

**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)**

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

Summary Report

Those present during the December 10, 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 Damas (National March of Dimes), Dr. Nancy Day (University of Pittsburgh), Jocie DeVries (FAS Family Resource Institute), Dr. Samia Noursi (Logicon/Row Sciences), Dr. Mary Dufour (NIAAA/NIS), Dr. Louis Floyd (NCBDDD/CDC and Designated Federal Official, NTFFAS/FAE), Laurie Foudin (NIAAA/NIH), Ms. 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. Terry 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), Dr. 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), Ms. Ann Waller (FAS Family Resource Institute), Dr. Kenneth Warren (NIAAA/NIH), Mary Kate Weber (NCBDDD/CDC), Georgiana Wilton (Family Empowerment Network/University of Wisconsin), Barbara Wybrecht (Parent Representative).

Opening Remarks
Monday, December 10, 2001

NTFFAS/FAE
Dr. Edward Riley
Dr. Dixie Snider
Dr. José Cordero
Dr. Louise Floyd

ICCFAS
Dr. Mary Dufour
Dr. Faye Calhoun
Dr. Kenneth Warren

Drs. Riley, Snider, Cordero, Floyd, Dufour, Calhoun, and Warren each welcomed those present, noting the challenges to be faced, and stressing the importance of communication between the National Task Force on Fetal Alcohol Effect and Fetal Alcohol Syndrome (NTFFAS/FAE) and the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS) in order to address those challenges and avoid duplication of efforts.

Dr. Ed Riley, Chair, NTFFAS/FAE, and Dr. Louise Floyd, of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC) facilitated the meeting, during which presentations were given on new Fetal Alcohol Syndrome (FAS)-related projects for FY 2001, promising "Works in Progress," and reports from agencies on what still needs to be done and how the Task Force can be of assistance. Dr. Floyd agreed that communication was critical between these two committees. Given that many issues have already been identified by the Task Force as priorities, it was thought that this joint meeting offers the opportunity for the Task Force to learn about the exciting new federal programs that have resulted from recent funding.

New FAS-Related Projects for FY 2001

National Institutes of Health, Tribal Research

Dr. Phillip Smith
Indian Health Services (IHS)

Dr. Smith indicated that the Indian Health Services (IHS) recently hired a full-time maternal child health officer, Dr. Judith Thierry. Dr. Thierry, a physician, will be taking the lead on FAS for IHS. The other person assigned to address the issue of FAS is Dr. Marlene Echohawk, a psychologist. Drs. Thierry and Echohawk will assist in coordinating activities relating to FAS in the coming year.

The Indian Health Service received funds in their alcohol program, totaling \$15 million. They used these funds to address a wide range of issues, but have directed some of those resources to children and prevention of FAS.

Some of the funds have also gone to Alaska to support some of their programs. The National Institute of General Medicine (NIGM) within NIH, initiated a program to increase research activity specifically for Native American programs. Collaborations among Tribes and university researchers will design research studies to addressing various issues. Six programs were funded to engage in community-based participatory research. The programs address many of the same issues the Task Force is discussing.

The amount of money NIGM has allocated for this research is relatively small, but compared to what IHS and the Tribes have, it is quite large. The first year of funding was \$3 million, and they are now in the second rounding of funding. The partnership is very important, and the work has focused a great deal on children. Dr. Smith expressed his gratitude for the opportunity to share this good news, and his excitement about the efforts the Task Force and ICCFAS are putting forth.

Four -State Consortium and Virtual Center for Excellence

Dr. Paul Brounstein
Substance Abuse and Mental Health
Services Administration (SAMHSA)

Speaking for the Substance Abuse and Mental Health Services Administration (SAMHSA), Dr. Brounstein said they were pleased to be at the table, and thought not only could they learn a great deal from the NTFFAS/FAE and the ICCFAS, but they also have a lot to contribute as well.

In 2001, given the work that SAMHSA has done (e.g., in pregnant, postpartum women, infants, teen parents, etc.), and given the fact that they are a substance abuse prevention agency, Congress assigned them with two earmarks for FAS: Alaska, and the Four-state Consortium (e.g., North Dakota, South Dakota, Montana and Minnesota). Both of these earmarks are now going to move to 5-year programs, and both are building infrastructures as well as developing comprehensive programming with a strong prevention component. Alaska had a head start having received CDC funding to build an identification and surveillance system.

In conjunction with this SAMHSA was also up for re-authorization. In the re-authorization, they were granted the responsibility of building up to four Centers for Excellence. Given the resources available, they decided to have one large FAS Center for Excellence rather than four separate centers. SAMHSA initiated a contract mechanism for the Center for Excellence. Initially, there was confusion about what the Center was supposed to be, what it was supposed to do, and how it was supposed to be managed. The primary purposes of the Center are laid out by authorizing legislation as follows:

- Provide/integrate information and services focused on a single issue: the prevention of FAS/Alcohol-Related Birth Defects (ARBD).
- Use a consortium of experts to bring together various academic, federal, and private agencies to leverage expertise, and potentially funds, while building a constituency base.
- Document obstacles, cost savings, cultural adaptations that occur as well as identify those that are needed.
- Generate new information needed to better develop and market effective programs.
- Develop and pilot targeted interventions.
- Develop training.

The first step is to conduct an environmental scan to learn what resources exist, who is already involved in FAS programs and what impact it is having so that work can begin validating (through expert consensus) what seems to be working, and to think about how to target these efforts for specific at-risk populations. In designing adaptations, they are looking at pilot testing them to see how they run, if they are accepted, and if they are efficient.

The Center for Excellence will also serve as a data-coordinating center, looking at common collection protocols and doing analysis, not just Alaska and the 4-state Consortium, but also all of the new grants that SAMHSA is funding. The agency recently funded 5 FAS grants, 2 of which are focused primarily on infrastructure development, and all 5 of which have comprehensive services and integration of services locally, as well as prevention components. These should generate a good deal of information from which they can learn. Until there is a consensus about the types of things that are working, for whom, and where, it is difficult to develop materials and training for the field. This task is part of the Center's purpose, but one, which must wait until more information is gathered.

SAMHSA views the Center as a national resource, and feel strongly that the best way to build it properly is through collaboration. Thus, they are counting on those at this meeting and others with specific useful expertise to participate in the Center's activities.

Virtual Center for Excellence

Dr. Samia Noursi, Director
SAMHSA FAS Virtual Center for Excellence

Following up on what Dr. Brounstein stated, Dr. Noursi explained SAMHSA is putting together a steering committee. The committee plans to meet early in February to discuss the work plan of the Center.

Center staff started in mid-September, but are already putting together a management information system that will incorporate information about FAS programs that can be accessed, allow application for technical assistance, obtain literature, etc. This will also serve as a coordinating center for FAS grants; that is, Alaska and the 4-State Consortium, as well as future grantees, to help them collect and analyze data, and assist in the identification of common instruments across the grantees.

