Fetal Alcohol Syndrome and Effects:
From Awareness to Action

Report from the Conference held
December 2, 1992
at the
Seattle Airport Hilton

Compiled by the
Washington Council on Crime and Delinquency

Larry M. Fehr
WCCD Executive Director

Carol E. Willett
WCCD Office Manager

Seattle, Washington
1993

The WCCD would like to acknowledge the support received from a variety of organizations that made this conference and report possible, including the Washington State Department of Health, Washington State Department of Social and Health Services, the Developmental Disabilities Planning Council, King County Division of Alcohol and Substance Abuse, the Seattle Indian Health Board.

Fetal Alcohol Syndrome and Effects:
From Awareness to Action

Post Conference Report

Table of Contents

Conference Introduction and Support

With an overflow crowd of nearly 450 participants, Donna Schram, Ph.D., Chair. of the Board of Directors of the Washington Council on Crime and Delinquency (WCCD), welcomed everyone on behalf of the WCCD and the FAS Interagency Conference Committee. She then introduced Larry Fehr, WCCD Executive Director. He apologized for the crowding, but due to the enormous interest the conference had attracted, the decision was made to try to accommodate as many people as physically possible. The benefits to such a large and diverse crowd were obvious; with representation from nearly every county in the state, nearly every Native American community and minority population, the participation of parents, foster parents, social workers, various facets of the health profession, members of the education profession, as well as substance abuse, justice and child care professionals, the diversity of input was expected to be tremendous.

As Conference Coordinator, Larry Fehr outlined the following objectives of the conference: (1) to **increase awareness of FAS/FAE** including findings of recent research and current activities that were going on around the state; (2) to **move beyond awareness of FAS to initiate action** throughout Washington State, with the purpose of such action being to improve both prevention of FAS and response to FAS once fetal damage from alcohol has occurred; and (3) **to emphasize participant diversity** (ethnically, geographically, and professionally), in both the conference attendees as well as the program presenters.

Materials distributed for use at the conference included: (1) a conference packet, including the agenda, resource materials and listing of conference participants, and an evaluation form; and (2) a resource guide of services, prepared by the **King County Department of Public Health, Division of Alcoholism and Substance Abuse Services.** Information tables in the lobby were also provided by the **Washington State Substance Abuse Coalition** and the **FAS Adolescent Task Force.**

Audio taping of the conference and all the workshops was done by Hal Lotzenhiser, Executive Director, and other staff members of Spokane's **New Horizon Care Centers.** Order forms for purchase of the audio tapes were available. *(A copy of the order form is also included at the back of this report.)* Continuing education credits were provided for nurses and chemical dependency professionals. Academic credit was arranged through **Northwest Indian College.**

The conference was made possible by a contract with the Washington State Department of Health; including financial support from the Department of Social and Health Services' Division of Children and Family Services, and Adoption Support Services; the Developmental Disabilities Planning Council; King County Division of Alcohol and Substance Abuse, and the Seattle Indian Health Board.

Special recognition is extended to the members of the FAS Interagency Conference Committee which planned this conference: Sandy Randels, State FAS Coordinator and Deb Fouts, both with the **Washington State Department of Health**; Dwight Bond, Rick Teboe, Pam Darby and Carol Owens with the **Division of Alcohol and Substance Abuse**; Jocie DeVries, **FAS Adolescent Task Force**; JC Ephraim, **WCCD Board of Directors**; Vince Collins, **DSHS, Adoption Support Services**; Donna Patrick-Todd, **Developmental Disabilities Planning Council**; Glen Felion, **Division of Developmental Disabilities**; Nancy White, **March of Dimes**; Kathy Boudreau, **Washington State Council on Alcoholism**; Amy Howarth, **Community Health Council of Seattle/King County**; Beth Scott, **Department of Corrections**; Jennifer McDougall, **Washington State Liquor Control Board**; Paul Dziedzic, affiliated with the **Department of Social and Health Services**; Laurie Lippold, **Children's Home Society**; Judy Neal, **Division of Juvenile Rehabilitation**; John Perkins, **Central Youth and Family Services**; and Carolyn Hartness, **I WA SIL Youth Program, United Indians of All Tribes.**

Comments or questions regarding this report can be addressed to: The WCCD, 1305 Fourth Avenue, Suite 602, Seattle, WA 98101-2401, 206/461-3421

The WCCD was pleased to be able to launch the conference with presentations by two leading pioneers in the field of FAS diagnosis and research to present the latest findings of research in Fetal Alcohol Syndrome and Effects.

***Sterling Clarren, MD**, is the Robert A. Aldrich Professor of Pediatrics at the UW School of Medicine. He is also the head of the Division of Embryology, Teratology and Congenital Defects at the UW as well as the Head of the Division of Congenital Defects at Children's Hospital and Medical Center. Dr. Clarren has been a prodigious producer of research on FAS and has received numerous awards for his efforts, e.g., from the National Institute of Alcohol Abuse and Alcoholism.*

Sterling is not only an outstanding scholar, but an outstanding advocate as well. Among his current community service responsibilities are serving as Chairman of the Fetal Alcohol Advisory Committee of the Children's Trust Foundation in Seattle, and Chairing the Health Birth Defects Advisory Committee for the state's Department of Health.

***Ann P. Streissguth**, Ph.D., is a clinical and developmental psychologist with nearly 20 years of experience working with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) patients. She is currently Director of the Fetal Alcohol and Drug Unit and Pregnancy and Health Studies at the University of Washington School of Medicine.*

Dr. Streissguth received her doctoral degree in clinical psychology at the University of Washington. She is a professor in the Department of Psychiatry and Behavioral Sciences at the UW. Dr. Streissguth has written over 100 articles for national and international medical and scientific journals. She travels extensively throughout the United States and around the world, lecturing on the Fetal Alcohol Syndrome. Last year, she was asked to testify before the U.S. Senate Subcommittee on Children, Family, Drugs and Alcoholism on FAS.

In 1992, the WCCD presented its award for "Outstanding Achievement in Scholarship" to Drs. Clarren and Streissguth.

Research Overview and Update on Fetal Alcohol Syndrome and Effects

Summarized by **Cheryl Milloy**,
Research Assistant, Urban Policies Research

Sterling K. Clarren, M.D., Professor of Pediatrics at the University of Washington School of Medicine, presented an update on issues related to the prevention and treatment of Fetal Alcohol Syndrome. First, he discussed four sets of problems that continue to complicate efforts to deal with FAS: scientific problems, ethical problems, problems with infrastructure and legal problems.

According to Dr. Clarren, it is still not known which women are at the highest risk of producing a child with FAS. FAS is related to dosage in that those women who drink in binge amounts, and/or become intoxicated at regular intervals, expose the fetus to the greatest risk. There is also no "safe" time to drink during pregnancy. In spite of this knowledge, the National Council on Alcoholism estimates that 16% of women drink in patterns that might be called reckless during their childbearing years. However, only one in 100 of these women produce a child with FAS. So the issue of finding the women who are at highest risk is more complex than simply naming the dose or the time in pregnancy.

Dr. Clarren also discussed some of the ethical issues surrounding FAS that are unique to this country. He stated that a hallmark concept for Americans is that we are all responsible for ourselves. This concept leads to the notion that alcoholics are bad people because they do not take responsibility for themselves. But, part of the disease of alcoholism is denial. Thus, as Dr. Clarren concluded, when we try to approach the issue of preventing FAS, we also have to try to mediate around the issue of individual responsibility.

According to Dr. Clarren, if all of the women at high risk of producing a child with FAS volunteered to enter treatment tomorrow, there would be no place for them for the infrastructure to serve these women does not exist. Thus, as we begin to push the agenda for more treatment, we also have to find the resources for more care for these women.

Finally, Dr. Clarren noted that the primary legal issue that needs to be understood when dealing with FAS is how to separate the rights of one family member from another.

Prevention of FAS

Dr. Clarren next discussed prevention efforts that have taken place in several Scandinavian countries, and then addressed what could be done in this country. Prevention efforts in Scandinavia are believed to have reduced the rate of FAS by 400%. This reduction was brought about through the use of a societal model in small communities, where everyone knew everyone, and further, where the high-risk women were known to the community. Public health nurses and educators "positively hassled" these women into treatment by teaching them that a healthy baby was the most wonderful gift that they could give their community. Women were taught, in a positive, supportive manner, that when they had a baby, that baby was a part of the community.

Dr. Clarren posed the question of how to develop the concept that children belong to all of us in this country. He stressed that two kinds of prevention efforts are needed. First the public needs to know about FAS and that it is everywhere. Such a public awareness campaign will not necessarily change the behavior of high-risk women, but it will set the state for changing the behavior of everyone else.

The second type of prevention effort that is needed is similar to that employed in Scandinavian countries. A campaign should be directed at teaching the community of people around alcoholic women how to help these women get into treatment. This community includes family members, friends, coworkers, bartenders, etc. In addition, Dr. Clarren noted, every time a child with FAS is identified, a mother who produces children with FAS has also been identified. We need to target these women as the first women who need to be positively hassled into treatment.

Treatment for Children with FAS

Dr. Clarren suggested that we need to build teams to work with FAS children and their families similar to those that work with children with other birth defects. These teams need to be able to sustain themselves for at least a year or two until the value of such an approach can be demonstrated and the legitimacy of the expense argued.

Dr. Clarren also discussed some of the educational issues that face FAS children. It has to be accepted that these children can never be "cured," but that they can be rehabilitated. Often children do better during their early years, when there is more support, assessment and special education resources available to them. The schools can succeed with FAS children at certain times better than others and should restructure educational programs to support these children on what they can do at all times.

Dr. Clarren concluded his presentation by stating that the energy for dealing with FAS will not come from Washington, D.C., or probably even from the state. Rather, it will come from grassroots efforts and trials of people like the conference attendees.

Ann P. Streissguth, Ph.D., Professor of Psychiatry and Behavioral Science at the University of Washington School of Medicine, spoke about new research developments regarding Fetal Alcohol Syndrome. Her presentation covered four topic areas: long-term follow-up studies of children with FAS; social drinking studies; studies of mothers with FAS; and a new FAS prevention/intervention project.

Dr. Streissguth began by stressing the importance of long-term follow-up studies of FAS children for understanding what happens to these children as they approach adolescence and adulthood. One such study, conducted by Dr. Streissguth and several colleagues, followed FAS children in Seattle and the Southwest. This study indicated that the outcomes for these youth during adolescence were not good. The children often developed other disabilities that made life difficult for them. However, only one-half of the group studied were actually mentally retarded and thus eligible for services. The other half were found to be the ones who suffered the most in the community due to a lack of resources and a lack of anyone understanding that they were disabled. Dr. Streissguth and her colleagues also found that there were four behavior characteristics that differentiated between those adolescents who were mentally retarded, and those who were not. These characteristics include:

1) Failure to consider the consequences of their actions;
2) lack of appropriate initiation of activities;
3) unresponsiveness to social cues; and
4) lack of reciprocal friendships.

These four characteristics were present in the adolescents who should have been doing well but who were having severe difficulties.

Dr. Streissguth's findings have been replicated by studies in other countries, such as France, Germany and Sweden. In general, these studies have discovered that over the long-term, FAS children have not done well. Dr. Streissguth argued that these findings demonstrate that we cannot put all of our findings into services for preschool and early education. Rather, she urged that the state put more resources into services for adolescents.

Dr. Streissguth next discussed her study of social drinking patterns among middle-class women in Seattle. This study first began almost 20 years ago, before the dangers of alcohol use during pregnancy were understood. Dr. Streissguth has followed the children of these women and found that there were subtle attention and memory problems among those who were prenatally exposed to alcohol. Thus, Dr. Streissguth found that children whose mothers did not use alcohol in ways we think of as dangerous were affected. These problems were not remediated by adolescence, even though these children were brought up in "good" environments.

Dr. Streissguth did find that certain patterns of drinking during pregnancy were more damaging to the fetus. For example, the extent of damage was related to dosage. The more that a woman drank, the more damaged her child was. In addition, binge drinking, defined as four to five drinks at a time, was found to be very dangerous, even if a woman did not drink very often.

Dr. Streissguth also reported on another study conducted at the University of Washington. The study has followed eight clients, all diagnosed as either FAS or FAE, who have gotten into legal trouble. She discussed several of the outcomes for these adolescent or young adult patients. Some of the common problems include: hyperactivity; alcohol and drug problems; history of suicidal ideation; homelessness; history of psychiatric hospitalization; fire-setting behavior; and history of shoplifting. As Dr. Streissguth stated, these outcomes are nothing less than devastating.

According to Dr. Streissguth, both rat and human studies have indicated that mothers who have FAS comprise a very high-risk group. These mothers have problems understanding the consequences of their own actions, as well as those of their babies. She stressed that these women need to be identified and helped.

Finally, Dr. Streissguth discussed a current project at the University of Washington that assists high-risk mothers in King County. The Birth-to-Three Project provides advocacy services to women who have abused drugs and/or alcohol during their pregnancy. These women are identified at the time of delivery. They often have not received any prenatal care, nor have any connection to social service agencies in the community. Many of these women have other children who have been removed from their care. The project helps mothers to meet basic needs such as housing, employment, alcohol and/or drug treatment, etc. The cost of the project, including the services of a trained advocate, average $3,600 per client per year.

Dr. Streissguth closed her presentation by stating that she and her colleagues would be happy to help others set up a project like this one in their community, for there is the need to work simultaneously on prevention and intervention with these high-risk women and their children.

Panel Presentation on Current FAS Activities

Summarized by **Marcy Kubbs**,
Program Analyst, King Co. Division of
Alcoholism & Substance Abuse Services

JC Ephraim, Jr., WCCD Board member and Substance Abuse Prevention Trainer, Puget Sound E. S. D. #121, moderated the panel which discussed current activities regarding FAS which are occurring around the state.

