritize and make recommendations, and CDC could come back and say what was possible in the next six months. Recommendations that were made by the Working Groups that do not appear on the 1-year priority list will be tabled and addressed at a later date.

* It was noted that different agencies/organizations often have different recommendations. The challenge will be in harmonizing the recommendations.

Research Issues

* Dr. Cordero asked if perhaps working on preventing FAS/FAE was more of a priority than research about diagnosis from the standpoint of advancing the efforts stated in the mission. Dr. Riley replied that if FAS/FAE cannot be identified by medical professionals, the impact of prevention cannot be ascertained, and there cannot be accurate surveillance. There was further discussion about whether getting a diagnosis for FAS enhanced outcome. Dr. Riley maintained that there is research that proves that it does. Task Force members who have personal experience working with people with FAS agreed that once a diagnosis was made, it made a big difference in patients' lives. However, Dr. Coles stressed that anecdotal evidence does not substitute for research.

* Dr. Day raised the issue of prevention, and Dr. Riley asked the Task Force what recommendations to make, or if there were additional data on the subject. There was discussion of this issue regarding the need for more research.

* Dr. Cohen raised the issue of research in the area of second births given that behaviors can be changed. There is some research on this.

* There was discussion of the need to document epidemiological studies among the group and summarize what is known. It was agreed that background information is critical to have and disseminate.

* Dr. Riley suggested that there be additional basic research on treatment, and for endorsement of more treatment. He asked the group if there was need for a "white paper" and research in the health services area. It was suggested that this would come after the town meetings.

* Dr. Day thought that recommendations regarding basic science wait for the "white papers" after the Task Force has the opportunity to see what the data look like.

* Dr. Robinson stressed that comparison of services available is necessary.

Town Hall Meetings/Hearings

* Dr. Riley asked whether there was consensus on obtaining additional information through town meetings around the country.

* It was suggested that there be 4 meetings. Possible locations for these town meetings included: Massachusetts, Texas, Oregon, California, and Pennsylvania.

* Dr. Riley pointed out that not every Task Force member needed to attend every town meeting. They should address the issue of inviting other people who may want to be on panels at town meetings, and he requested that a Logistics Working Group be formed. Dr. Cordero said that CDC could handle logistics.

* Volunteers for the newly formed Town Hall Meetings Logistics Working Group included: Ms. Mitchell, Ms. DeVries, Dr. Cohen, Dr. Riley, Dr. Maresca, Dr. Floyd, and Ms. Weber.

Uniform Definitions

* There was some discussion that further attention did not need to be paid to surveillance. Some agreed, some did not. There was general agreement that the Task Force could convene a consensus panel or panels on diagnostic issues to create a uniform case definition (looking to the NIH model), a surveillance definition (looking to the CDC/CSTE model), and to determine impediments to getting diagnoses.

* Dr. Floyd stressed that uniform definitions of FAS/ARND were needed throughout the health care community. If professionals hold different points of view on criteria, diagnoses will vary from location to location. Dr. Snider agreed there is a need for case and surveillance definitions. It was suggested that the Task Force collaborate with other agencies to define these.

* Dr. Coles pointed out that unless a person with FAS has a clinical diagnosis, they cannot obtain services, which is a different issue from awareness of the diagnosis. Dr. Cordero emphasized the importance of early diagnosis.

Ms. DeVries talked about the importance of early recognition in order to take care of the complexities associated with FAS. She recalled her work with Senator Daschle=s original legislation on FAS/FAE and trying to get a way to get medical diagnosis funding. That is what he put in the legislation.

* Dr. Maresca pointed out that there must be verbiage to cover diagnoses for adults with FAS as well as children. Dr. Riley agreed that this was of critical importance.

I hereby certify that, to the best of my knowledge, the foregoing Minutes are accurate and complete.

Edward P. Riley, Ph.D., Chair

Date

End of Summary Report