As part of the environmental scan, Center staff are looking at training manuals and curricula that have already been developed. Following that, they will identify manuals/training and will soon be able to provide technical assistance. They have already received requests for technical assistance and are in the process of identifying the best consultant to provide this assistance. Center staff are also in the process of compiling a database of information about consultants across the country who will be available to provide technical assistance. The Center has very solid expertise on board, but they will also rely on many consultants across the country who are not part of the core staff.

Discussion Summary:

- Dr. Cohen pointed out that it is critical to open this "virtual" Center to everyone and synthesize and integrate the information so that everyone can use it. Dr. Noursi stated that there are plans for a strong evaluation component, and a capability for people to access that. They provide technical assistance through a program called "As an Evaluator," and there is an 800 number for those who need to an immediate response.
- With regard to scope, Dr. Snider inquired as to what Dr. Brounstein meant by "what is working," that is, was he referring to the spectrum of community-based interventions, including prevention and preventing alcohol effects and providing service for those individuals and families affected by FAS. Dr. Brounstein responded that the primary mandate of the Center is prevention, but there is an understanding that prevention cannot be 100%, and that there are still services required to deal with the problems individuals with FAS/FAE experience. While the primary focus of the Center is prevention, they have no problem sharing information and pooling expertise on treatment and services.
- Dr. Stone emphasized that the steering committee will have treatment and mental health services representatives from within SAMHSA and other agencies with whom they can partner. They will look to the NTFFAS/FAE for expertise to understand and provide best practices to the field.

- Dr. Cohen asked what kind of training would be provided and for whom. Dr. Stone responded that they are pursuing the training issue. Currently, they have some exciting work going on in Minnesota with a curriculum for justice/judges - those who deal with overall sentencing and those who deal with people with FAS on daily basis. In Alaska, they are thinking about policy changes where there are neurological disorders. Persons with diagnoses of FAS would be required to have alternative sentencing and would not be placed with the general population. In the next round of funding, they will be looking at an inner city, federally registered health center to learn what they will do to prevent FAS. They will also fund 5 to 7 community planning grants, which are designated for communities that do not normally have a chance to access grants. There will be technical assistance to teach these communities about needs assessments, building infrastructure, and prevention programs for FAS in order to help them leverage more federal funding in the future. Dr. Brounstein added that they currently offer technical assistance based on the needs of the requester. The piece that remains is determining interventions and protocols for family treatment plans.
- Dr. Stone indicated there are model programs for high-risk youth that work. They have a set of 15 criteria through which these are reviewed. What they do not have is understanding and expertise in the field of FAS issues. Input on this issue is the kind of assistance they will seek from NTFFAS/FAE.

Fetal Alcohol Syndrome (FAS) Prevention Program

Dr. Louise Floyd FAS Prevention Program Centers for Disease Control and Prevention

The goal of the Fetal Alcohol Syndrome (FAS) activity at CDC is to prevent FAS and other alcohol-related adverse outcomes, and to ameliorate the conditions among those affected. They CDC has been working in this field for about 10 years, and for a period of time were working with a budget of about \$2.5 to \$3 million. The activities that CDC undertakes generally fall into three categories that are characteristic of the way CDC approaches any condition:

- Develop surveillance systems
- Conduct epidemiologic studies
- Conduct prevention programs

Dr. Floyd described the programs CDC had with previous funding, and what they were able to add with increased funding:

Previous Funding Supported:

- FASSNet, their model surveillance program
- Provider education activities
- Prevalence work in South Africa
- Monitoring of prenatal and preconceptional alcohol use, using the Behavioral Risk Factor Surveillance System (BRFSS)
- Identifying risk factors for alcohol exposed pregnancies, and targeting populations at risk primarily done through Project Changing High-Risk Alcohol Use and Increasing Contraception Effectiveness Study (CHOICES) Epidemiological Survey, and the BRFSS
- Project CHOICES, a preconceptional approach to reducing alcohol exposed pregnancies, with a dual behavioral intervention: reducing alcohol exposure and postponing pregnancy
- Survey of obstetricians and gynecologists to learn what their knowledge, attitudes, and practice behaviors were, and to understand what providers needed to improve the practices
- Coordinating the activities of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (NTFFAS/FAE)

New Funding:

- Expand FASSNet to realize better case identification
- Expand surveillance work and conduct FAS risk factor studies in South Africa
- Expand support of the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (NTFFAS/FAE)
- Under epidemiological studies, investigate alcohol exposure effects in a collaboration with Denmark through their longitudinal birth cohort study
- Investigate the use of biomarkers
- Expand prevention programs

With regard to the expansion of programs due to additional funding, CDC's FAS program went from 8 to 25 cooperative agreements. New activities include a group of grantees looking at effective intervention strategies for children with FAS/ARND. There is research supporting comprehensive services that have likelihood of improving the outcomes of children affected by FAS/ARND. However, there is no research yet on specific intervention components. This intervention project will contribute to the science in a way that provides a better understanding of whether there are things that should be done for children with FAS/ARND because they are affected.

CDC is also in the process of developing effective FAS/ARND education curricula for parents, providers, teachers, and law enforcement. In addition, have funded 3 university-based projects have been funded to develop, implement and evaluate targeted media campaigns to prevent alcohol-exposed pregnancies. In addition, two grantees have developed epidemiological and intervention studies for reducing alcohol exposed pregnancies in Latina and Hispanic women, an emerging population at risk. CDC is also conducting a Project CHOICES randomized control trial. In this next phase of Project CHOICES, the CDC FAS prevention program established a data coordination center. Twelve hundred women will participate in the randomized control trial. Half will be control subjects who are participants, and half will be testing the efficacy of the dual focused intervention. New funding also enabled CDC to fund a project that adapted the Project CHOICES Phase 1 intervention to young women, 18 to 24 years of age (Project Balance). New funding also expanded the support of the NTFFAS/FAE.

In summary, as of 2001, CDC funds 20 states funded for FAS projects, with 5 of them funded for more than one project, for a total of 25 projects. Project CHOICES is in 3 states, Project Balance in 1 state, FASSNet in 5 states, FAS Education Awareness in 4 states, Media Campaigns in 3 states, and Interventions with Children in 5 states. California is a recipient of funds from a number of programs. Dr. Floyd stressed that CDC is open to collaboration, particularly with those agencies that have new funds and are simultaneously planning the same types of activities CDC is planning.