Sandy Randels: Coordinator of the FAS Program, Washington State Department of Health, reported that through a Centers for Disease Control (CDC) funded Disabilities Prevention Grant, Snohomish and Clallam counties both have FAS prevention projects under way. These projects which are testing survey techniques for FAS, provide education and screening to all first graders. The counties have also developed community FAS task forces to assist with FAS activities.

Three additional CDC grants were recently awarded in Washington, one, a FAS Prevention grant, to the State Department of Health. Activities under this grant will take place in King County and at two Native American communities selected through a Request-For-Proposal process. The grant will provide education to groups such as health care workers and foster parents, to increase the identification of FAS children and referrals to Dr. Sterling Clarren's FAS clinic. Birth mothers of FAS children will also be identified to establish a profile of women at high risk of birthing a FAS child.

Two other CDC grants were awarded to the University of Washington. One will fund Dr. Sterling Clarren's FAS clinic, and the other Dr. Ann Streissguth's research on the secondary disabilities of individuals diagnosed as FAS.

The State FAS Coordinator's office has also helped produce the *Iceberg* newsletter and a March of Dimes prevention video educating sixth, seventh and eighth graders about problems associated with drinking during pregnancy. In addition, the Office continues to be a resource for health departments and other state agencies on FAS issues.

Carol Strong: Supervisor, Substance Abuse Education, Office of Superintendent of Public Instruction, supervises the Drug Free School Program within the Office of Superintendent of Public Instruction. Through this office, $15 million is provided for prevention and intervention services, training for teachers and for school security purposes. Much local control is maintained for these activities through the nine school districts located in the State. The local Education Service Districts (ESD), working with the Western Center for Drug Free Schools, provide a significant amount of training.

Jocie DeVries: Coordinator, FAS Adolescent Task Force reported that for the first time, two years ago, she heard of FAS/FAE and learned that she was the parent of two prenatally exposed children. Because of her personal experience, she was inspired to form a FAS Adolescent Task Force which provides support to parents of FAS children. Parents in this organization have provided testimony before the legislature on this issue, testimony which was at least in part responsible for the development of "Public Policy Options on Fetal Alcohol Syndrome" prepared by Paul Dziedzic for the Washington Department of Social and Health Services.

Some resources are available to parents in our community. The Children's Home Society has developed two programs with grant funds which are an important resource for parents with FAS children. These are the Post Adoption Program and the Biological Family Program. Prenatal exposure to alcohol is among a variety of problems with which these programs can assist parents. In addition, DSHS is developing a group care pilot project for FAS boys ages 12-18.

Rick Teboe: Native American Specialist, Division of Alcohol and Substance Abuse (DASA), reported increased interest in the subject of FAS/FAE across the state. Many more invitations to speak on the subject have been received from a wider variety of organizations than in the past, such as an invitation to speak to a Tavern Association. Mr. Teboe reports increased interest in the subject from the State Liquor Control Board which has designated a Prevention Coordinator. Yakima and Lummi Indian Tribes both have programs with which Mr. Teboe is working, and DASA will soon be sponsoring Ethnic FAS Conferences targeting African Americans, Hispanics and Native Americans.

Mary Ellen O'Keefe: Director, Children's Trust Foundation, reported that the Children's Trust Foundation which works closely with the Washington Council for the Prevention of Child Abuse and Neglect was created five years ago to help prevent child abuse in the State of Washington. An FAS Advisory Committee was formed which recently surveyed 770 individuals and organizations regarding their FAS/FAE activities. Seventy-one (9%) of the surveys were returned and preliminary results of priority action items reported were as follows:

Priority Action Items:

- Develop continuum of treatment services for substance abusing pregnant women

- Increase identification of people with FAS/FAE very early in life to avoid ineffective, counterproductive responses

- Development of primary and secondary curricula (culturally relevant). Provide in-service training.

- Develop school district plans for meeting the needs of students with known or suspected effects.

- Graphic displays and pamphlets in health care facilities that reach women prior to pregnancy

- Provide continuing education for health professionals

- Develop a comprehensive treatment center/community

- Study educational strategies for teaching people with FAS

- Mass media/communication public awareness campaign (radio, television, print media, billboards, bus signs)

- Conduct parent support groups

Vince Collins: Program Manager, Adoption Support Program, Division of Children and Family Services, reported that during the last two years, with 20% of children involved in the Adoption Support Program affected by drugs or alcohol, there has been an increased focus on FAS at this agency. This focus has been aided by the development of the "Public Policy Options for DSHS" which outline activities for the Department. Currently all adoptive and foster parents are trained on FAS/FAE and an important ongoing activity for DSHS will be the training of state workers on this issue. Mr. Collins acknowledged a number of individuals across the state who have made an important contribution to the FAS/FAE field.

Prevention and Public Awareness Workshop

Facilitators: •**Carolyn Hartness**, Drug and Alcohol Prevention Counselor, I-Wa-Sil Youth Program, United Indians of All Tribes, and •**Nancy White**, Director of Programs and Communications, March of Dimes
Reported by: **Pamela Darby**, Program Manager, Washington State Division of Alcohol and Substance Abuse

Overview: The goal of the workshop was to explore what FAS "prevention" might look like in our communities and to chart how we might "get there."

Point of Departure: With an introduction consisting of a Lakota prayer/song acknowledging and asking for the powers of the four directions to come into the circle and bring clarity and truth. This was juxtaposed with the opening of a can of beer, ironically in a bar where this presentation was being held due to the overflow conference registration.

The intent of the opening was to demonstrate two things. First, the prayer is one tool to strip away the masks we wear that block communications. Alcohol is often a mask or a barrier to honest communications and thus the sharing of prevention messages. Second, connecting with the four directions brings the message of relating to issues through generations, and alcohol is often and intergenerational issue.

The symbolism of the prayer/song allows those of us not familiar with another's perspective to understand that as we deliver prevention/interventions and messages, we must consider there are many approaches we can use. Still we can connect with others, even though their ways are different than ours.

Understanding that prevention messages must be tailored to the recipient, we went around the circle to find out people's expectations and knowledge regarding prevention of FAS. This list is as follows:

- how do we provide more information prior to conception
- we need to teach primary providers about FAS prevention
- need more treatment programs for pregnant women
- increase health education to send out message earlier - head start, middle school, and teens with appropriate continuous messages
- train teachers
- train health care providers
- train DSHS, juvenile justice and other system folk who might come into contact with FAS issues
- address the "isms," racism, sexism, etc.
- importance of including community and family in solutions
- link with substance abuse agencies
- develop positive images "welcome to recovery"
- address self esteem issues as to cause of drinking
- identify and use peers in recovery
- explore mentorship programs
- realize that a "brochure approach" is not always successful
- ID women at risk for alcohol abuse in teen years
- recognize a woman's right to refuse treatment
- provide professional training to recognize chemical dependency of pregnant women and to develop appropriate interventions
- develop prevention programs
- bridge between Native and non-Native communities on FAS issues
- connect between organizations for materials development
- develop strategies that really work so that women don't drink
- understand negative enabling
- make clear the economic consequences/impact of FAS with better statistics
- make sure there is a voice for children
- make policy makers and the general public aware of FAS/alcohol issues
- how to help homeless street youth
- establish a safe and sober network for moms without alcohol
- networking opportunities
- investigate connection between sexual/physical abuse and FAS
- recognize and create a brighter future for children
- opportunity to share and know that we are not alone
- understanding whether or not any alcohol consumption is okay
- make a difference in my community
- become aware of what is working
- identify and contact teen audiences
- heighten public awareness
- how to talk to kids who are abusing alcohol
- incorporate FAS information into larger programs
- build supportive communities

- what can a parent do?
- focus on native youth
- gather information to take back to community/workplace
- establish strong advocacy for pregnant women to get them into treatment
- develop personal understanding of FAS issues to facilitate support systems for self and others

The group then broke out to discuss the following areas: advocacy/public policy, public awareness, education and treatment for substance abusing mothers.. Reporting back to the group the following items were suggested by the group with no clear consensus:

- stop alcohol sponsorship where youth are present
- discourage use of alcohol logos on clothing
- help CPS identify FAS cases as opportunity for prevention with mom's future pregnancies
- change concept of alcohol from a life-style issue to an abuse issue
- understand why women drink vs. why women drink dangerously
- get past the issue "my mom drank and I was okay"
- find discussion points around the "Russian roulette" style where women feel the chances are good that they can drink and still have an unaffected child
- re-educate the public about alcohol as has been done with tobacco
- have sit-ins in bars
- ban alcohol on college campuses
- call FAS a birth defect consistently
- explore legislative avenues
- support research on why women drink
- support greater pre-conception education
- identify existing prevention resources
- identify parties interested in primary prevention
- identify parties interested in secondary prevention issues.

Conclusion:

1. There is little understanding about which women are most at risk for having an alcohol affected baby, so we have a hard time identifying our target audience.
2. There is a large variance in the "helping community" on fetal alcohol issues, as well as the community at large, making it difficult to "be on the same page." More collaboration is needed.
3. There are cultural and socio-economic issues surrounding both alcohol use patterns, marketing of alcohol and health provision and education issues that need to be addressed.
4. There is both immense opportunity and need in the FAS prevention arena and the work has just begun. The degree of participant frustration with the situations they are dealing with in schools, agencies and homes showed us that, in the little time allotted at this workshop, we could do little more than identify ourselves as interested in the prevention of FAS and commit to further work. This topic would merit a full conference of its own.

Identification & Assessment of Fetal Alcohol Syndrome Workshop

Presenters: •**John Wegman, M.D.**, Peninsula Children's Clinic and Clallam County FAS Task Force; and •**Barbara Woodward**, OTR, MPH Developmental Consultant, Office of Children with Special Health Care Needs, State Department of Health
Recorded by: **Amy Howarth**, M.P.H., Coordinator, Community Health Council

Dr. Wegman reported that children with FAS/FAE are often not identified. In order to best serve these children, the community must be educated about the risks of FAS and FAE. A community which is aware of the serious behavioral and cognitive problems of these children will be better able to develop strategies to help these children and their families.

In response to concern about FAS and FAE, a task force of local services representatives was created in Clallam County in 1991. The Clallam County FAS/FAE Task Force decided that an important component of the Task Force mission was to identify all the children in Clallam County affected by FAS/FAE. An evaluation clinic staffed by local professionals was developed (Child Development Clinic). The role of the clinic was expanded to include evaluations of children under 6 at-risk or showing signs of developmental delay, regardless of etiology.

The clinic staff is multi-disciplinary and includes an administrator, a child and family services caseworker, a public health nurse, a psychologist, a physical therapist, a communications disorders specialist, an occupational therapist, and a pediatrician. The staff serves children identified through the public health system and the school district. The clinic staff meets on a monthly basis in a local church and three children are evaluated during each one-day clinic session. After the full assessment by all team members, the information is presented to the parent or guardian and the child is referred into community services as necessary.

The physician's services are donated to the Child Development Clinic. If the client had medial coverage (eg., DSHS, IHS), the office evaluation is billed to these agencies. A written summary of the medical report is sent to the team members prior to the monthly meeting to reduce the amount of time spent away from private practice. The role of this physician in the assessment team is to detect abnormal patterns of morphology as well as delays in physical and cognitive development. The pediatric evaluation includes a personal health and behavioral history of the child, a family and social history and the examination of the child.

During his work with the Child Development Clinic, the problems encountered by Dr. Wegman have been relatively minor. These problems include patients not keeping appointments, referral of children who do not meet the diagnostic criteria, and children referred for developmental assessment who are clearly FAS/FAE and not in need of extensive diagnostic services. In addition, the amount of time a physician can provide uncompensated care may vary by organization.

In summary, Dr. Wegman encourages rural residents to find the resources within their communities to provide comprehensive identification and assessment of FAS/FAE children. A well-trained physician with an interest in developmental and behavioral pediatrics can serve as an essential component to an assessment team. Using local professionals to eliminate the logistical barriers to seeking special clinical services means that more children and families will get the help they need.

Barbara Woodward, Developmental Consultant with the state Office of Children with Special Health Care Needs, discussed the process of early identification and referral services for children with special health care needs (including children with FAS/FAE). Accurate early identification services are essential as they contribute to the well-being of the parents, utilize limited resources in the most cost-effective manner, and ensure that children who need intervention are identified as soon as possible.

Often the parents are the first to realize that their child may have some developmental delay. The health care system through well-child clinics, private health care providers, and neuro-developmental centers, may also identify a child who may need further assessment. The educational system, through "Child Find," serves to identify and track children who may have a developmental delay. Children who are insured through Medicaid are eligible for the EPSDT (Early Periodic Screening, Diagnosis and Treatment). However, this program is under-utilized.

A complete basic screening is the first step to identify a child at risk and in need of early identification services. All children should have a basic health screening by a qualified professional. The basic screening should raise public awareness about child health, provide periodic screening of nutritional, developmental, physically, oral, and mental health status. In addition, basic screening should provide the caretaker with anticipatory guidance, information and referral, and tracking. The basic health screening should be periodic and a brief examination of many aspects of the child's health and development.

Early identification services are further divided into several categories: **focused screening, assessment**, and **specialty assessment**. A **focused screening** should be focused on specific areas of concern identified at the basic screening. Family education, resource coordination, and tracking should be implemented. An **assessment** is for the child who is identified as having established health or developmental problems. This screening is multidisciplinary and focuses on assessment, family education, resource coordination and tracking. A diagnosis may result from this assessment. Finally, the child who appears to have complex health or developmental problems should receive a **specialty assessment**. This assessment should be done by specialized medical personnel and may utilize high-tech assessment tools. Family education, resource coordination and tracking should continue. Providers who make referrals need to be aware of community resources, the training of the health care provider, and the degree of severity of the child's syndrome.