Intervening with Children and/or Adolescents with Fetal Alcohol Syndrome/Alcohol-Related Neurodevelopmental Disorders

Dr. Jacqueline Bertrand
FAS Prevention Program
Centers for Disease Control and Prevention

Dr. Bertrand is the CDC principle investigator for their Intervening with Children and/or Adolescents with Fetal Alcohol Syndrome/Alcohol-Related Neurodevelopmental Disorders project. This project the result of a very large collaborative effort on the part of most everyone in attendance at this meeting. Many people have been working toward the goal (e.g., parents, agencies, clinicians, researchers, etc.) to have a scientific program to develop interventions for children with FAS/ARND. This is the first federally-funded, systematic program in this area. Strategically, with this large collaboration, interested parties held and attended meetings, listened to people at diagnostic clinics and parents support groups, and attended education meetings. CDC has a public inquiry system where people can contact topic experts through a variety of media (e.g., Internet, telephone calls, e-mail, and regular mail). These kind of communication efforts have paid off substantially not only by leveraging funding, but also by allowing CDC to incorporate all of the information to develop a solid protocol/framework for these interventions.

When intervening with a child with FAS/ARND, one must deal with the whole child as opposed to working on one specific skill at a time, with fragmented services. Working with the child includes working with his or her family and various systems (e.g., education, foster care, etc.). Thinking must be broad and global in interacting with these children. Those affected by FAS area is a very heterogeneous group. They cannot come up with a single disability to characterize all children. Many researchers are trying to do so, but there are poor vulnerability areas that are at high risk in the population. There must be interventions to target core vulnerabilities in addition to the global, overarching intervention framework.

Most of the support/services in place were non-specific, such as basic special educational programs. None that CDC could find had gone through the scientific rigor of controls, intervention groups, and comparisons. Thus, CDC put out a call for proposals that would evaluate interventions for children and caregivers. The interventions had to not only target the children and skills within the children, but also had to develop a program for working with parents, teachers, and/or other caregivers to help these caregivers learn how to interact with the child and to teach them what services they are entitled to and should be seeking out. In addition, CDC was not satisfied with the information available on the cost of this disability. What they found out from their inquiries was that many studies, which use large, national surveys to obtain cost data, most often do not capture the unique cost associated with this disability (e.g., instability of placement, time off from work, replacement of furniture, etc.).

When CDC put out the Request for Proposals (RFP), they received many excellent applications. The following 5 grantees with their targeted area of intervention are:

- Marcus Institute (Learning Readiness/Math Curriculum);
- University of California, Los Angeles (Development of Best Friendships/General Social Skills);
- University of Oklahoma Health Services (Social Skills/Training Behaviors);
- University of Washington (Behavior Regulation/Social Communications with Peers); and
- Children's Research Triangle - Chicago(Stability of Placement and Behavior).

The overall framework is that across each site, CDC will collect a pooled set of data on diagnostics and evaluation, and cost analysis data. This will provide CDC with a very large database of systematic diagnostic and evaluation information (e.g., standardized testing across domains, etc.). Each site will have 50 intervention children and 50 control children, for a total of over 500 children in the pooled data set. In addition, each site will carry out any further evaluation procedures they wish, and will develop a targeted area of intervention, and their family caregiver protocol and intervention. In addition to their chosen domains, all of the sites will be seeking to improve developmental outcomes and reduce secondary conditions.

Highlights of Promising "Works in Progress"

Improving Screening for Alcohol Use During Pregnancy Among Providers Demonstration Project

Dr. Ellen Hutchins

Maternal and Child Health Bureau (MCHB)

Health Resources and Services Administration (HRSA)s

The Health Resources and Service Administration's (HRSA) Maternal and Child Health Bureau's (MCHB) demonstration project known as, "Improving Screening for Alcohol use During Pregnancy Among Providers" is designed to motivate providers to screen systematically for alcohol use during pregnancy using the 4P's Plus screening system. This is the 3rd and final year for the project, and despite the fact that they have a very low budget they have gotten some really good findings. Their demonstration projects are currently funded in the range of \$150,000 per year, and they are currently funding four. These are similar to pilot projects in that they do not have rigorous evaluations, but instead have process evaluations to determine what does and does not work.

MCHB is funding a diverse group of states, which has provided richness in terms of testing out the settings and rural and urban parts of the country. Their settings include an Indian Health Service clinic, a hospital-based prenatal care clinic, private practices, and publicly funded pre-natal clinics. Those who have worked with prenatal patients know that it is somewhat of a problem to get alcohol screening conducted on a universal basis in prenatal clinics. A recent study conducted by Dr. Michael Fleming indicated that approximately 50% of prenatal patients are asked about their alcohol use during pregnancy. Another interesting survey conducted in the last year was of obstetricians/gynecologists who were asked approximately how often they screen their pregnant patients for alcohol use during pregnancy. Of those surveyed, 97% said that they do screen, but only 30% of those in the sample reported feeling comfortable doing so. This indicated that there are issues around motivation and comfort level. Another issue that has come up is the notion by some obstetric providers that they would be much more likely to screen for alcohol use if they could provide accurate information about outcomes at various levels of exposure. Certainly, HRSA, representing the federal government, has said there is no safe level.

The MCHB projects have been using a screening instrument known as the 4P's Plus. Interestingly, 2 of the 4 projects began using this instrument, and now all have adopted it. The other 2 began with the TWEAK alcohol-screening instrument, which is somewhat confrontational. They like 4P's Plus and hope that others will adopt it. However, to date, it has not been tested for reliability. The projects like the instrument because it takes the emphasis away from the woman as the provider starts the screen, and looks at people in her environment. (e.g., her partner, parents, etc.), and then looks at the woman's alcohol use pre-pregnancy and during pregnancy.

Some of the findings include:

- Small, incremental changes in the office setting will make the screening part of the routine.
- Everyone in the office setting should be included in the training/re-training on a regular basis. Often, the clerk who does the intake is most likely to be confided in, and would be in a position to flag charts if a patient was missed on the last visit.
- Screening tools need to be administered very quickly. Most of these can be done in about two minutes.
- Screening should be conducted with every patient, and repeated throughout the pregnancy, perhaps as often as every trimester, because patient comfort levels with staff deepen further into the pregnancy.

Dr. Hutchins shared some of the findings of Dr. Ira Chasnoff, a pediatrician from Chicago, who spent many years studying the medical effects of in utero exposure to cocaine. Dr. Chasnoff has spent the last 10 to 12 years as a trainer of prenatal providers around the country, teaching them how to assess for substance use during pregnancy. One of the sites that the MCHB Illinois project has used is the Westside Healthy Start Project. In its second year, the site went from a 50% to a 90% screening level. One of the things this project did early on was to put a substance abuse specialist within each prenatal care clinic. Dr. Chasnoff has termed their intervention "a warm handoff," which means that the screen is done; the referral is made immediately to the substance abuse treatment person who works in the clinic who then conducts a full-blown assessment. In terms of motivating providers, it is critical to get across to them that all they are being asked to do is a very short screen for risk, and if any of the questions are positive, providers would then refer the person to someone trained to conduct a complete assessment. With this method, providers are also able to get a referral made the same day. Another thing that has worked well in the Illinois projects is that, through legislation, they have been able to get full reimbursement for the nurses to do the assessments. This has been a great motivator. Another incentive that the Illinois projects have found to work with their physicians is continual feedback about what happens to their patients who do test positive for alcohol use. MCHB currently has 13 sites in Illinois.

The MCHB Nebraska project is using a computerized, patient-directed screening tool, so there is no face-to-face assessment. There is some evidence that this is a good way to screen since it is less stressful for the patient. The two sites where they are testing this methodology are an Indian Health Service Clinic in Winnebago, Nebraska, and a health center in Omaha, Nebraska. They also had a private practice site that was part of this project but withdrew toward the end of the first year, primarily because of their fear of losing patients due to screening. Clearly, one of the major challenges with all of these projects has been getting private providers to get on board with screening. One of the lessons learned in Nebraska is the importance of clinic leadership and of getting the cooperation from the providers on staff. The Nebraska project began with the TWEAK and now is using the 4P's Plus.

The Puerto Rico project has not been as successful in terms of getting the providers on board, but has been successful at getting pediatricians on board. Initially, the project targeted obstetricians, but was not getting a good

turnout. However, pediatricians were very interested and made a case that they are seeing these women during the post-partum period, which is a good time for the practitioner to raise issues around alcohol use as well. The Puerto Rico project also has switched to the 4P's Plus screening tool.

Two sites outside the Boston, Massachusetts area began with an initial strategy to train the providers who were most interested in the process of screening, and then gradually to expand the numbers of sites. There is a very good group of trainers in the Boston area who are nationally known and well respected. The trainers have had a lot of success, both conducting screening and brief interventions. The providers disseminate information about the dangers of alcohol. The project also has expanded into the Harvard Vanguard Health System, and they are adding a health center in the third year in the Springfield area. Some of the interventions they have used collectively, and they have a self-administered screening instrument. They are using the 4Ps Plus, and are very attuned to office system integration and how to be as least disruptive as possible. The project coordinates with the statewide substance abuse hotline, and have a statewide transit campaign on subways and buses to alert pregnant women to the dangers of alcohol use during pregnancy. Harvard Vanguard, the largest HMO in the state, has incorporated the screening tool in the pre-registration packets for patients covered under their plan, and they ensure that the completion of the screen will be done on the first visit. Their advice to other projects is to make as few changes to the normal office flow as possible, do not overburden the system, and use data to highlight the need for screening.

Discussion Summary:

- Dr. Day inquired as to whether the MCHB project had been validated. Dr. Hutchins responded that it has not. These are the only projects that have been used with many patients. She stressed that further testing is needed. With this initiative ending, their agency would like to do something to encourage that it be further tested. They have found that it is not intrusive, and compared to some other baseline data, they are getting better results than some of the other screens that they have tried, particularly the TWEAK.
- A question was raised regarding the lost site in Nebraska. Dr. Hutchins responded that she did not know whether it was actually the provider's or the women's anxiety that caused them to withdraw from the project. They assume that providers believe women will not return if they are screened, but there is no good evidence that this actually occurs.
- Dr. Warren inquired as to whether there is a standard procedure, or plans for one, for assessment after a positive screen. Dr. Hutchins responded that positive screens are given a full-blown assessment (e.g., screening for quantity, types, support systems, etc.) by a counselor as a standard procedure.

Alaska Fetal Alcohol Syndrome Surveillance Network (FASSNet)

Dr. Deborah Stone
Substance Abuse and Mental Health
Services Administration (SAMHSA)/
Center for Substance Abuse Prevention (CSAP)

The Alaska project just completed a conference that was attended by over 400 participants. When this program began 4 years ago, they had fewer than 40 participants in attendance at the first conference. They now have 33 of their own community grantees, and a consortium of university-based evaluators across the entire state in attendance to learn what is happening in terms of programming. The work that CDC started with the surveillance teams is growing as well. Alaska had 6 teams and this year will complete 14 teams. They are getting out to many rural areas in Alaska to begin screening and provide services for people with FAS and to prevent FAS births. They are doing an incredible job very quickly.

They have also been able to leverage funds, and have taken data from the State Incentive Grant Prevention Programs to inform what additional prevention programs they need to put into place in the state. It was noted by Joyce Hall that there have been some significant delays for the 4-State Consortium due to Internal Review Board (IRB) delays, in Minnesota especially for their prenatal surveys. Dr. Stone indicated that they expect to convene another grantee meeting in February 2002, to which they will invite the 4-State Consortium and Alaska to share ideas with the 5 new grantees, and to network.

The National Institute on Alcohol Abuse and Alcoholism (NIAAA)
and The Interagency Coordinating Committee of FAS (ICCFAS)

Dr. Faye Calhoun
National Institute on Alcohol Abuse and Alcoholism's (NIAAA)

Dr. Calhoun reported that the ICCFAS has made progress, although they do not yet have a budget. The National Institute on Alcohol Abuse and Alcoholism's (NIAAA) supports and convenes the ICCFAS. There was a report to Congress in 1999, and there was a recent progress report put together in January 2000. The ICCFAS has made progress, but their strategic plan, like all strategic plans, was made with hope, good intentions, and projections into an unknown future. The strategic plan does include many of the activities currently in progress, and for which they desperately hope to have continued funding. Given that they still do not have their budget, those things in the plan for FY 2002 are still up in the air.

Six approaches have been identified by the Interagency Coordinating Committee (ICC), and individual agencies have been working on some of the activities. They started at a point when some of the organizations and

institutions involved in the ICC did not know a lot about ARND, nor did they have programs specifically targeted to the area. Thus, education, promotion, and fostering of interest in ARND was a priority. The ICCFAS has been able to support organizations to expand and adapt existing programs, develop new initiatives, and expand awareness of professional groups and communities they serve. The ICCFAS has co-sponsored some projects to develop plans and review progress made on some initiatives, and to develop complementary initiatives that are aligned with other organizations. The ICCFAS is particularly pleased to have very active involvement from the Department of Justice and the Department of Education. Communication between health-related organizations and education and justice systems is a challenge given that the languages are so different, however, they are making progress.

NIAAA has been maintaining its interests and its research portfolio in ARND and FAS. Dr. Calhoun pointed out that she said "ARND" first because she believes it to be most important. From September 9-12, 2001, NIAAA co-sponsored (with the Director General of the Drug Dependencies in Valencia and the Valencia Center for Mediterranean Culture) a meeting in Valencia, Spain titled Prenatal Alcohol Exposure: Advancing Knowledge Through International Collaboration. This meeting presented an opportunity for United States researchers to retreat and focus for 3 days on the progress made and the gaps in knowledge around ARND, and to determine with their international colleagues and collaborators what needs to be done and where the resources are. Representatives from around the world assessed progress and developed a comprehensive agenda on international research. They also reviewed progress and identified gaps in basic science, genetics, epidemiology, diagnosis, imaging, and prevention. In attendance were representatives from South Africa, Spain, Sweden, Russian, Chile, Germany, Finland, and the United States (Buffalo, Seattle, Detroit, San Diego, and Atlanta). There will be a published report, which will be a strong foundation for further work in a number of areas, including neurobehavioral assessments.