The common findings of children who have FAS were described. These findings, which vary from child to child, include facial anomalies, microcephaly, small stature, and central nervous system abnormalities. These CNS abnormalities include developmental delay, feeding problems, hyperactivity and short attention span.

Social and School-Based Services Workshop

Presenters: •**Donna M. Burgess**, Ph.D., Research Assistant in Special Education at the University of Washington, and •**Nancy Albrecht,** Social Worker with the Division of Children and Family Services (DSHS), Port Angeles
Recorded by: **Carol E. Willett**, WCCD Staff

Dr. Burgess began the presentations for this workshop reminding everyone of the guiding concepts for educators of FAS/FAE children: (1) remember that they are children first, not the label of FAS or FAE, they can and will learn and respond; (2) the age ranges that educators will be dealing with start at birth and go to adulthood; (3) intelligence quotients of FAS children range from gifted to severely cognitively impaired, so no single curriculum can apply to them all; (4) neither FAS and FAE is a continuum, what is true for one child, may not be true for another, and a diagnosis of FAE does not mean the absence of delayed development, while the diagnosis of FAS does not necessarily mean that delayed development is always present; and (5) there is still no clear picture of the mother's part in producing an FAS child

The severest dysfunction of an FAS child is that of learning survival and living skills. FAS children are easily victimized because of their poor judgment. They are prime targets for gangs, and will often make decisions to stay in them because it "feels good to belong." Unfortunately for FAS children and their families, the first contact some educators and social workers have with an FAS child is when they've become involved in the juvenile justice or mental health system. By then, it is too late. Training in living skills may never be learned. The reason for this is late identification of the diagnosis of FAS, which isn't unusual at all. As recent as last year, one leading training hospital in the United States had a 100% failure rate in identifying FAS -affected people. Additionally, because there are so many different ranges to FAS, neither FAS nor FAE are disorders that the federal government likes to fund.

Dr. Burgess explained what was currently happening in Washington State in the area of FAS. She is currently preparing a recommended list of priorities for the legislature in addressing the need for services for FAS at the state level. The Office of the Superintendent of Public Instruction has two programs currently providing services for children with FAS; they are, the "Drug Free in the Schools Program" and the "Fair Start Program." Local school districts are providing independent training on FAS for various groups of child services workers. Dr. Burgess has developed a booklet on what to look for and behavioral management of FAS children for educators and she is currently involved in developing a program for the Centers for Disease Control for the training of educators, including a slide presentation, script, resources, handouts and behavioral management techniques. She is also working personally with individual families.

Nancy Albrecht briefly described her background as a social worker in the juvenile justice system in Idaho before coming to Clallam County in Washington State. Clallam County feels isolated from the rest of the state by being on the peninsula with no easy access to the services on the eastern side of the sound. Most of the children she works with are adopted and the original home had alcohol in the background. There are four Native American tribes in Clallam County and within the past couple of years, several parent support groups have developed. Also, the assessment team approach to diagnosing and developing a program of services for FAS children has begun. However, there is a need for more training of professionals in identifying FAS people to ensure early intervention services and to help ensure successful adoptions. Two grants have recently been applied for in the Clallam County area to help in this area; a two-year grant from the State Department of Health has just been received to provide training for more assessment teams and there is a request in with the March of Dimes for prevention programs.

Parent Support Groups and Community Efforts Work shop

Presenters: •**Marceil Vadheim**, M.C./CCDC II, Counselor in Private Practice and •**Jack C. Wilson**, Substance Abuse Prevention Coordinator, Snohomish County Human Services
Recorder: **Donna Patrick-Todd**, Developmental Disabilities Planning Council

Marceil Vadheim, in addition to being a practicing psychologist, is the biological mother of a seventeen year old daughter with FAS and a twenty two year old daughter with FAE. She distributed pictures of her daughters, noting that diagnosis of FAS is difficult during the older years of a child's life because the distinguishing characteristics have flattened out by then. Adolescence is also the period of time when FAS is the hardest to deal with, due to the surge of hormones, mounting peer pressures, and the inherent inability of the FAS child to understand cause and affect. Because FAS children learn differently from other children, Ms. Vadheim's daughter wrote a letter to her teachers, detailing her disabilities and how she learned best. She gives a copy of that letter to each new teacher every quarter and it has been a great help.

Ms. Vadheim described her own involvement with parent support groups and helping to start the *Iceberg* newsletter. She said that FAS has been an unknown entity for so long, and guilty-feeling parents have been in denial for as long, that now parents are clamoring for the formation of groups to help give them support in dealing with children that even psychologists don't seem to understand. She, as well as other FAS parents in the task forces and parents support groups, feel that talking about their kids in the groups is the best therapy they've found. She said that the emotions FAS parents go through are actually stages of grief; denial, pain, anger and finally resolution. In forming a parent support group, she cautioned that those emotions be recognized and that the group be formed around the issues the parents want to deal with. It should be a group serving parents as well as simply being made up of them.

Jack Wilson discussed the processes of developing effective parent support groups. Those processes are as follows:

Process for parent support groups:
- Form Group
- Call together all interested parties to form a broad coalition.
- Identify tasks, goals, resources, focus and mission
- Brainstorm solutions/possible resources
- Volunteer to be a model

- Find leaders in the group, ask for technical assistance
- Show everyone what's in it for them
- Acknowledge people's emotions
- Check back on goals, needs
-Empowerment of parents is a community issue, a support issue; look at the needs of the group, especially parents who have a personal stake in keeping the family together. Use parents as a valuable resource.
- A Family Resource Coalition person should be included in the group as a support for parents of FAS children and starting the local support groups.
- Communities should be mobilized to help organize and finance the needed services of counseling for the FAS person and the parents, services that are both community- and home-based, foster care, and ensuring the system's responsiveness

Adult and Juvenile Corrections Workshop

Co-Presenters: •**Robert Jones**, Ph.D., Chief of Clinical Services, Division of Offender Programs, Washington State Department of Corrections; and •**James W. M. Owens**, M.D., M.P.H., Medical Director, Echo Glen Children's Center, Division of Juvenile Rehabilitation. Assisting Dr. Owens' presentation was **Marian Rothwell**, school psychologist at Echo Glen.
Recorded by: **Kathryn Boudreau**, Director, Washington Council on Alcoholism

Robert Jones:

In 1991, the Department of Corrections (DOC) had the opportunity to participate in the Washington Council on Crime and Delinquency's "Conference on Fetal Alcohol Syndrome/Fetal Alcohol Effects." It was as as result of participation in that conference that DOC became all the more awere of the direct impact of this syndrome upon activities within adult corrections.

DOC is continually dealing with individuals whose problems far exceed a simple violation of the law. These individuals present problems the solutions to which are as yet unknown. These problems, historically, have been viewed as being a function of an individual's upbringing or their personality and yet, under closer inspection, we find that they are consistent with Fetal Alcohol Syndrome.

It is not uncommon to look at an offender as being an individual who fails to understand the consequences of his behavior or an individual that demonstrates little appreciation for long-term effects. His/her impulsivity is viewed as being consistent with a lack of attention which is often what the community has commonly referred to as being a learning deficit.

The person's inability to internalize rules of behavior and a subsequent lack of remorse over acting in a manner that violates such rules has commonly simply been identified as misbehavior. While individuals continually demonstrate organic signs through their inappropriate and impulsive actions, through their inability to understand the concepts of stealing and their inability to provide self-governance, we, nevertheless, continue to treat them as if they were fully capable of self-will.

DOC now has a better understanding of these offenders, that they are not classically developmentally disabled nor are they psychotic. The atmosphere in which they live and the expectations we place upon them can, indeed, influence their behavior.

As a result of observing behavior that is impulsive, lacks inhibition, demonstrates poor social judgment, and is consistent with social isolation, DOC begins to look for other problems. Does the individual suffer from seizures, a hearing loss, a loss of visual acuity, or clumsiness? Are their misbehaviors a result of wilful intent or as a result of an inability to predict outcome and an unresponsiveness to social cues?

Certainly, all of these symptoms directly bear upon an individual's involvement in the criminal justice system. As professionals in DOC have come to study FAS/FAE more closely, they have learned that those individuals who have acted without concern for the effect of their behaviors are likely to liable themselves. Individuals who are unaware of any type of code of behavior and who are socially inappropriate, to the point that they can be in violation of the law, are clearly those with more of a medical problem than a social problem and yet they are the same people who may ultimately be handled by the criminal justice system.

The experience these people have had within correctional facilities is often tragic. Taking into consideration all of the previous limitations that have been addressed, we must also keep in mind the inability of these individuals to really develop any kind of reciprocal friendships and, as a result, their tendency toward victimization. They lead very isolated and frustrating lives in correctional facilities with ambitions to be a part of the group and succeed in program assignments and the reality of not being able to be accepted nor to meet their own expectations of success.

One could almost describe the offender with FAS/FAE as having three distinct phases as they make contact with the criminal justice system. First is the demonstration of the limitations created by FAS/FAE, secondly are the criminal behaviors that come about as a result of FAS/FAE and the individual's involvement with the criminal justice system, and finally, is the marginal life of the individual in the system as a result of their poor social judgments, isolation, and lack of friendships due to their unresponsiveness to social cues and victimization.

In the past year, the Department of Corrections has attempted to initiate programs in two separate areas. First, a grant request was submitted to the National Institute of Corrections in order to provide an in-house program at the Washington Corrections Center for Women for female offenders who may either have FAS/FAE or need the self-discipline to care for an FAS/FAE child. Women identified as high risk for having an FAS/FAE child in the future were also included.

At the same time, DOC took the opportunity to join with Ann Streissguth in her research proposal to CDC. Of particular interest to us was the development of a fetal alcohol questionnaire which would allow for the identification of offenders with probable FAS or FAE and their subsequent need for special services. This was hoped to be incorporated into the reception process at the Washington Corrections Center in Shelton where a treatment plan could be developed that would follow the individual throughout their stay with the Department influencing both their living assignments as well as their program activities.

In the meantime, DOC has assigned a full-time staff member to work with the FAS/FAE Interagency Coordinating Committee. That staff member has now been able to create a greater sense of awareness, particularly at the Washington Corrections Center for Women, with regard to the needs of these particular offenders.

There is no doubt that, given the direct relationship that exists between FAS/FAE and criminal behavior and given the relationship that exists between this condition and the manner in which the individual must be treated, a mandate exists which requires not only early identification of the individual's situation but also subsequent treatment to the best of our ability. It is with that in mind that Dr. Jones anticipates an involvement on the part of the department in activities such as this conference.

James W. M. Owens, M.D., M.P.H.:

Dr. Owens agreed with many of the points made by Dr. Jones, however, he stressed the importance of early identification of FAS individuals to give these kids the best start possible. Most of the developmentally disabled children he's seen at Echo Glen, including the FAS/FAE children, usually have had poor pre-natal care, childhoods full of chaos and in adolescence ended up with a lot of risk-taking behavior. He also stresses the importance of early identification of FAS children because the obvious distinguishing features of the FAS infant have flattened out by adolescence and become less apparent. In working with kids in an institutional setting, he said it was often difficult to tailor the services needed by the child with the problems of that child. This is especially true of children thought to be FAS/FAE.

Marian Rothwell, the school psychologist at

Echo Glen, took over Dr. Owens' presentation and explained some of the programs that Echo Glen has available for developmentally disabled children, including those with FAS. She stated that while many of the FAS kids end up being incarcerated in state institutions—in fact fully 45% of the children at Echo Glen meet federal guidelines for special education, which is four times the rate of regular public schools in the community—none of the state juvenile institutions are eligible to receive medicaid moneys or special education funds for these children. She stressed the importance of creating a new style of teaching for these children that would help them learn daily living and survival skills. Teachers, especially those in the institutional setting, needs to know more about the individual child and that child's cognitive deficits and tailor a program of learning around the capabilities of that child.

Providing Culturally Competent Services Workshop

Presenters: •**Barbara Revey**, P.A., M.C.H./W.I.C Coordinator, Lummi Business Council; •**Dian E. Ferguson**, Community Organizer, DRUGS: Draw the Line!; and •**Jose Hernandez**, Community Liaison, Kennewick School District
Recorded by: **Judy R. Neal**, Drug and Alcohol Program Administrator, Washington State Division of Juvenile Rehabilitation

Barbara Revey encouraged the group to focus on the influence of "natural helpers" within the Indian community. She reviewed the history of Native Americans, how all things were equal in the beginning, but, she says, Indians are now victims of cultural oppression. Motivations for drinking in the Native American community—especially by the women—were discussed. In 1924, Indians were made American citizens. By 1953, they were finally allowed to purchase liquor, thus making the formerly prohibited seem very desirable. Native American women are naturally shy and drinking alcohol removed their inhibitions, allowing them to talk, interact and communicate more easily.

Now, the Native American community has six times more alcoholism than the rest of society. Effective programs in the Native American community should target the proud history of the society and stress the values of families. Currently, the Indian community is aggressively targeting mothers at risk of producing FAS children and offering education/information through prenatal seminars.

Jose Hernandez told about how he has used the familiar things of his Latino culture to negotiate appropriate behavior with clients, such as singing a familiar song to a drunk who had committed a traffic violation (After the song, the person admitted the need for treatment.). He discussed the transitions of the Latino community and the burden that language barriers put on many of the members of that community. Issues for Latinos focus on language, education, employment and social status. Effective programs for the Latino community would be geared toward drawing out the richness of the culture from the individuals.