NIAAA co-sponsored the Surgeon General's Initiative on Mental Retardation and Health Disparities. The things learned in this arena directly impact on what they are all trying to do. Clearly, there is a problem with definitions. All children are not classified as "mentally retarded," and the language is changing to "intellectual impairment" and several other terms. When the report comes out from that meeting, Dr. Calhoun requested that they all read it to determine how they can learn from the efforts that are being made at the Surgeon General's level and how these efforts can inform what they are all doing through this effort.

NIAAA is working with the National Organization on Fetal Alcohol Syndrome (NOFAS) on the development of a media campaign, which will be initiated in January 2002. In addition, NIAAA is working with SAMHSA to develop an evaluation of the NOFAS media campaign.

NIAAA co-sponsored a working group meeting August 6-7, 2001, with the National Institute of Child Health and Human Development (NICHD), on prenatal alcohol exposure and the risk for adverse pregnancy outcomes and

sudden infant death syndrome (SIDS). There is likelihood that there may be a common cause, or some common causes, of some sudden infant deaths. There may be a progression of prenatal alcohol effects that result in stillbirths, ARND, FAS, and possibly SIDS. If there is a continuum of effects, they must study this from neurobehavioral and pathology standpoints. NIAAA is preparing to do so nationally and internationally in collaboration with NICHD.

In addition to NIAAA's other work, the South African project is progressing nicely. There they are doing work in all areas (e.g., diagnosis, epidemiology, maternal risk factors, prevention, foundation for genetic studies, ultrasound studies, and metabolism studies) through prospective and retrospective studies on FAS. They also have ongoing work in Russia in collaboration with many of the participants in this meeting.

National Institute on Alcohol Abuse and Alcoholism's (NIAAA) Portfolio

Dr. Kenneth Warren
National Institute on Alcohol
Abuse and Alcoholism (NIAAA)

Dr. Warren indicated that although NIAAA was pleased that at least two of their sister agencies, CDC and SAMHSA, did receive funding for FAS, NIAAA did not receive additional funding. Thus, the relative size of their portfolio remains at about the same level that it was previously. While their portfolio is certainly significant, considering the magnitude of the problem and all of the issues they must face, additional funding would have been beneficial. In FY 2001, with new projects, renewals, and competing activities that were continuing from prior years, they had 111 projects, which addressed a number of areas. Included in those 111 total projects are:

- 12 prevention projects which focus on prevention
- 10 intervention/treatment projects which focus on intervention (treatment)
- 2/3 of all of the ongoing projects involve etiology (NIAAA has been the primary funder of etiology research in this area from the early years)

The first two papers on fetal alcohol syndrome appeared in 1973. NIAAA began to support fetal alcohol syndrome research in 1972, before those papers came out. It was interesting to look at the remnants they could find from that project. The investigator had no idea that there was such an issue as FAS, and it was probably more of a "shot in the dark," but it was very timely. By 1973, NIAAA had 2 projects on FAS, and it grew from

there. By 1973, investigators clearly knew that FAS was an issue. Currently, applied questions are being asked at the same time, within the same projects, as the basic etiology questions. This is a major transition from years ago when they were simply attempting to identify the mechanisms and not really thinking about the next steps and how to get there. Many of the current cutting edge technologies, such as stem cell technology and micro array technology to identify specific genes that are affected by alcohol, are being applied into the alcohol area. Not only are they working on and contributing to the knowledge base to get it into practices, families, etc. as fast as possible, but they are also using the latest cutting edge technologies that are available to the basic research community to address this important problem.

Of other interest, soon to be out is a public education campaign, jointly sponsored by NIAAA and the National Organization on Fetal Alcohol Syndrome (NOFAS), and they have already have some publications in the field (e.g., alcohol alert on FAS). In addition, the next issue of the journal Alcohol Research and Health will focus on this topic.

Fetal Alcohol Syndrome Network (FASSNet)

Karen Hymbaugh, M.P.H.
National Center on Birth Defects and
Developmental Disabilities (NCBDDD)
Centers for Disease Control and Prevention (CDC)

Ms. Hymbaugh indicated that CDC has 5 states that are involved in FASSNet, 4 of which she included in her discussion. She did not include Wisconsin given that it uses a different methodology.

With regard to prevalence rate, normally CDC says that it is somewhere between .67 and 2.2 per 1,000 live births. That varies by race, geographic area, etc. One can also look at different proxy exposures such as alcohol exposure in pregnant women in different states to see what the problem might be in a given area.

When CDC began FASSNet in 1988, they had 4 major goals, which were to:

- Improve the capacity to ascertain true cases and generate population-based surveillance data

CDC wanted to develop a multiple source surveillance system. They had tried using birth defects monitoring programs, birth certificates, community-based screening, and case findings, but none of those worked. What did seem to be a promising way of conducting surveillance for fetal alcohol syndrome came out of some work in

Alaska where multiple sources were used to identify children with FAS. They funded 5 states, with the goal of generating population-based surveillance data.

- Establish relationships with programs where children with FAS are diagnosed or provided services

CDC recognized that the grantees needed to establish relationships with people who provide services to children with FAS. This has been a great part of this project in that now, CDC and the grantees have set up positive relationships with hospitals, genetics clinics, private providers, early intervention programs, alcohol treatment programs, etc. They can now expand to look at issues such as barriers to services for children when they add future funding. This is an exciting way that they can logically extend the surveillance activities to not only collect data on children, but also to tie it into services and prevention activities.

- Evaluate the completeness of the surveillance system methodology, ability to generate prevalence rates, and potential for monitoring trends

CDC set out to evaluate what the best way to conduct surveillance is for children with fetal alcohol syndrome. They are currently in the process of doing this. The system became complex because of the multiple sources they have used, but they are at a point that, over the next couple of years, they can phase out the use of some of those as they are getting all of the information they need from a few of the sources.

- Improve case ascertainment, referral, case management, and prevention through implementation of provider training and education

Provider education and training are critical. Many materials have been developed by people in the state health departments. They brought together committees to determine what needed to be done. There were two major goals for the provider training and education activities, which were to: 1) improve case finding and diagnosis; and 2) improve documentation in records. People are coding children with fetal alcohol syndrome in charts, but it may not really mean anything. CDC will be able to get better information about this. Ms. Hymbaugh offered to share any materials they have with others who are seeking to educate providers.

FASSNet has developed many materials (e.g., educational materials, videotapes, manuals, reports of the multiple sources, etc.). A lot of work has come out of Alaska and Colorado in terms of provider education and training.

The FASSNet methods have targeted four states (e.g., Alaska, Arizona, New York, and Colorado), and the system includes about 146,000 live births per year. They have been targeting most of their efforts on birth years 1995 through 1997. They thought it was important, if they were going to publish a prevalence rate, that these children have had several years' opportunity to see providers. They wanted to extend the activities beyond the usual birth defects monitoring programs that typically only go up to one year of life. The children have to be born to residents of the study area. In Arizona and Alaska, they include the entire state. In New York and Colorado, they use defined geographic areas.

They began with the surveillance case definition from the Institute of Medicine report (IOM), which while it is a great surveillance case definition, did not completely serve CDC's purposes for surveillance. They had to be very strict in including children they would call "cases." The detailed FASSNet case definition is detailed on the FASSNet website. They are collecting information on growth, CNS, the face, and maternal alcohol exposure.

The sources being used by abstractors include hospitals, early intervention programs, etc. These locations provide a list of children they show as having fetal alcohol syndrome. Every child who has been called FAS in a geographic area has their records abstracted into the laptop, which is subsequently uploaded to the state. Because they are going to multiple sources, there are often multiple records for any one child in the database. The identifying information is kept at the state level. All 4 states have state legislation mandating surveillance through their birth defects monitoring programs, and 2 states have specific state legislation mandating surveillance of fetal alcohol syndrome. The abstractors collect the data, strip the identifiers, and it is pooled at CDC. They are currently finalizing the data for 1995 through 1997.

A crucial factor in this effort was standardization of the data across all of what Alaska is calling "fetal alcohol syndrome" is the same as what New York is calling "fetal alcohol syndrome." To do that, CDC had to build in computer algorithms that had parameters for standardized head circumference, birth length, birth weight, etc. and the computer goes through a process to determine whether the child meets surveillance case definition. A clinician could also go in and indicate whether he or she agreed with the diagnosis that the computer generated so that CDC could report the prevalence rate both ways. They used the WHO/CDC Growth Charts that were developed in 1997. Some new growth charts came out in 2000 that have also been programmed into the system. This growth information is available to everyone. Interestingly, there is a major difference in what physicians record and what the computer generates about 25% to 35% of the time. This begs for standardization across all states.

To date, about 5,000 records have been abstracted on children suspected of having fetal alcohol syndrome. This represents approximately 2,100 children who have been referred for fetal alcohol syndrome. Surprisingly, about 60% of the record abstractions have credible alcohol exposure information. If all records are combined for any one child, approximately 70% have credible documentation of maternal alcohol exposure in the records. If there is information available on amount or frequency, they are collecting that as well. However, they did not include

things such as third party hearsay as credible. There is a range of prevalence rates coming out, but they are in the process of evaluating the sources. They have not included the clinicians' diagnoses. These are children who meet the face, growth, and CNS criteria - both functional or structural. The prevalence rate appears to be falling between .37 and 1.6 per thousand live births.

With regard to the strengths of the system, it is a multiple source methodology, which CDC hopes will improve the completeness of case ascertainment. FASSNet set out 8 criteria that each state goes through to determine how complete they feel their case ascertainment is. The exciting feature is that this was designed for and with state health departments; it was not merely prescribed by CDC. The system standardizes criteria for determining case status, and case status can be determined immediately after a record has been abstracted. CDC can evaluate the sources of referrals and information with regard to which are more productive in helping them determine when a child meets the case status. They can evaluate the case definition to determine different components. There are children in the database who have been diagnosed by the "gold standard" of clinical geneticists and dysmorphologists, so they will be able to see how that is similar to children who meet the CDC case status. Also of importance is that the system can adapt to changes in standards. In the middle of the project, NCS/CDC came up with the new growth charts. This will be the largest database on children referred to FAS. Even if a child does not meet what CDC calls their "confirmed case status," they will have a lot of children in the data base who they will be able to look at to better define ARND and/or FAE.

CDC has submitted a methods paper for publication, which they hope, will be out in Spring or early Summer of 2002. They are finalizing their assessment of completeness of case ascertainment for their priority birth years, and they are in the process of evaluating the case definition against the "gold standard." They hope to put out the first prevalence report in Spring or early Summer of 2002 based on those target birth years. Moreover, CDC will evaluate the multiple sources and streamline methodology in order to be able to give a package to other states, which they hope to have ready within the next 6 months to a year. Currently, over half of the birth defects applications for funding that come in to CDC's birth defect groups express an interest in FAS surveillance, and people frequently call to find out the prevalence rate for specific geographic areas. They hope the package they are creating will be beneficial with regard to these issues.

Capacity Building for Fetal Alcohol Syndrome (FAS) Surveillance, Epidemiology, and Prevention in the Gauteng Province, Republic of South Africa (RSA)

**Karen Hymbaugh, M.P.H.
National Center on Birth Defects and
Developmental Disabilities (NCBDDD)
Centers for Disease Control and Prevention (CDC)**

Ms. Hymbaugh indicated that NIAAA staff set the stage for a lot of FAS work in South Africa. Their team invited her to go there in 1997. Definitely, there was a need for doing more surveillance, epidemiology, and expanding into prevention. There is a very high prevalence of FAS in South Africa. Data from unpublished reports indicate that 1 in 4 pregnant women drink heavily, 1 in 10 children referred to genetics clinics are diagnosed with FAS, and 10% to 25 % of children in institutions for the mentally handicapped have a primary diagnosis of FAS. This high prevalence rate could give the United States an opportunity to learn more about prevention and intervention activities quickly and help inform the United States activities.

Work by Philip May, Kenneth Warren, and Faye Calhoun, with NIAAA, was recently published in the American Journal of Public Health. Ms. Hymbaugh pointed out that these researchers reported that 40 to 46.4 per 1,000 school entry children, ages 5 to 9, had full-blown fetal alcohol syndrome. This team had an incredible methodology, which gives great credibility to these numbers. The Western Cape, where this work was done, consists of what is known as the Cape Colored or Mixed Ancestry population. The major question regarded whether this was only a problem in the Western Cape or if it occurred throughout South Africa. The Western Cape is a very large wine-producing region, so the idea was that FAS probably did not occur in the rest of the population, and was isolated to wine-growing regions. The South African government also wanted to know what was happening with the majority population. CDC's goal was to help build capacity in South Africa by assisting the investigators in doing a prevalence study in some other province outside of the Western Cape, and provide training and technical assistance to build an ongoing surveillance system so that they could monitor fetal alcohol syndrome as they developed prevention and intervention activities.