Dian Ferguson encouraged participants of the workshop to become sensitive to others by asking themselves, "Who am I? Where did I come from and what makes up my familiar surroundings?" In dealing with clients of color, she suggested that professionals ask the clients about the view they have of themselves. Get a sense of their history and family background, and replace any preconceived notions about the person with accurate information by asking them questions. Over many generations ethnic minorities have reacted stressfully to cultural assimilation by internalizing the negative, resisting the assimilation, over-compensating, or simply by just "going under." She believes that we can all break the cycle of racism by: getting good client information, reaching out to other cultures, traveling, studying, joining groups, studying the issues of various cultures, and calling people on insensitive behavior.

Luncheon Keynote Address:

A Public Policy Perspective on FAS

by **Kristine Gebbie**, Secretary
Washington State Department of Health
Summarized by: **Leslie McDonald**,
Program Assistant, Childrens Trust Foundation

FAS is an emerging and complicated policy issue. It exists within a larger group of "newly acknowledged" issues—rather than those "newly identified." It is now a syndrome with "capital letters," even federal grants have been given for research.

The problem is that FAS is difficult to identify. And the populations affected by it are disenfranchised; they have trouble accessing services and getting their problems recognized. It is a "subtle" problem, so it can be ignored. There is a problem teaching both providers and the public. Providers don't have recent learning and are often not even familiar with the terms. FAS is not a disease people are comfortable with.

How does FAS affect health care reform and policy?

Large numbers of people now are trying to look at the big picture of health care reform. Washington State is fairly committed to "universal health care," financed at a reasonable rate, available to all residents of Washington. But how does long term care and support, substance abuse-related services, and one-to-one care fit into this package of personal services? If we want them fully included, we have to be very articulate about the kinds and structure of services needed. One fear is that we will need a bottomless pocketbook to pay for these things we don't consider "normal" health care.

If this comprehensive package of personal care benefits is to be passed, we must know the costs and have clear definitions, now! Figure out what is needed, now. Be clear so we can look for appropriate funding and systems. We need to figure out how to integrate at the points of services, even though funding comes from different places.

Two ways health care in Washington State is unique:

1. The system is being reformed to make the state healthier, instead of just to pay for the services.
2. It is not enough just to have care paid for, it must be backed up by prevention services to minimize the need for services. We must look for the most efficient way to give services. Prevention must be wrapped around the personal care system.

She suggested three directions as being needed:

•**Assessment**: How do we know what's going on now? Need to know the health status of citizens between birth and death. Assess the risks, experiences, illness, death cause, and threats to health. Need to understand the service networks now. What questions need to be asked?

•**Policy Development**: Integrating wishes into reality.

•**Assurance**: Build services so if you need help, you get it. Providers need to be educated; right now there is a big gap. Prior to the arrival of a child, what do we do? What about services for mothers?

Alcohol is so prevalent in society and health data are fuzzy for the public. Drinking behavior is accepted. We need to build a system all over the state to be able to ask these questions. FAS is an uncomfortable issue, so it is much harder to deal with. It must be done at the community level and statewide.

There must be quality assurances. Guidelines are fuzzy. Passion may take over. People committed must know it should be quality. Watch and monitor. The next two years will be hard because of our expectation of the new administrations. We hope health and socially-related issues will be dealt with, but it costs money. With the budget problems now, it will be hard to finance. And there would be tax questions. Be aware that at the state level, it is a budget issue. Nationally, the new administration can't do much in one year. It will take awhile. The state movement will probably come first.

The number of people working Washington is impressive. There is such energy in this room. We must translate our wishes, dreams and needs into a comprehensive package.

Afternoon Regional Workshops:

Developing Local FAS Action Plans

Each afternoon workshop was a local action-planning session which were divided into the six regions of the state (as determined by the Department of Social and Health Services—DSHS). Each session generally was facilitated by two people, a DSHS representative from the region who had been identified to help coordinate FAS activities, and a FAS care-provider from the region who had been identified by the FAS Adolescent Task Force. Workshop facilitators were asked to share three things with participants of their group: (1) Introductions of themselves, their organization and their interest in FAS, (2) activities relating to FAS in their region that is already happening, and (3) a discussion of what kinds of activities the group would like to see happening in the future. Action plans for each region were discussed, each reflecting the uniqueness of that region.

The following is a list of DSHS regional representatives, who are knowledgeable of FAS and services in their region, and Parent-Advocates for each region.

• Region 1	Spokane DCFS/DSHS, **Dean Lynch**	509/458-3915
	Parent Advocates:	
	Jodie Hardy, Wenatchee	509/662-9452
	Mary Lee Gaston, Spokane	509/467-7309
	Karen Blaine, Spokane	509/326-1722
• Region 2	DSHS Representative Undetermined	
	Parent Advocates:	
	Susan Alexander, Ellensburg	509/962-5505
• Region 3	Everett DCFS/DSHS, **Dorothy Dolin**	206/339-3970
	Parent Advocates:	
	Trudy Wise, Burlington	206/757-3733
	Jocie DeVries, Lynnwood	206/778-4048
• Region 4	King Central DCFS/DSHS, **Pat Ossorio**	206/721-4114
	Parent Advocates:	
	Linda LaFever, Woodinville	206/488-8956
	Sherry Roth, Vashon	206/933-3396
	Roberta Wright, Seattle	206/323-9136
• Region 5	Pierce Central DCFS/DSHS, **Nancy Tyson**	206/593-3754
	Parent Advocates:	
	Vicky McKinney, Tacoma	206/531-2878
• Region 6	DSHS Representatives:	
	Carol Aldred, Olympia	206/586-5695
	Myrth Ogilvie, Vancouver	206/696-6388
	Nancy Edwards, Port Angeles	206/457-2620
	Parent Advocates:	
	Santha Glintenkamp, Sequim	206/683-4967
	Jackie & Chuck Price, Vancouver	206/256-2506

Keynote Address: *Community Empowerment*

Summarized by: **Cheryl Milloy**, Research Assistant, Urban Policy Research

Cecilia Firethunder, Training Specialist for the South Dakota Department of Health; Maternal and Child Health Division, gave a moving and powerful keynote address on how to organize and empower communities to deal with the issue of Fetal Alcohol Syndrome. The following is a summary of her major points:

1) First, we should get away from the label "FAS" and instead use the term "Alcohol Related Developmental Disability" or ARDD. The problem is that there is still extensive drinking and denial in communities, especially Indian communities, and when you start talking about the damage people have caused, they are not going to hear or listen to you.

2) We have to recognize that alcohol itself is not the problem, but only a symptom of a deeper pain. We need to work with people to heal that pain. The goal is to build strong healthy people.

3) We also need to recognize that women drink for different reasons than men. Treatment programs need to be developed that are female-based. We need programs for women where they can have their children with them. Finally, we should never give up on these women.

4) When we think about organizing within the community, we must always think of how to empower people within that community, because they know the norms of the community.

5) We can develop generic plans and curricula, but we need to empower the people within the community to take this information and make it fit their community. We should only act as facilitators, and try to find the natural leaders within each community to bring about the necessary change.

6) Community empowerment really means: How do we get people to own it and make it theirs? When they own it, there will be a long-term commitment to making change happen.

7) The greatest challenge is to translate what we know so that the knowledge can be used by a community.

CONFERENCE PROGRAM AGENDA

"Fetal Alcohol Syndrome and Effects: *From Awareness to Action*"

December 2, 1992; Seattle Airport Hilton

7:00 AM	REGISTRATION	*Lobby*	
8:00	WELCOME	*Ballroom*	Donna Schram, Ph.D., Chair. WCCD Board of Directors
8:15	CONFERENCE OVERVIEW	*Ballroom*	Larry Fehr, M.P.A. Executive Director, WA Council on Crime & Delinquency
8:30	RESEARCH OVERVIEW AND UPDATE ON FETAL ALCOHOL SYNDROME AND EFFECTS	*Ballroom*	Sterling K. Clarren, M.D. Professor of Pediatrics School of Medicine University of Washington Ann P. Streissguth, Ph.D. Professor, Department of Psychiatry and Behavioral Science, School of Medicine University of Washington
9:30	PANEL PRESENTATION ON CURRENT FAS ACTIVITIES	*Ballroom*	<u>Panel Moderator:</u> J.C. Ephraim, Jr., Substance Abuse Prevention Trainer, Puget Sound E.S.D. #121 <u>Panelists:</u> Sandra P. Randels, Coordinator Fetal Alc. Syndrome Program WA Department of Health Vince Collins, Representing WA Department of Social and Health Services (DSHS) Rick Teboe, Native American Specialist, WA Division of Alcohol and Substance Abuse Carol R. Strong, Supervisor Substance Abuse Education Office of the Superintendent of Public Instruction Jocie DeVries, Coordinator FAS Adolescent Task Force Mary Ellen O'Keeffe, Director Children's Trust Foundation

10:30 MORNING BREAK

10:45 WORKSHOPS: *"Assessing Current Efforts and Planning the Future"*

- Prevention and Public Awareness — *Columbia East*

  Co-Presenters:
  Nancy White, Director of
  Programs & Communications
  March of Dimes

  Carolyn Hartness, Drug and
  and Alcohol Prevention
  Counselor, I-Wa-Sil Youth
  Program, United Indians of
  All Tribes

  Moderator/Recorder:
  Pamela Darby, Prog. Manager
  WA State Division of Alcohol
  and Substance Abuse

- Identification, Assessment & Referral — *Columbia West*

  Co-Presenters:
  John Wegman, M.D.
  Peninsula Children's Clinic
  Clallam Co. FAS Task Force

  Barbara Woodward, OTR, MPH
  Developmental Consultant
  Office of Children with
  Special Health Care Needs
  State Department of Health

  Moderator/Recorder:
  Amy Howarth, M.P.H., Coord.
  Community Health Council

- Social Services and School-based Services — *Elliott East*

  Co-Presenters:
  Donna M. Burgess, Ph.D.
  Special Education Area
  University of Washington

  Nancy Albrecht, Social Worker
  Division of Children & Family
  Services (DSHS), Port Angeles

  Moderator/Recorder:
  Carol Owens, Program Manager
  WA State Division of Alcohol
  and Substance Abuse

- Parent Support Groups and Community Efforts — *Elliott West*

  Co-Presenters:
  Marceil Vadheim, M.C./CCDC II
  (Parent of FAS Adolescent)
  Counselor, Private Practice

			Jack C. Wilson, Substance Abuse Prevention Coord. Snoh. Co. Human Services Moderator/Recorder: Donna Patrick-Todd, Prog. Mgr. Developmental Disabilities Planning Council
	•**Adult and Juvenile Corrections**	*Peninsula East*	Co-Presenters: Robert R. Jones, Ph.D. Chief of Clinical Services, Div. of Offender Programs WA State Dep't. of Corrections James W. M. Owens, M.D., M.P.H. Medical Director, Division of Juvenile Rehabilitation Echo Glen Children's Center Moderator/Recorder: Kathryn Boudreau, Director WA Council on Alcoholism
	•**Providing Culturally Competent Services**	*Peninsula West*	Co-Presenters: Dian E. Ferguson, Community Organizer, DRUGS; Draw the Line! Jose Hernandez, Community Liaison, Kennewick Schools Barbara Revey, P.A. MCH/WIC Coordinator Lummi Business Council Moderator/Recorder: Judy Neal, Drug and Alcohol Program Administrator, WA State Division of Juvenile Rehabilitation
12:00	LUNCHEON		
	•Recognition of Supporting Organizations and Conference Planning Committee		
	•Luncheon Keynote Presentation		Kristine Gebbie, Secretary WA State Department of Health

1:30	REGIONAL WORKSHOPS: *"Networking and Beginning to Develop a Regional Action Plan"*		
			Co-Facilitators
	•*Region 1* (Okanogan, Ferry, Stevens, Pend Oreille, Spokane, Whitman, Lincoln, Adams, Grant, Douglas, and Chelan Counties)	*Columbia East*	Mary Lee Gaston (FAS Care-giver) (DSHS Region 1 Rep.)
	•*Region 2* (Kittitas, Yakima, Benton, Franklin, Walla Walla, Columbia, Garfield, and Asotin Counties)	*Columbia West*	Susan Alexander (FAS Care-giver) (DSHS Region 2 Rep.)
	•*Region 3* (Snohomish, Skagit, Island, San Juan And Whatcom Counties)	*Elliott East*	Jocie DeVries (FAS Care-giver) (DSHS Region 3 Rep.)
	•*Region 4* (King County Service Area)	*Elliott West*	Sherry Roth (FAS Care-giver) (DSHS Region 4 Rep.)
	•*Region 5* (Pierce and Kitsap Counties)	*Peninsula East*	Victoria McKinney (FAS Care-giver) (DSHS Region 5 Rep.)
	•*Region 6* (Clallam, Jefferson, Grays Harbor, Mason, Thurston, Pacific, Lewis, Wahkiakum, Cowlitz, Clark, Skamania, and Klickitat Counties)	*Peninsula West*	Santha Glintenkamp (FAS Care-giver) (DSHS Region 6 Rep.)
3:00	BREAK (Beverages)		
3:15	KEYNOTE ADDRESS: *"Community Empowerment"*	*Ballroom*	Cecelia Firethunder, Training Specialist, So. Dakota Department of Health; Maternal and Child Health Div.
3:45	CONFERENCE EVALUATION AND CLOSURE	*Ballroom*	Larry M. Fehr Director, WCCD
4:00	CONFERENCE RECEPTION	*Glacier/Horizon*	

EVALUATION RESULTS

December 2, 1992

CONFERENCE ON FETAL ALCOHOL SYNDROME AND EFFECTS: *FROM AWARENESS TO ACTION*

PARTICIPANTS WERE ASKED TO RATE, ON A SCALE OF 5 (EXCELLENT) TO 1 (POOR), ONLY THE SESSIONS OF THE CONFERENCE IN WHICH THEY PARTICIPATED.
OF THE 444 PEOPLE ATTENDING, 169 RESPONDED WITH A RETURNED EVALUTION FORM.
THE FOLLOWING ARE THE AVERAGED RATINGS TAKEN FROM THOSE 169 RETURNED EVALUATION FORMS.

	AVERAGED RESPONSES 5 (Excellent) to 1 (Poor)
I. CONFERENCE PROGRAM	
A. Research Update: Presentations by Drs. Clarren and Streissguth	4.71
B. Panel Presentation on Current FAS Activities in Washington	3.74
C. Morning Workshops:	
•Prevention and Public Awareness	3.48
•Identification, Assessment & Referral	3.54
•Social Services and School-based Services	3.91
•Parent Support Groups and Community Efforts	4.2
•Adult and Juvenile Corrections	3.85
•Providing Culturally Competent Services	4.39
D. Luncheon Keynote by Sec. Kristine Gebbie	4.1
E. Afternoon Workshops:	
•Region 1	3.68
•Region 2	3.5
•Region 3	3.91
•Region 4	3.35
•Region 5	3.76
•Region 6	3.74
F. Afternoon Keynote by Cecelia Firethunder	4.82
G. **OVERALL ASSESSMENT OF PROGRAM**	4.36
II. CONFERENCE ARRANGEMENTS	
A. Conference Location	4.13
B. Conference Meal	4.11
C. Conference Length	4.66
D. Conference Value (Benefits of Conference in Light of Cost of Conference)	4.57
E. **OVERALL ASSESSMENT OF ARRANGEMENTS**	4.07
III. OVERALL CONFERENCE EVALUATION	4.29

EXCERPTS FROM LETTERS

From: **Mary Lee Gaston**, parent of an FAS child and conference participant

Wow! How do I respond regarding what I have learned at the recent WCCD/FAS conference? Do we have time to write a book?

The conference was stupendous! More than that, it was a time to re-root with friends with whom I have developed an uncanny bond—a tragic bond it is! That of having an FAS/E child in common. I feel at ease, at rest, supported, informed, affirmed, re-fueled, and ready to tackle Spokane County and demand awareness of prevention, education, support and acceptance that FAS/E is alive and doing terribly unwell in our county because we are still in denial. Denial that it exists, denial that if it exists it cannot be cured, denial that treatment is the way to go, etc. I'm also re-energized in my quest to continue to search for services and help for my child and try to keep him alive and safe (us too!).

From: **Deborah Fisher**, WCCD Board Member and conference participant regarding Followup to FAS Region 4 Workshop

In my opinion, work on FAS needs to be done in two major arenas: 1) within social services and 2) within the community. There also needs to be a strong link developed between the two. Perhaps the emerging network of Family Support Centers in Seattle, King and Snohomish Counties could provide that link? These Family Support Centers are certainly a logical vehicle for community education as well as building capacities within neighborhoods to help deal with the problems of FAS/FAE.

Other good channels when we speak of how to reach people and educate them regarding this topic include the Parent Education Departments of all the community colleges in the state as well as the "Cities in the Schools" networks in King County and developing "Communities in the Schools" in Snohomish County...

From: **Michelle Detwiler**, foster parent and conference participant

I am a foster parent for children who are medically fragile and developmentally delayed. Five years ago we received our first foster child. We were told that he had Fetal Alcohol Syndrome. Once we were told that, no one ever mentioned it again, not even when talking about his severe developmental delays. This little boy, whom I'll call Dusty, at three years old could not take his own clothes off to get dressed for bed. He couldn't talk either, the words came out backwards or mixed up. He was such a happy little boy, and yet, there was a rage inside him ready to well up and explode at a moment's notice...

After six months, Dusty went back to his family. He went back to a family who couldn't control him, and a mother who most likely had alcohol related disabilities herself. My advice to his case worker and guardian ad litem was to put Dusty in a therapeutic foster home or group home. Even at his young age I could see that he had a very rocky future ahead of him. I didn't know how any home would be able to support him the older and bigger and stronger he got. I knew nothing about fetal alcohol syndrome. I do not know what happened to Dusty...

Five years after Dusty we take in a baby. He is medically fragile, and looks like he has Downs Syndrome. We test for Downs and the test is negative. His records do indicate that his mom exposed him to drugs and alcohol. I try to deal with this child a little differently, and I hope he doesn't have fetal alcohol syndrome. He is smart, he looks at everything, tries to play with everything. He's going to be put up for adoption. No, I don't think he has fetal alcohol syndrome, he couldn't. He looks so good, and he's so happy!...

I heard about the conference for fetal alcohol syndrome, I fill out the paperwork and am signed up to attend. I call the new mom and tell her about it, I'm sure she'll need to know what's on the horizon for her new son. She signs up for the conference also, as does the caseworker.

We all go to the conference. I'm still sure our baby doesn't have fetal alcohol syndrome, still hoping. By the end of the day I'm sure, I'm sure he is affected. I talk to his new mom about it. We talk about life and growing up, about hardships, and about probable learning disabilities. And we also talk about HOPE. Now that so many are involved and interested in fetal alcohol syndrome, there is hope! Now the schools can look at the children who are disabled by alcohol and drugs in a new light. And family support groups are starting! There was a lot of love and a lot of care in the conference that day. Although my heart was aching and breaking for our long lost Dusty, it was also growing and learning and figuring out what I do as a foster mom, for the next few kids I'll probably have, who are affected by alcohol...

Again, I want to thank you for the hope extended to those of us who care for children with fetal alcohol syndrome. This conference really made aware the needs of these children to the public.

The Washington Council on Crime and Delinquency

presents

Fetal Alcohol Syndrome and Effects

From Awareness to Action

December 2, 1992 Seattle, WA

Recorded by N.H.C.C. Tapes, Inc. - Box 4735 - Spokane, WA 99202

Special Offer ...

Pick Any 8 or 12 Cassettes and
Receive a Free Cassette Storage Album
and Free Shipping

MINIMUM CREDIT CARD CHARGE OF $20.00

To order, please check your selections and complete this section, then return entire form.

____________	Individual cassettes at $8.00	$ 8.00	$	____________
____________	Set of 8 cassettes in Storage Album	$ 64.00	$	____________
____________	Set of 12 cassettes in Storage Album	$ 96.00	$	____________

HANDLING / SHIPPING

Add $2.00/1st cassette + 50¢ each additional cassette ($2.00 per cassette foreign) $ ____________

GRAND TOTAL $ ____________

☐ Yes ☐ No Please include me on your mailing list regarding future availability of recorded conferences.

SIGNATURE ______________________________ Date ____________

Name ______________________________

Firm ______________________________

Street Address (no P.O. Boxes please) ______________________________

City State ______________________________ Zip ____________

Telephone (   ) ______________________________

Please indicate: ☐ Check enclosed payable to N.H.C.C. Conference Tapes, Inc. P.O. No. ________

☐ VISA ☐ MasterCard ☐ American Express

Card # ______________________________ Exp. Date ____________

MAIL TO:

N.H.C.C. Conference Tapes, Inc.
Box 4627
Spokane, WA 99202
(509) 624-1244

Thank You for the Order! We Appreciate Your Business!

WEDNESDAY, DECEMBER 2, 1992

☐ S101 **Research Overview and Update on Fetal Alcohol Syndrome & Effects**
Sterling K. Clarren, M.D .- Professor of Pediatrics, School of Medicine, University of Washington
Ann P. Streissguth, Ph.D. - Professor, Department of Psychiatry and Behavioral Science, School of Medicine, University of Washington

☐ S102 **Panel Presentation on Current FAS Activities in Washington**
Panel Moderator: *J.C. Ephraim, Jr.*
Vince Collins, representing WA Department of Social and Health Services
Sandra P. Randels, Coordinator FAS Program WA Department of Health
Rick Teboe, Native American Specialist, WA Division of Alcohol and Substance Abuse
Jocie DeVries, Coordinator FAS Adolescent Task Force
Mary Ellen O'Keeffe, Executive Director Chidren's Trust Foundation
Carol Strong, Supervisor of Substance Abuse Education, OSPI

☐ S103 **Prevention and Public Awareness**
Presenters:
Nancy White, March of Dimes
Carolyn Hartness, Drug and Alcohol Prevention Council I-WA-SIL Youth Program
Moderator/Recorder:
Pam Darby, Division of Alcohol and Substance Abuse

☐ S104 **Identification, Assessment, Referral & Other Health Services**
Presenters:
John Wegman, M.D., Pediatrician, Port Angeles
Barbara Woodward, Children with Special Health Care Needs
Moderator/Recorder:
Amy Howarth, Coordinator, Community Health Council

☐ S105 **Social and School-based Services**
Presenters:
Donna M. Burgess, Ph.D., University of Washington
Nancy Albrecht, DCFS and Clallam Co. FAS Task Force
Moderator/Recorder:
Carol Owens, Division of Alcohol and Substance Abuse

☐ S106 **Parent Support Groups and Community Efforts**
Presenters:
Marceil Vadheim, Counselor and Parent of FAS Child
Jack Wilson, Snohomish Co. Sub. Abuse Prevention Coord.
Moderator/Recorder:
Donna Patrick-Todd, Dev. Dis. Planning Council

☐ S107 **Adult and Juvenile Corrections**
Presenters:
Robert R. Jones, Ph.D., Chief of Clinical Services (DOC)
James Owens, M.D., Medical Director, Div. of Juvenile Rehab.
Moderator/Recorder:
Kathryn Boudreau, Dir., WA Council on Alcoholism

☐ S108 **Providing Culturally Competent Services**
Presenters:
Jose Hernandez, Community Liaison, Kennewick School Dist.
Barbara Revey, MCH/WIC Coord. Lummi Business Council
Dian Ferguson, Community Organizer "Drugs: Draw the Line"
Moderator/Recorder:
Judy Neal, Division of Juvenile Rehabiliation

☐ S109 **Luncheon Keynote Presentation**
Kristine Gebie, Secretary WA State Department of Health

AFTERNOON WORKSHOPS
Regional Efforts to Foster Action

☐ S110 Region 1 - (Okanogan, Ferry, Stevens, Pend Oreille, Spokane, Whitman, Lincoln, Adams, Grant, Douglas, and Chelan Counties)

☐ S111 Region 2 - (Kittitas, Yakima, Benton, Franklin, Walla Walla Columbia, Garfield, and Asotin Counties)

☐ S112 Region 3 - (Snohomish, Skagit, Island, San Juan and Whatcom Counties)

☐ S113 Region 4 - (King County Service Area)

☐ S114 Region 5 - (Pierce and Kitsap Counties)

☐ S115 Region 6 - (Clallam, Jefferson, Grays Harbor, Mason, Thurston, Pacific, Lewis, Wahkiakum, Cowlitz, Clark, Skamania, and Klickitat Counties)

☐ S116 AFTERNOON KEYNOTE ADDRESS
Community Empowerment
Cecelia Firethunder, Oglala Sioux Training Specialist

Fetal Alcohol Syndrome in Adolescents and Adults

Ann Pytkowicz Streissguth, PhD; Jon M. Aase, MD; Sterling K. Clarren, MD;
Sandra P. Randels, RN, MSN; Robin A. LaDue, PhD; David F. Smith, MD

Fetal alcohol syndrome is a specific recognizable pattern of malformation. Manifestations in 61 adolescents and adults suffering from alcohol teratogenesis are presented. After puberty, the faces of patients with fetal alcohol syndrome or fetal alcohol effects were not as distinctive. Patients tended to remain short and microcephalic, although their weight was somewhat closer to the mean. The average IQ was 68, but the range of IQ scores widely varied. Average academic functioning was at the second- to fourth-grade levels, with arithmetic deficits most characteristic. Maladaptive behaviors such as poor judgment, distractibility, and difficulty perceiving social cues were common. Family environments were remarkably unstable. Fetal alcohol syndrome is not just a childhood disorder; there is a predictable long-term progression of the disorder into adulthood, in which maladaptive behaviors present the greatest challenge to management.

(*JAMA*. 1991;265:1961-1967)

FETAL alcohol syndrome (FAS) now is recognized as the leading known cause of mental retardation in the United States,[1] surpassing Down's syndrome and spina bifida. Over 2000 scientific reports have now appeared, confirming that alcohol is a teratogenic drug capable of producing lifelong disabilities after intrauterine exposure. Fetal alcohol syndrome does not include all individuals affected by alcohol in utero, but rather it represents the severe end of the continuum of disabilities caused by maternal alcohol use during pregnancy.

Fetal alcohol syndrome was independently identified in France[2] and the United States.[3,4] Most of the patients described have been infants or young children.[5] What the physical and mental manifestations of the syndrome in adolescents and adults are has remained an important unanswered question. Although isolated clinical reports of older patients with FAS have appeared,[6,7] as well as follow-ups of primarily preadolescent children,[8-11] to our knowledge this is the first systematic follow-up study that has examined adolescent and adult manifestations of this important cause of developmental disability. Some data from this overall project have been mentioned in the literature.[12]

METHODS

Patients who had been previously diagnosed as having FAS were eligible for this study if they were 12 years or older at the time of follow-up. Patients with possible fetal alcohol effects (FAE) were seen as time permitted. Approximately half of the sample was clinically ascertained (patients of A.P.S., S.K.C., or D.F.S.). The rest were identified through an FAS screening study on four Indian reservations.[13] Original diagnostic examinations were conducted by three of us (J.M.A., S.K.C., D.F.S.) or our coworkers.