CDC had only \$60,000, but that went a long way in terms of FAS screening. They went to 4 sites around Johannesburg, each of which represented a different racial/ethnic composition. They used an anthropometric screen, capturing height, weight, and head circumference. They screened 834 school entry children, of whom 33% screened positive, and of whom 482 received complete clinical exams by two teams. This was very similar to the Western Cape methodology. Interestingly, 2 children in the comparison group were diagnosed with FAS or deferred. The final results showed that while the rate was not as high as the Western Cape, clearly it is a problem in other provinces outside the Western Cape, and is probably higher than in the U.S.

Ms. Hymbaugh and Dr. Cordero visited a 1st grade classroom of about 45 children where immediately, without any examination, they recognized at least 5 children who had FAS. South Africa estimates that approximately 10% of 1st grade children have FAS, studies are ongoing. They talked to a province coordinator who works part-time on HIV prevention and part-time on FAS prevention. When asked if this was like having two jobs, the coordinator said that it was not because she is working with the same women. Clearly, this points to the need to work together with HIV programs and to collaborate with other partners that are dealing with the same high-risk group. There are many opportunities for collaboration in South Africa in high-risk prenatal care, screening, and interventions for children with special needs, etc. Alcohol treatment programs do not exist there, and it takes 3

hours to get a child with special needs from one province to speech or occupational therapy. The speech and occupational therapists only go there once every 6 weeks. There is a real opportunity to find out what works in this population. Ms. Hymbaugh reminded the group that 20 years ago, alcohol treatment programs for women did not exist in the Indian Health Service, nor were pregnant women a priority for treatment. Other needs in South Africa include community development, employment programs, primary prevention, public education, health care provider and teacher education, etc.

The U.S. has the expertise to bring to those needs/efforts. Thanks in large part to NIAAA, South Africa is really struggling and trying to model a lot of the NIAAA, CSAT, and CSAP materials. Ms. Hymbaugh took photographs of warning posters she saw while in South Africa, many of which are really nice and slick while others are grassroots efforts committed to preventing FAS. Ms. Hymbaugh thought it would behoove them all to consider ways they could partner with South Africa to develop a unique model and prevention program. She cited a New York Times article from 2000 that indicated that South Africa had increased their wine production and had an excess, much of which will be sold in foil bags to customers who pull up in pick-up trucks, and supply taverns in poor neighborhoods. The situation in South Africa is only going to grow increasingly worse. However, it is a major struggle to get FAS on the radar screen in South Africa because of HIV/AIDS prevalence rates, the skyrocketing tuberculosis rates, malnutrition, substance abuse, poverty, violence, injury, sanitation problems, etc. It is happening, however.

Discussion Summary:

- Regarding the South Africa presentation, Dr. Calhoun asked Ms. Hymbaugh if their FAS diagnoses were based on dysmorphology only, indicating that in NIAAA's own projects, they do not give an FAS diagnosis until there is a neural-behavioral test and maternal interview. Ms. Hymbaugh responded that if the head circumference is below the 10th percentile, they are put into the FAS category. If the head circumference is not below that level, they are deferred to neural-developmental evaluation - very similar to the Western Cape model. Eventually, all children receive the neural-developmental evaluation, and they do maternal interviews.
- Regarding the neural-developmental assessment, Dr. Warren inquired as to whether any of the children who appeared to be positive because they had circumferences below the 10th percentile had fallen out of the category. Ms. Hymbaugh thought some children were removed from that category and were placed in the deferred category following their neural-developmental evaluations.
- Dr. Day asked whether the children do better or worse in terms of social connections, or ability to adapt to life than in the U.S. society. Dr. Robinson responded that it was difficult to say. There are children in

Russian orphanages who are thought to adjust better than children in the United States. However, he was not certain how "better" translated.

- An inquiry was posed of Dr. Jan Harlow, of the Department of Education, as to whether she had any data on this issue. She responded that in talking to people about the Russian studies and how self-contained their programs were for those children; she thought it was very interesting because in the U.S. programs are very inclusionary.

Department of Education Programs

Dr. Jan Harlow

Department of Education (ED), OSEP

Dr. Harlow said that as she was trying to summarize for herself all of things that they are and are not doing in FAS at the Department of Education, she thought the main thing she wanted to stress was that she would like to see more applications come into the Department of Education for field-initiated research to look at interventions for children and families with FAS. They do have some funding for such programs, although it is an extremely competitive process. However, they really do not have any projects that specifically focus on FAS or ARND. They should have, which is why she would like to see some solid applications.

The Department of Education does have two personnel preparation projects in Alaska. One of the projects is a Masters level program to help teachers and providers with children, most of whom have severe disabilities including FAS and Autism. There is another project that is recruiting and training rural under-represented Alaskan Natives to provide effective early childhood services and local/rural leadership in policy and programming decisions in early childhood systems. The coursework includes Autism, FAS, and speech and language issues. They also have an early childhood longitudinal study birth cohort in which they are beginning to collect data. She worked diligently to get FAS included as one of the specific categories for data collection, but in the end she was told that investigators would do the best they could, but they did not think the prevalence was high enough to look at this, as they would like. Nevertheless, it is on their radar screen. There probably will not be any information from this project for a couple of years.

There is another study known as the Pre-Elementary Education Longitudinal Study (PEELS). Plans are to begin data collection for this study in early 2002. This is a nationally representative longitudinal study of 3 to 5 year olds receiving special education. The study is being designed by SRI International. While this study promises to provide good information, it is doubtful that they will get any information on FAS or ARND given that the numbers may be too small. There is also the issue of whether people will volunteer information that their child has this diagnosis. Nevertheless, Dr. Harlow conversed with the Project Officer for this study and asked her in all

of the planning to consider any possible ways to get information in on FAS and ARND. The Project Officer indicated that they would do so.

What Needs to Be Done

The participants engaged in an open discussion period pertaining to what needs to be done and how the Task Force can be of assistance. 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 deliberated on included:

- Diagnosis, Service Delivery, and Reimbursement Issues
- Education Issues
- Funding Issues
- Legal, Ethical, and Confidentiality Issues
- Task Force-Specific Issues

Discussion Summary:

Diagnosis, Service Delivery, and Reimbursement Issues

- A suggestion was made that most importantly they needed services delivery to children who have been screened and their families. One of the problems with this is the issue of reimbursement. Fetal alcohol syndrome has an ICD-9 designation, but is not acknowledged in any other way (e.g., the DSM IV, etc.). It would be helpful to have it categorized in one way or another. Dr. Cordero responded that it is categorized in different ways, for example, autism can be defined as a "disability" by some insurance carriers and a "medical condition" by other insurance carriers, while sometimes the "unknown" category is utilized. Thus, carriers choose not to cover it. Perhaps they could work with the Center for Medicaid Services to develop some coverage guidelines for children with FAS.
- Dr. Cohen inquired as to whether FAS was covered by WIC, given that it could be categorized as a nutritional disability. Dr. Hutchins said that WIC does not go by diagnosis; it is income-based.
- There was further discussion among panel members regarding what is covered by WIC and Medicaid, the overlapping of the two agencies, and how they differ on a state-to-state basis. Dr. Cohen clarified that sometimes, whether the child is eligible for Social Security Insurance (SSI) or disability insurance as well will determine the status for state services. If a child with FAS diagnosis receives WIC, he or she is most likely to

be referred to special child health services. WIC coverage would be an income issue. For Medicaid, eligibility is determined on a monthly basis, so one could be eligible one month but not another. It was generally agreed that reimbursement is a major issue.