Fetal alcohol syndrome was diagnosed when patients had a positive history of maternal alcohol abuse during pregnancy and (1) growth deficiency of prenatal origin (height and/or weight); (2) a pattern of specific minor anomalies that included a characteristic facies (generally defined by short palpebral fissures, midface hypoplasia, smooth and/or long philtrum, and thin upper lip); and (3) central nervous system manifestations (including microcephaly or history of delayed development, hyperactivity, attention deficits, learning disabilities, intellectual deficits, or seizures).[14,15] Patients exposed to alcohol in utero with some partial FAS phenotype and/or central nervous system dysfunction, but without sufficient features for a firm diagnosis of FAS or strong consideration of any alternative diagnosis, were identified as "possible FAE" for these analyses.

The follow-up examination occurred for the most part between 5 and 12 years after the original diagnostic examination and was conducted by three of us (A.P.S., S.P.R., and R.A.L.). It consisted of an intellectual examination (Wechsler Adult Intelligence Scale—Revised or Wechsler Intelligence Scale for Children—Revised[16,17]), an academic

---

From the Departments of Psychiatry and Behavioral Sciences (Drs Streissguth and LaDue and Ms Randels) and Pediatrics (Dr Clarren), Child Development/Mental Retardation Center and the Alcoholism and Drug Abuse Institute of the University of Washington Medical School, Seattle; and the Department of Pediatrics, University of Vancouver, British Columbia (Dr Smith). Dr Aase is in private practice in Albuquerque, NM.

Reprint requests to Department of Psychiatry and Behavioral Sciences, GG-20, University of Washington School of Medicine, 2707 NE Blakeley, Seattle, WA 98195 (Dr Streissguth).

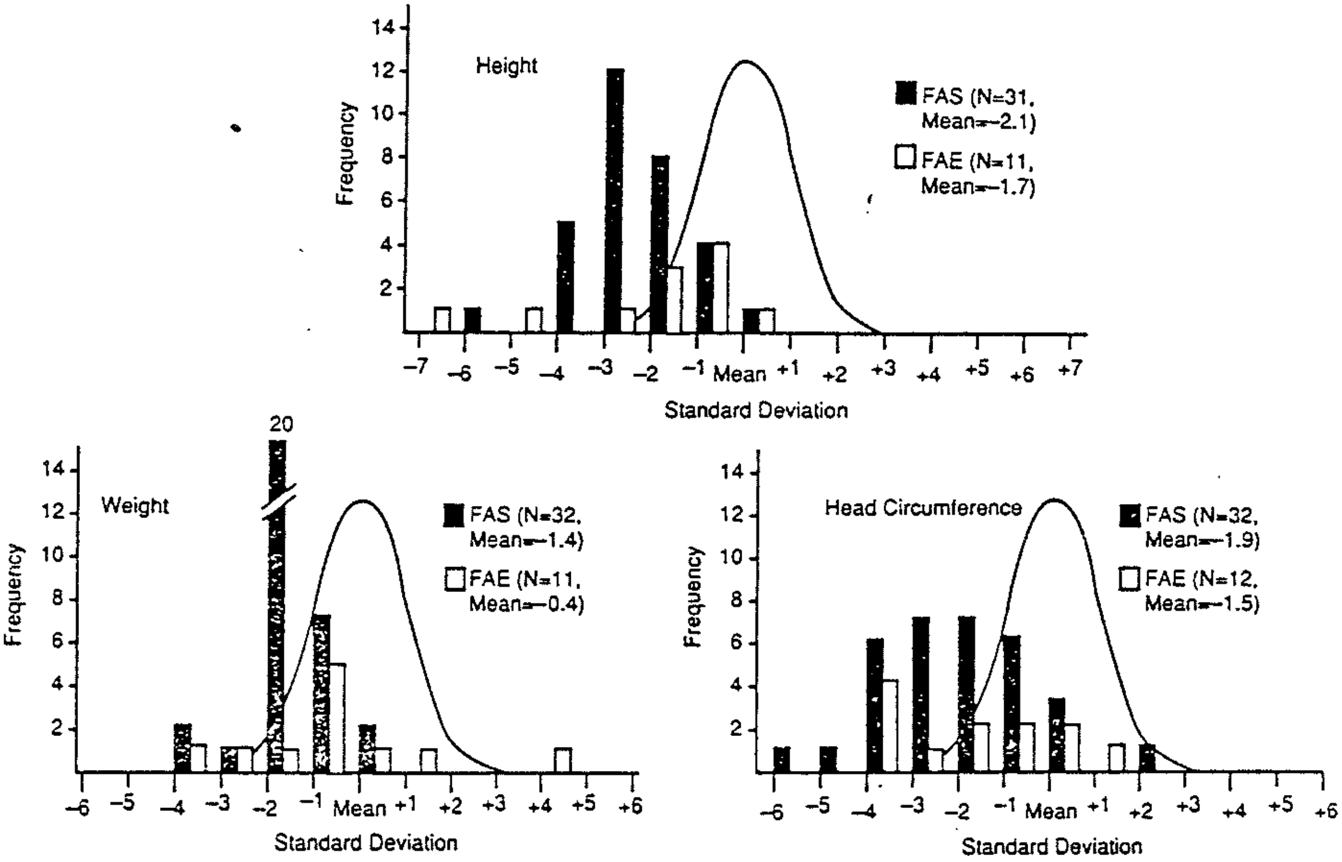

Fig 1.—Frequency distribution of height, weight, and head circumference for adolescents and adults with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE) plotted in SDs from the mean, according to the National Center for Health Statistics.[20] Mean chronological age was 18 years 3 months. The bell-shaped curve represents the normal distribution.

examination (Wide-Range Achievement Test—Revised[18]), physical measurements (eg, height, weight, head circumference, palpebral fissure width, and inner-canthal distance), photographs, a medical records review, and an interview with the primary caretaker for social-behavioral information, which included the Vineland Adaptive Behavior Scale (VABS).[19]

It was not always possible to get full information on each patient due to clinical constraints. Furthermore, some data were not systematically collected until the study was under way. Relevant sample sizes and mean age are presented with each analysis. Despite discrepancies in sample size, the average age, IQ, reservation status, and FAS-FAE ratio for patients in each subgroup of data were approximately the same.

RESULTS

Subjects

The 61 patients (38 males and 23 females) ranged in age from 12 to 40 years; 43 were adolescents (12 to 17 years old) and 18 were adults (18 to 40 years old). Seventy-four percent of the sample were American Indian, 21% were white, and 5% were black; 47% lived on reservations of the southwest and northwest United States, 39% lived in urban areas of the Pacific Northwest; and 14% lived in rural, nonreservation areas. Seventy percent had an FAS diagnosis; 30% were classified as FAE.

Physical Characteristics

As Fig 1 indicates, FAS shifts the normal distribution of height and head circumference about 2 SDs down from the population mean[20] for adolescents and adults, but has less effect on weight. The patients with FAS had an average head circumference of −1.86 SDs. Two patients had extreme microcephaly, −4.6 and −5 SDs, but 28% had normal head sizes. One man had macrocephaly, which may have resulted from an arrested hydrocephalus.

The shortest patients were 5 and 6 SDs below the mean at full height: one 29-year-old woman was 124 cm tall and a 14-year-old sexually mature female was 130 cm tall. Although height was the most severely affected growth parameter, not every patient was "short": 16% of the patients with FAS were within the average range; none were above 1 SD.

Weight deficiency, which is so typical of young children with FAS, was less noticeable in these adolescents and adults. Twenty-five percent of patients with FAS and 50% with FAE were *not* underweight; two with FAE were overweight, including a 40-year-old man who weighed 103 kg. Males and females were equally affected on growth parameters, although females who were not growth deficient for weight tended to increase adipose tissue at an earlier age than males.

Calculations of the weight-height proportion (weight for height age) available for 31 patients with FAS revealed an extremely wide distribution of scores, from 3% (very thin) to 90% (very heavy). The mean weight-height proportion for these adolescents and adults with FAS was 48%, much higher than the 1% to 15% for children with FAS.[12] The time of onset of puberty was gener-

Fig 2.—Severely retarded American Indian adolescent diagnosed with fetal alcohol syndrome at birth and photographed as a neonate and at ages 5, 10, and 14 years. He has been growth deficient and microcephalic throughout his life. With increasing age, there is a considerable relative growth of the nose, resulting in a high, wide nasal bridge. Note persistence of smooth philtrum. This patient was originally described by Jones and Smith.[4]

Fig 3.—Adolescent girl diagnosed with fetal alcohol syndrome at birth, with later intellectual functioning in the borderline range. Photographed at birth, 9 months, and 5 and 14 years of age. While gradual maturation of facial features is taking place, note persisting small palpebral fissures, relatively long, smooth philtrum, and narrow upper vermilion.

Fig 4.—Adult white woman diagnosed with fetal alcohol syndrome at 4 years of age; IQ level of 85 to 90; photographed at 9, 13, and 19 years of age. In this patient, facial manifestations of fetal alcohol syndrome have evolved into a fairly normal facial phenotype by adult life, illustrating the value of a photographic record in the assessment of adults with fetal alcohol syndrome. At 19 years, her head circumference was below the first centile, height was below the fifth centile, and weight was around the 10th centile.

Table 1.—Ocular Measurements in Adolescents and Adults With FAS and Possible FAE*

	FAS (N=31)		Possible FAE (N=11)	
	Mean	Range	Mean	Range
Palpebral fissure length				
Left eye, cm	2.30	1.80-3.00	2.62	1.80-3.50
Right eye, cm	2.34	1.80-3.00	2.53	1.90-3.30
Inner-canthal distance, cm	3.14	2.30-4.10	2.92	2.30-3.50

*Mean age was 18½ years. FAS indicates fetal alcohol syndrome; FAE, fetal alcohol effects.

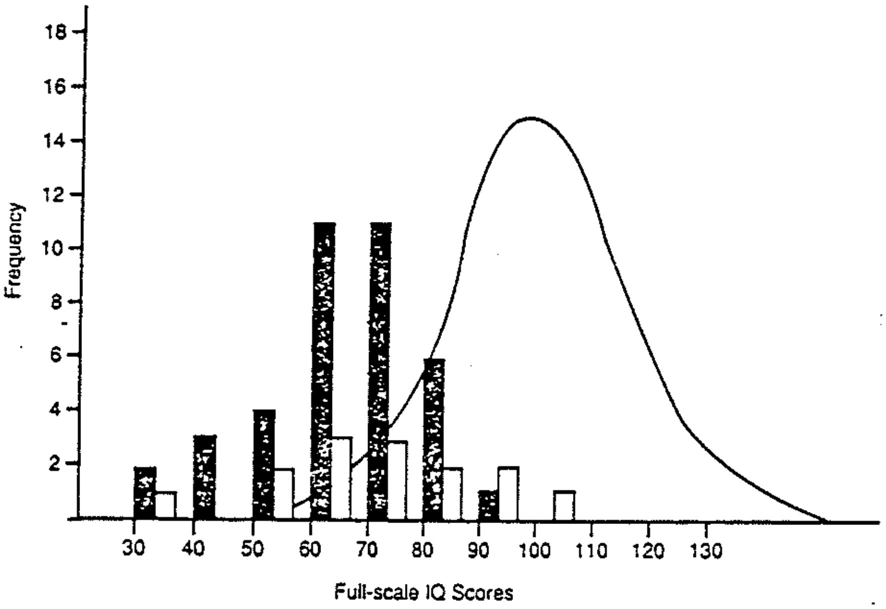

Fig 5.—Frequency distribution of IQ scores from the Wechsler Adult Intelligence Scale—Revised[16] and the Wechsler Intelligence Scale for Children—Revised,[17] whichever was age appropriate. Mean chronological age was 18 years. The bell-shaped curve represents the normal distribution. Solid bars indicate fetal alcohol syndrome (N=38, mean IQ=66); open bars, fetal alcohol effects (N=14, mean IQ=73).

Table 2.—Percent of School or Work Placement of Patients With FAS-FAE*

Regular classes	6
Regular classes plus tutoring	11
Regular classes plus special education†	24
Self-contained special education classes	28
Vocational program	6
Sheltered workshop	9
Working	2
Not in school or work	15

*FAS indicates fetal alcohol syndrome; FAE, fetal alcohol effects. N=36 for FAS; N=11 for FAE. Mean age was approximately 17 years. This information was not available for five of the patients who had taken IQ tests.

†Half of each.

ally within normal limits. While there may have been some slight delay in puberty for males, it did not appear to be clinically significant.

The characteristic facies of children with FAS gradually became less distinctive with increasing age. In many cases, eye anomalies, short palpebral fissures, and abnormalities of the philtrum and lips remain useful diagnostic features in adolescents and adults (Figs 2 through 4). For example, mean palpebral fissure length for patients with FAS remains low in adolescence and adulthood: 2.30 and 2.34 cm (left and right, respectively) compared with a mean of 3.05 cm for normal 16-year-olds.[21] Mean inner-canthal distance also remained larger than palpebral fissure length in patients with FAS (Table 1).

However, continued growth in four facial areas changed the adolescent and adult facial phenotype in FAS as noted by (1) continued growth of the nose in two dimensions: height of the nasal bridge and nasal length from root to tip; (2) continued growth of the midfacial region correcting the earlier midfacial hypoplasia; (3) improved soft-tissue modeling of the philtrum and upper lip; and (4) continued growth of the chin. A further description of dysmorphic features in the clinical diagnosis of malformation syndromes has been previously published.[22]

The most common specific facial anomalies identified in 80% or more of patients with FAS included abnormalities of the philtrum (which could be smooth, long, or short), abnormal lips (thin or wide), and malformed and/or misaligned teeth. Nonfacial minor malformations were also often present: 68% of the patients had joint abnormalities of the fingers (camptodactyly or clinodactyly), 56% had palmar crease abnormalities, and 24% had incomplete rotation at the elbow.

Intellectual Functioning

The average IQ score for the combined FAS-FAE group was 68, technically just into the mentally retarded range, representing "significantly subaverage intellectual function," according to the classification system of the American Association on Mental Deficiency.[23] The range of IQ scores was wide, from 20 (severely retarded) to 105 (normal). Fifty-eight percent of the patients had an IQ score of 70 or below, a frequent cutoff point for the classification of developmentally disabled and qualification for special community services.

As Fig 5 indicates, patients with a diagnosis of FAS had lower average intellectual functioning (mean IQ, 66) compared with those with FAE (mean IQ, 73). The average performance scale IQ score was about 10 points higher than the average verbal scale IQ score for both FAS and FAE.

Academic and Adaptive Functioning

The academic placement of these patients at the time of examination can be found in Table 2. Only 6% were in regular classes without supplemental help; 28% were in self-contained special education classes; 15% were not in school or work; and 9% were in sheltered workshops. One man worked but did not live independently.

The average reading, spelling, and arithmetic grade levels for these adolescents and adults were fourth grade, third grade, and second grade, respectively. Arithmetic deficits were the most characteristic academic disability of patients with FAS-FAE. Older patients did not, in general, function better academically than younger patients, as Fig 6 depicts. Considerable variability in academic functioning was noted, from some older men who were functionally illiterate to one who read at a high school level. Several adolescent girls had careful penmanship and relatively good spelling skills.

These adolescents and adults with FAS-FAE had an average level of adaptive functioning on the VABS of around 7 years, although they averaged 17

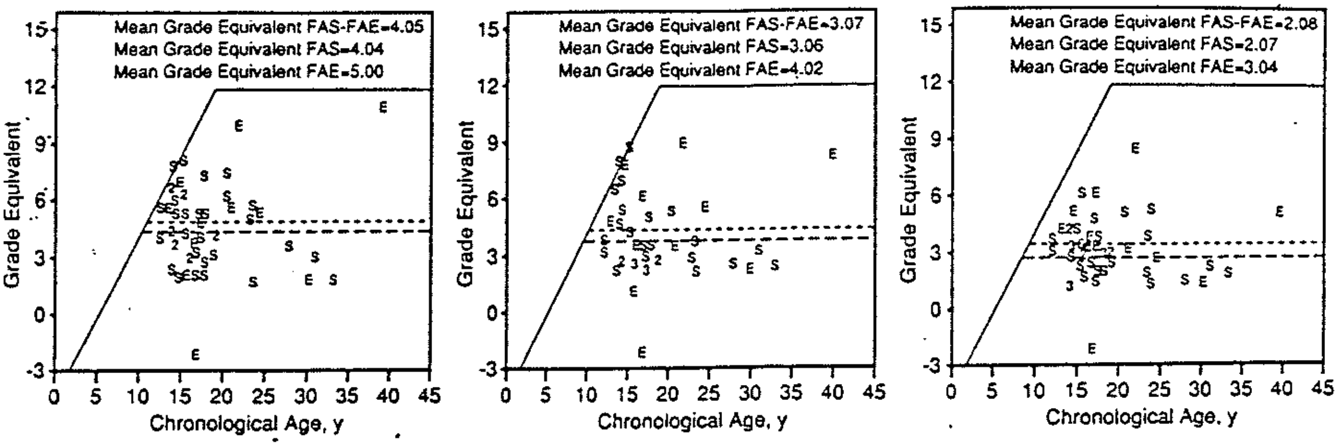

Fig 6.—Scatterplot of reading (left), spelling (middle), and arithmetic (right) grade equivalent scores by chronological age. Mean chronological age was 18 years; 36 patients had fetal alcohol syndrome (FAS); 11 had fetal alcohol effects (FAE). Data are from the Wide Range Achievement Test—Revised.[18] Solid lines indicate the expected academic performance for each age; dashed lines, mean scores for FAS; dotted lines, mean scores for FAE; S, scores of individual patients with FAS; E, scores of individual patients with FAE; 2, points on which two patients fell; and 3, points on which three patients fell. The curves on this test do not continue to accelerate after the 12th grade.

years chronologically (Fig 7). Of the three domains making up the adaptive behavior composite of the VABS,[19] patients performed best on daily living skills (mean at the 9-year level) and most poorly on socialization skills (mean at approximately the 6-year level). Although there were one or two patients whose daily living skills were approximately age appropriate, none were age appropriate in terms of socialization or communication skills. The VABS revealed that failure to consider consequences of action, lack of appropriate initiative, unresponsiveness to subtle social cues, and lack of reciprocal friendships were problems that were characteristic of those patients with FAS-FAE who technically were *not* retarded according to IQ scores.

The maladaptive behaviors inventory of the VABS[19] (obtained on the full VABS subgroup) indicated that 62% of the patients had a "significant" level of maladaptive behaviors and 38% had an "intermediate" level. Not one patient with FAS-FAE in this subgroup had a maladaptive behaviors score in the "insignificant" range. The most frequent types of maladaptive behaviors noted were poor concentration and attention, dependency, stubbornness or sullenness, social withdrawal, teasing or bullying, crying or laughing too easily, impulsivity, and periods of high anxiety. In addition, many of the patients were noted to lie, cheat, or steal, to show a lack of consideration and to exhibit excessive unhappiness. None of the patients were receiving help with mental health problems at the time of the examination.

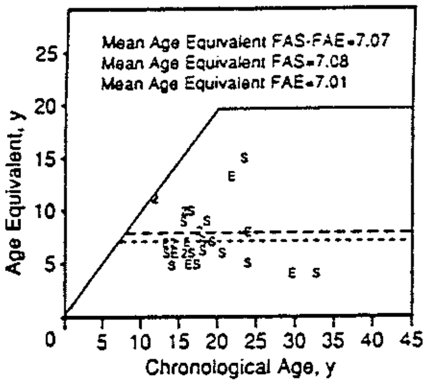

Fig 7.—Scatterplot of scores on the adaptive behavior composite of the Vineland Adaptive Behavior Scale—Revised.[19] Mean chronological age was 17 years; 24 patients had fetal alcohol syndrome (FAS); seven had fetal alcohol effects (FAE). Solid line indicates the expected adaptive behavior level at each age; dashed line, the mean scores for FAS; dotted line, mean scores for FAE; S, scores of individual patients with FAS; E, scores of individual patients with FAE; and 2, points on which two patients fell. The curves on this test do not continue to accelerate after 20 years.

Table 3.—Family Environment of Patients With FAS-FAE*

Where Living at Follow-up (n = 58), %	
With both biologic parents	9
With biologic father	10
With biologic mother	3
Cared for by relatives	26
With adoptive parents	19
In foster home	19
In group home or institution	7
Living alone but not independent	3
Rent subsidy program	2
Unknown	2
Average No. of Regular Homes at Follow-up	
For patients ≥18 y (n = 10)	5.5
For patients 12-17 y (n = 33)	3.5
Additional Information on Family Environment, %	
Never cared for by biologic mother (n = 45)	31
Not with biologic mother by 6 y (n = 45)	64
Biologic mother deceased (n = 51)	69
Maternal rights terminated (n = 34)	26

*FAS indicates fetal alcohol syndrome; FAE, fetal alcohol effects; and n, the number of subjects for whom this information could be reliably determined (percentages use this figure as the denominator).

Family Environment

These patients came from remarkably unstable family environments: they had lived, on average, in five different principal homes in their lifetimes (not counting receiving homes or temporary shelters) (Table 3). Only 9% were still with both biologic parents; only 3% were still with their biologic mothers. Of those for whom accurate data could be obtained, 69% of the biologic mothers were known to be dead. Although many died of alcohol-related illnesses, others died of other alcohol-related causes such as suicide, homicide, falls, and automobile accidents. Nearly one third of these patients with FAS-FAE were never raised by their biologic mothers; they were given up for adoption at birth or abandoned in the hospital.

COMMENT

The natural history of FAS can now be traced into adulthood. Although mental retardation is not necessarily predictable from the diagnosis alone, major psychosocial problems and lifelong adjustment problems were characteristic of most of these patients.

Short stature and microcephaly appeared to be the most prominent growth deficiencies as the children got older. The thin prepubescent torso (so characteristic of younger children with FAS) often gives way to a normal weight-height proportion (or even plumpness in adolescent girls), which considerably modifies the physical phenotype after puberty.

Facial anomalies were more subtle in adolescents and adults with FAS than in children with FAS. Increased growth of the nose and chin during adolescence and thickening of the philtral ridges changed the overall facial appearance in many patients. Relatively short palpebral fissures, smooth philtrum, and thin upper lip remain important discriminating characteristics in the older patient, but joint anomalies (particularly clinodactyly, camptodactyly, and incomplete rotation at the elbow) and altered palmar crease patterns should not be overlooked. In some adults, the faces of affected individuals become so normalized that early childhood photographs can be crucial in confirming the diagnosis.

The developmental and cognitive handicaps persist as long in life as these patients have been studied. None of these patients were known to be independent in terms of both housing and income.

The average academic functioning of these adolescents and adults was at the early grade school level; most had required some remedial help in school. Yet 42% had an IQ level above 70 and would not readily qualify for special community services on leaving school. A particular deficit in arithmetic skills was noted, which reflected their extreme difficulty with abstractions like time and space, cause and effect, and generalizing from one situation to another. The severity of their arithmetic disability, often masked by superficial verbal skills, appeared to be central to their difficulty with independent living, poor judgment, and generally dysfunctional lives. The overall level of adaptive functioning of these patients was also surprisingly low, especially as they often appeared alert and verbal on clinical examination.

Attentional deficits and problems with judgment, comprehension, and abstraction were the most frequently reported behavior problems. One recent neuropsychological study indicates spatial memory problems to be particularly notable in a small group of adult patients with FAS-FAE.[24] Conduct problems, such as lying and defiance, also characterized a number of these patients. Data on trouble with the law and substance abuse were not systematically obtained but should be evaluated in future studies.

While many persons who are retarded have increasing behavioral problems with increasing age, the particular type of problems observed in these adolescents with FAS appeared to be different in magnitude and severity, especially compared with patients with Down's syndrome. Harris[25] cites studies finding only 15% to 32% of adolescents with Down's syndrome with severe behavior problems compared with the 62% of patients in this study with significant levels of maladaptive behaviors.

Although we believe that this is the most extensive study available on the long-term consequences of FAS, several cautions should be addressed. First, this is a clinical study and thus suffers from the problems with ascertainment bias that plague all clinical studies that depend on referrals.

The sample size of patients with FAE is too small to draw firm conclusions. This is primarily a study of the long-term consequences of FAS. A small number of patients with possible FAE were examined as time permitted. They are presented herein to indicate that the problem of alcohol teratogenesis extends beyond those patients with the full syndrome and to encourage other investigators to look beyond the full syndrome in considering the possible range of alcohol teratogenesis.

It is admittedly difficult to separate the primary origins of the behavioral problems described herein. On the one hand, IQ and achievement problems can be seen as manifestations of central nervous system dysfunction that are consistent with the alcohol-related brain damage now reported in numerous experimental animal models,[26,27] including nonhuman primates.[28] For example, many maladaptive behaviors, such as deficits in learning, inhibition, attention, regulatory behaviors, and motor performance, have been produced in animal offspring prenatally exposed to alcohol[29] at circulating blood alcohol levels comparable with those found in humans.[30] On the other hand, further studies are needed to clarify the role of adverse postnatal environmental factors that may exacerbate maladaptive behaviors in already vulnerable children. Have children with FAS been put in multiple foster placements *because* they are difficult to manage? Or have their multiple placements *made* them difficult to manage? The question cannot be answered with these data.

Few of the patients in this study were diagnosed as having FAS in infancy. It is possible that with early diagnosis more appropriate early interventions could have reduced at least some secondary psychopathology. Unfortunately, the prospect of generalized early identification of patients with FAS seems unlikely in light of a recent report from one of the largest obstetrical services in the United States documenting a 100% failure rate in diagnosing FAS at delivery.[31]

Mothers of patients in this study were primarily chronic alcoholics; their retrospective histories were not precise enough to warrant dose-response analyses. Population-based studies carried out with social drinkers have shown subtle offspring effects, including IQ and achievement decrements (especially arithmetic), attentional and memory problems, and learning problems,[32-35] but of a smaller magnitude than those reported herein in patients with FAS. These studies all support the surgeon general's recommendation of not drinking during pregnancy.[36] The full syndrome, as described in this study, is associated with maternal alcohol abuse.

The implications of these findings for the long-range impact of alcohol-related birth defects are overwhelming. In Seattle, Wash, the prevalence rate for the full syndrome is one in about 700 live births.[37] On Indian reservations in the southwest United States, minimal prevalence rates range from one in 97 to one in 750 live births.[13] The highest reported prevalence is one child in eight in a Canadian Indian village, where all children and mothers were systematically evaluated.[38]

Conservative estimates of the economic costs of FAS have ranged from $321 million per year in the United States (calculating only to age 21 years)[1] to $1.4 million across the lifetime of one child (J. Binkeley, unpublished data, 1989). None of these estimates has projected the mental health costs or that patients with FAS would be unable to be at least partially productive in the workplace.

Our present experience suggests that the severe behavioral problems often clinically associated with FAS in later adolescence make many of these patients unsuitable candidates for the usual job training programs (particularly those developed for patients with Down's syndrome). That a poor outcome is found, even among patients with normal intellectual functioning, suggests that subtle manifestations of prenatal brain damage are involved. Further evaluation of the long-term neuropsychological deficits associated with alcohol-related birth defects is urgently needed. It is also imperative that we challenge schools and communities to provide more appropriate remedial experiences and shelter for these patients in order to prevent victimization, dysfunctional lives, increased psychopathology, chronic mental illness, and homelessness.