- Ms. DeVries pointed out that as child grows, there are different funding streams. In Washington State, the EPSDT screening includes FAS. SSI includes FAS, but one must prove how it disables the child, and that depends on the parents. Dr. Day stressed that people with FAS grow up and there are no services for them whatsoever, which is a critically serious issue.
- Dr. Coles pointed out that mental health services are functional, not diagnostic. Very rarely is mental health automatically covered. Even if someone has behavioral problems associated with the FAS, the insurance may not cover behavioral services. Dr. Cordero said there is a trend to have many of the developmental disabilities diagnoses based on functional limitations. World Health Organization (WHO) has come up with a new classification of functional limitations, which he believes will be in widespread use over the next few years.
- Dr. Stone raised the complicating factor of co-occurring disorders. She said that 85% of people who have a substance abuse problem are mentally ill, and she believes FAS is involved in those percentages as well, although nobody seems to get that.

Education Issues

- Dr. Harlow stressed that people need to be educated about the value of a FAS diagnosis. If the children are not showing the functional disability when they are young, they will not qualify for services. Early diagnosis and intervention are very important. The special education community does not currently believe the diagnosis of FAS to have added value.
- Dr. Floyd said that many of the agencies are developing initiatives to educate and develop curricula for FAS/ARND. Currently, there is a lack of precision in certain aspects of the diagnosis.
- Dr. Riley said that the education piece is key, and noted that it had been repeatedly. There are certainly expectations with regard to someone who has cerebral palsy, and they have to set the same kinds of expectations with regard to FAS. They do not want to have to convince people that there are developmental disabilities present.

Funding Issues

- A suggestion was made that some funding be earmarked for those who have FAS, but also have normal IQs.
- Ms. Mitchell asked that small grants be made available at the grassroots level of \$5,000 and under. There is no mechanism for getting funding to the grassroots level, not for those affiliated with universities, but instead for those who are working in the trenches. Dr. Floyd agreed and said there should be competition for groups who never receive funding. This was one of the stipulations in the announcement they crafted. CDC can use their conference support mechanism as well. Dr. Riley said that perhaps the NTFFAS/FAE could have a grass-roots budget. There was general agreement that there should be an equal opportunity to receive funding.
- A representative from the audience noted that the March of Dimes restructured all of their small grants because they found they were not getting good results. It was suggested that there be a mix of small and large grants.
- Dr. Cohen suggested that there might be a need to evaluate funding and how it is spent, as well as where each organization begins and ends with regard to responsibilities. If the strategic plan is being defined, and NTFFAS/FAE is giving support to grassroots, roles need to be clear. She would also like to see more state involvement. An audience member responded that the Juvenile Justice Advisory Committee receives block grant funding, and they decide how the money goes out to the communities.
- Dr. Cordero said that one of the issues of developing the new Center is the role of states. When states take on the responsibility of prevention and monitoring, it is part of the state budget. Until states received funding for injury prevention, it was not considered a public health issue. Since the NTFFAS/FAE is taking on prevention in the broadest sense, helping families and children/adults with FAS can only happen once federal, state, and local governments work together. Drs. Harlow and Cordero said that health works with education at the state level, along with coordination of early intervention at the state level. With regard to developmental disabilities in general, the relationship with schools and health is critical, whether it is autism, cerebral palsy or FAS.
- Dr. Calhoun pointed out that some things overlap and funding is being giving to the same people, which may or may not be a bad thing.

Legal, Ethical, and Confidentiality Issues

- A comment was made that the Juvenile Justice Advisory Committee receives block grant funding, and that the NTFFAS/FAE and ICCFAS have an opportunity to lobby Congress for the same thing. Dr.

Cordero reminded the group that they could not be involved in lobbying. Dr. Snider added that the Task Force cannot advocate with Congress or the Administration, nor can they lobby individually. He explained that, as part of the Task Force, members are special government employees and are, therefore, subject to the ethical rules of the federal government. However, as a part of the independent programs of which they are a part, they may be able to do so.

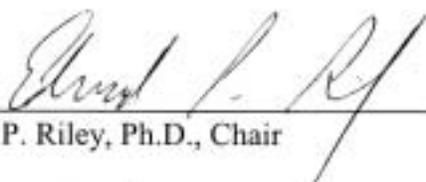
- Dr. Calhoun suggested that all of the agencies need to have input on confidentiality and ethics. Perhaps an ethicist needs to be brought on board.

Task Force-Specific Issues

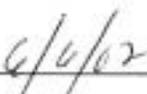
- A comment was made about the power that the Task Force has when they endorse agendas, plans, guidelines, etc.
- Dr. Stone encouraged the Task Force to develop a systematic way of creating a constituency base. For example, growing a voice through education is positive.
- Dr. Calhoun stressed that they needed to strengthen the network of state coordinators by convening meetings for them to exchange ideas. There are other models within states, so the Task Force should document successful programs and networks such as the Minnesota Network Model. There should ultimately be FAS offices in every state.
- With regard to how the Task Force should be structured in the future, the following suggestions were offered:
- Consider the Immunization Committee as an example. It has appointed voting members, ex officio members (e.g., FDA, NIH, HRSA, HCFA, IHS, DoD, VA, etc.), and up to 40 liaison representatives (e.g. members of organizations who have an interest in assuring that programs are carried out such as ACOG, AAP, AAFP, ACP, etc.) who are not voting members of the committee.
- Is it important to have people from the education community and others, etc. If so, which would be important to invite to sit on a regular or ad hoc basis, so that they could participate in discussions and advocate and pass on messages?
- Perhaps an ethicist should be brought on board to deal with legal, ethical, and confidentiality issues. The Task Force and ethicist might craft a paper on the issues.

- Dr. Day said that one thing they had not discussed as a Task Force was defining the breadth of FAS/FAE and its effects on children, families, society, etc. This will help define who they need to bring to the table.
- Perhaps the Task Force could work with the Center for Medicaid Services to develop some coverage guidelines for children with FAS.
- Perhaps the Task Force could guide the effort to explicitly define FAS and ARND and publish a consensus document that all organizations could use. This could also be used to help get reimbursement.
- Dr. Cohen would like to see the blue print for agency activity more clearly. She also did not feel that there was enough state participation, or discussion of grants for FAS prevention and treatment on the state level.
- Perhaps the NTFFAS/FAE could have a grassroots foundation to enable them to distribute funds down to the grassroots level.

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