The physician can play an important role in the recognition of FAS[14,15] among disabled youths and adults. Information on maternal and paternal drinking history should be routinely obtained in workup of patients of any age with developmental disabilities, attentional defects, and/or conduct disorders. Families often find the diagnosis of FAS helpful in obtaining suitable programs for their children. Patients often express relief at understanding the cause of their lifelong difficulties.

Fetal alcohol syndrome is not just a childhood disorder.[39] There is a predictable, long-term progression of the disorder into adulthood in which maladaptive behaviors present the greatest challenge to treatment. Gestational exposure to alcohol can cause a wide spectrum of disabilities that have lifelong physical, mental, and behavioral implications.

This work was partially funded by contracts 240-83-0035, 243-88-0166, and 243-89-0019 from the Indian Health Service, Rockville, Md, and grant AA01455 from the National Institute of Alcohol Abuse and Alcoholism, Rockville, Md.

The collaboration of Phillip May, MD, Karen Hymbaugh, MAPA, and Helen M. Barr, MA, MS, is greatly appreciated, as is the technical assistance of Cara C. Ernst, MA, and Greg Owen.

References

1. Abel EL, Sokol RJ. Incidence of fetal alcohol syndrome and economic impact of FAS-related anomalies. *Drug Alcohol Depend*. 1987;19:51-70.
2. Lemoine P, Harrousseau H, Borteyru JP, Menuet JC. Les enfants de parents alcooliques: anomalies obsérvees: a propos de 127 cas. *Ouest Med.* 1968;8:476-482.
3. Jones KL, Smith DW, Ulleland CN, Streissguth AP. Pattern of malformation in offspring of chronic alcoholic mothers. *Lancet.* 1973;1:1267-1271.
4. Jones KL, Smith DW. Recognition of the fetal alcohol syndrome in early infancy. *Lancet.* 1973;2:999-1001.
5. Dehaene P, Samaille-Villette P, Crepin G, Walbaum R, Deroubaix P, Blanc-Garin AP. Le syndrome d'alcoolisme fetal dans le nord de la France. *Reveu L'alcoolisme*. 1977:145-148.
6. Streissguth AP, Herman CS, Smith DW. Stability of intelligence in the fetal alcohol syndrome: a preliminary report. *Alcohol Clin Exp Res.* 1978;2:165-170.
7. Iosub S, Fuchs M, Bingol N, Stone RK, Gromisch DS. Long-term follow-up of three siblings with fetal alcohol syndrome. *Alcohol Clin Exp Res.* 1981;5:523-527.
8. Steinhausen HC, Gobel D, Nestler V. Psychopathology in the offspring of alcoholic parents. *J Am Acad Child Psychiatry.* 1984;23:465-471.
9. Spohr HL, Steinhausen HC. Follow-up studies of children with fetal alcohol syndrome. *Neuropediatrics.* 1987;18:13-17.
10. Majewski F, Majewski B. Alcohol embryopathy: symptoms, auxological data, frequency among the offspring, and pathogenesis. In: Kuriyuma K, Takada A, Ishii H, eds. *Biomedical and Social Aspects of Alcohol and Alcoholism*. Amsterdam, the Netherlands: Elsevier Science Publishers BV; 1988:837-844.
11. Streissguth AP, Clarren SK, Jones KL. Natural history of the fetal alcohol syndrome: a ten-year follow-up of eleven patients. *Lancet.* 1985;2:85-92.
12. Streissguth AP, Sampson PS, Barr HM. Neurobehavioral dose-response effects of prenatal alcohol exposure in humans from infancy to adulthood. In: Hutchings DE, ed. *Prenatal Abuse of Licit and Illicit Drugs.* New York: New York Academy of Sciences; 1989;562:145-158.
13. May PA, Hymbaugh KJ, Aase JM, Samet JM. Epidemiology of fetal alcohol syndrome among American Indians of the Southwest. *Soc Biol.* 1983;30:374-387.
14. Clarren SK, Smith DW. The fetal alcohol syndrome. *N Engl J Med.* 1978;298:1063-1067.
15. Smith DW. *Recognizable Patterns of Human Malformation: Genetic, Embryologic and Clinical Aspects.* 3rd ed. Philadelphia, Pa: WB Saunders Co; 1982.
16. Wechsler D. *WAIS-R Manual: Wechsler Adult Intelligence Scale—Revised.* New York, NY: The Psychological Corp; 1981.
17. Wechsler D. *WISC-R Manual: Wechsler Intelligence Scale for Children—Revised.* New York, NY: The Psychological Corp; 1974.
18. Jastak S, Wilkinson GS. *Manual for the Wide-Range Achievement Test—Revised.* Wilmington, Del: Jastak Associates Inc; 1984.
19. Sparrow SS, Bella DA, Cicchetti DV. *A Manual for the Vineland.* Circle Pines, Minn: American Guidance Services; 1984.
20. NCHS growth charts. In: *Monthly Vital Statistics Report.* Washington, DC: National Center for Health Statistics; 1976;25(3). Suppl (HRA): 76-1120.
21. Hall J. *Handbook of Normal Physical Measurements.* New York, NY: Oxford University Press Inc; 1989.
22. Aase JM. *Diagnostic Dysmorphology.* New York, NY: Plenum Press; 1990.
23. Grossman HB, ed. *Classification in Mental Retardation.* Washington, DC: American Association on Mental Deficiency; 1983.
24. Gray JK, Streissguth AP. Memory deficits and life adjustment in adults with fetal alcohol syndrome: a case-control study. *Alcohol Clin Exp Res.* 1990;14:294.
25. Harris JC. Psychological adaptation and psychiatric disorders in adolescents and young adults with Down syndrome. In: Pueschel SM, ed. *The Young Person With Down Syndrome: Transition From Adolescence to Adulthood.* Baltimore, Md: Paul Brokes; 1988:35-51.
26. West JR, ed. *Alcohol and Brain Development.* New York, NY: Oxford University Press Inc; 1986.
27. Savage DD, Montano CY, Paxton LL, Kasarskes EJ. Prenatal ethanol exposure decreases hippocampal mossy fiber zinc in 45-day-old rats. *Alcohol Clin Exp Res.* 1989;13:588-593.
28. Clarren SK, Astley SJ, Bowden DM, et al. Neuroanatomic and neurochemical abnormalities in nonhuman primate infants exposed to weekly doses of ethanol during gestation. *Alcohol Clin Exp Res.* 1990;14:674-683.
29. Riley EP. The long-term behavioral effects of prenatal alcohol exposure in rats. *Alcohol Clin Exp Res.* 1990;14:670-673.
30. Driscoll CD, Streissguth AP, Riley EP. Prenatal alcohol exposure: comparability of effects in humans and animal models. *Neurotoxicol Teratol.* 1990;12:231-237.
31. Little BB, Snell LM, Rosenfeld CR, et al. Failure to recognize fetal alcohol syndrome in newborn infants. *AJDC*. 1990;144:1142-1146.
32. Streissguth AP, Barr HM, Sampson PD. Moderate prenatal alcohol exposure: effects on child IQ and learning problems at age 7½ years. *Alcohol Clin Exp Res.* 1990;14:662-669.
33. Landesman-Dwyer S, Ragozin AS, Little RE. Behavioral correlates of prenatal alcohol exposure: a four-year follow-up study. *Neurotoxicol Teratol.* 1981;3:187-193.
34. Sampson PD, Streissguth AP, Barr HM, Bookstein FL. Neurobehavioral effects of prenatal alcohol, II: partial least squares analysis. *Neurotoxicol Teratol.* 1989;11:477-491.
35. Streissguth AP, Bookstein FL, Sampson PD, Barr HM. Neurobehavioral effects of prenatal alcohol, III: PLS analyses of neuropsychologic tests. *Neurotoxicol Teratol.* 1989;11:493-507.
36. Surgeon General's advisory on alcohol and pregnancy. *FDA Drug Bull.* 1981;2:10-16.
37. Hanson JW, Streissguth AP, Smith DW. The effects of moderate alcohol consumption during pregnancy on fetal growth and morphogenesis. *J Pediatr.* 1978;92:457-460.
38. Robinson GC, Conry JL, Conry RF. Clinical profile and prevalence of fetal alcohol syndrome in an isolated community in British Columbia. *Can Med Assoc J.* 1987;137:203-207.
39. Dorris M. *The Broken Cord.* New York, NY: Harper & Row Publishers Inc; 1989.

Meeting the Needs of Northwest Native Youth Challenged by Fetal Alcohol Syndrome

Program Proposal Summary

Background:

American Indian tribes across the nation have begun to recognize that Fetal Alcohol Syndrome (FAS) is one of the most serious consequences associated with the alcohol problems that plague many of the men, women, and young people in their communities. While the nationwide FAS incidence estimate of 1 in 750 live births indicates that this condition is not a uniquely Native American problem, FAS rates as high as 1 in 8 births documented in some Indian communities suggest the need for immediate, culturally relevant prevention and intervention programs. Although FAS education and prevention programs are becoming increasingly available, services for Indian people already living with FAS remain virtually nonexistent. In many tribal communities, children exposed to alcohol in utero who show the physical and behavioral symptoms of FAS often remain undiagnosed, at least in part because no services are available once the diagnosis has been determined. Thus, it is quite likely that undiagnosed FAS accounts for the repeated academic, social, behavioral, and legal problems observed in some of the young people in Indian communities in the Puget Sound region.

While FAS affected children require a great deal of attention and special care during infancy and childhood, in adolescence their behavior becomes even more difficult to manage. Due to the poor judgement, impulsivity, anger outbursts, substance abuse, legal violations, academic delays, unprotected intercourse, inappropriate sexual behavior, and lack of social skills they often exhibit, adolescents and young adults with FAS are rarely able to maintain an adequate level of adjustment in home, school, or work settings. The result is that many young people with FAS either fail, drop-out, or are expelled from school and are unable to maintain employment. They often fall into illegal activities and spend time in juvenile detention or jail. Their repeated acting out and failure to learn from consequences often leaves parents, foster parents, or other caretakers searching for an out of home placement or day treatment program that can provide the structure they need. <u>The goal of this project is to establish a comprehensive treatment, education, and vocational rehabilitation program tailored to the specific needs of American Indian adolescents and young adults challenged by Fetal Alcohol Syndrome.</u>

Overview:

Because of the variety of needs and wide range of functioning observed in this population, a coordinated, multidisciplinary, individualized program is required. In the initial phase, a day treatment program will be developed and later, as funds allow, a residential treatment center will be established. Long range plans include combining this program with an Elders Housing Complex in order to create a multigenerational healing community. The service population will be American Indian males and females aged 12 to 21 years who are diagnosed with FAS. The program will be centrally located in the Puget Sound Region of Washington State in order to allow as many participants as possible to reach the program site by bus from their home communities. (The exact location for the program has yet to be determined.) Once the residential portion of the program is in place, youth who live beyond commuting distance or who do not have a viable living arrangement will be included. Assessment of potential participants will be available through Sterling Clarren, M.D., one of the world's leading experts on FAS, at the Child Development and Mental Retardation Center at the University of Washington in Seattle.

The program will seek to ensure the physical, mental, emotional, and spiritual well being of participants through a series of services designed to enhance their ability to function at their highest possible level. In addition to state-of-the-art health, education, and substance abuse services adapted to meet the special needs of each participant, activities emphasizing Indian culture and spirituality will be included in all aspects of the program. Special education and mental health services will be integrated into hands-on vocational and recreational activities, including therapeutic horsemanship, camping, canoeing, and ropes courses. Spiritual development will be encouraged by visiting religious leaders and medicine people from a variety of traditions who will lead talking circles, sweat lodges, and prayer ceremonies for interested participants. Vocational rehabilitation will take place in workshops set up by elders or others skilled in basketry, woodcarving, beadwork, drum and rattle making, and smoking salmon. An apprenticeship model will be utilized to provide participants with close supervision and to encourage the development of mentor relationships. As participants are ready, vocational training in community work settings will be arranged, facilitated by on-site job coaches who will ensure that participants receive the individualized support they need to make a satisfactory adjustment.

The overall goal of this program will be to help participants to develop practical independent living and work skills that will enable them to make a contribution to their home communities.

The Challenge:

Development of a comprehensive Native American FAS program will require the identification of substantial human and fiscal resources. Collaboration from a variety of public and private organizations will be necessary to achieve this goal. Grant support will be sought from government and private sources. Several private foundations, such a Robert Wood Johnson, Kellogg, and Medina have been identified as potential sources of funding. Increasing tribal involvement, identifying potential sites for the program, getting one or more grant writers involved, and actively applying for grant money are the next steps.

A planning group consisting of representatives from Indian tribes and organizations, government agencies, the University of Washington, and private citezens has convened on six occassions and a steering committee to guide the development of this program is being formed. Discussion of how the program will be organized and administered has so far focused on creating a private non-profit cooporation made up of a consortium of urban and tribal groups. The option of joining with an existing non-profit organization such as the United Indians of All Tribes, N.W. Indian College or the Seattle Indian Health Board is also being explored.

If you would like a more complete description of this proposal, or would like to make some suggestions about how or where it should be developed, please contact:

Lew Abrams, Ph.D.
Chief, Mental Health and Social Services
Puget Sound Service Unit - Indian Health Service
2201 Sixth Avenue Room 300
Seattle WA 98121
(206) 553-4932

or

Carolyn Hartness
I Wa Sil Youth Program
102 Prefontaine Place South
Seattle WA 98104
(206) 543-1530