Report to the Governor's Council on Substance Abuse

Fetal Alcohol Syndrome Interagency Workgroup (FASIAWG)

July 2007 – Final Report

EXECUTIVE SUMMARY

Prenatal alcohol exposure is the leading preventable cause of birth defects and development disabilities in our country. Each year, as many as 40,000 babies are born with Fetal Alcohol Spectrum Disorders (FASD)[1], costing the United States about $4 billion. An estimated 320 to 1,000 children are born with FASD each year in Washington State.

The State of Washington has led the nation in strategies to reduce the incidence of FASD and to support children and adults who are affected. Federal funding in 1979 allowed the Fetal Alcohol Drug Unit (FADU) to carry out the first large scale program to educate communities, screen for high-risk mothers, intervene with alcohol-abusing mothers during pregnancy, and to evaluate and make recommendations for their children. This two-year program with a staff of 27 trained 6,300 professionals; one in every 44 pregnant women in the community called the 24-hour hotline. It was the first program in the country to recommend that women not drink alcohol during pregnancy. Washington State has since achieved a significant decline in maternal use of alcohol during pregnancy and in the number of children born with FASD. Washington State is home to the first multidisciplinary network of FASD diagnostic clinics (FAS Diagnostic and Prevention Network); the first and oldest longitudinal study of affected individuals (by FADU); the only national family-run educational organization on FASD (Fetal Alcohol Syndrome Family Resource Institute); unique programs such a FASt Friends, FASD Family Summer Camp, FASD teen social skills groups (NOFAS Washington, the Washington State affiliate to the National Organization on Fetal Alcohol Syndrome); development and distribution of the Iceberg Newsletter (Fetal Alcohol Syndrome Information Services); and an innovative and effective statewide primary prevention program (Parent Child Assistance Program). Progress has also been made toward changing eligibility criteria in the Division of Developmental Disabilities to include more individuals disabled by FASD who have normal IQ levels; this has been one of the top recommendations of the Fetal Alcohol Syndrome Interagency Workgroup (FASIAWG) since its inception in 1995.

In order for Washington State to further reduce the FASD incidence rate and the impact on those citizens who have FASD, we must implement statutory changes, modify policy and practice, and identify new funding sources and allocations. A conservative lifetime cost estimate for one person with FASD is $2,000,000, but the cost of preventing FASD in a baby is less than $10,000. Therefore, the cost offsets of prevention and intervention dollars will result in a reduction in the use of multiple social service systems by individuals with FASD and their families. These systems include chemical dependency, mental health, developmental disability, education, child welfare/social services, health care, vocational rehabilitation, and juvenile/criminal justice. For instance, FASD is ten times more prevalent in children who are in Foster Care (1 out of every 100 according to the FAS DPN) than in the general population. If we reduce the rate of FASD in these children and prevent or reduce secondary disabilities in those who are affected, the results will be huge savings for state agencies and increased quality of life for these individuals and their families.

Therefore, the members of FASIAWG propose the exploration, implementation and/or funding of the following general recommendations.[2] (Specific recommendations are included beginning on page 15.)

I. Institutionalize a “no wrong door” approach to providing appropriate services to children and adults with FASD and their families.
II. Provide practical FASD education and training to professionals in the eight state systems listed in this report and to parents of affected children.
III. Support public agencies, professional organizations and family-run FASD advocacy and educational organizations to provide effective prevention, identification, intervention and support services and programs.

[1] FASD is the latest, federally accepted umbrella term used to refer to all conditions caused by prenatal alcohol exposure, such as fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD).

[2] Note: Opinions stated in this report do not necessarily reflect the individual state agencies or the governor’s office.

THE HISTORY AND EVOLUTION OF THE FETAL ALCOHOL SYNDROME INTERAGENCY WORK GROUP

Background and Definition: "Fetal Alcohol Spectrum Disorders" (FASD) is a term describing the range of effects (from subtle to serious) that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, developmental, and/or learning disabilities with lifelong implications. The term FASD is not intended for use as a clinical diagnosis. FASD is an umbrella term that includes all conditions and disabilities caused by prenatal alcohol exposure, such as fetal alcohol syndrome (FAS), fetal alcohol effects (FAE), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). Prenatal alcohol exposure is commonly cited as the leading preventable cause of birth defects and developmental disabilities. Each year, as many as 40,000 infants are born in the United States with FASD, costing the United States about $4 billion. An estimated 320 to 1,000 children are born with FASD each year in Washington State. FASD is a state and national problem that can impact any child, family, or community.

History: The negative impact of alcohol on the developing fetus was noted in Washington State at the University of Washington in 1968. The term Fetal Alcohol Syndrome (FAS) was coined in 1973 when the malformation syndrome was identified in children of alcoholic mothers. In 1995, the Washington State Legislature unanimously passed Substitute Senate Bill (SSB) 5688. This legislation directed the Department of Social and Health Services (DSHS), the Office of Superintendent of Public Instruction (OSPI), the Department of Health (DOH), and the Department of Corrections (DOC) to execute an agreement. This agreement was to ensure the coordination of programs serving children who have fetal alcohol effects, and women at high risk of having children with fetal alcohol effects. The legislation included the first provision in Washington State history for representatives of family-run advocacy groups to participate in the planning, development, delivery, and review of services administered or contracted by the agencies executing the agreement. Representatives from the following additional agencies and groups (which were also involved in the concurrent 1995 Governor's Advisory Panel on FAS) voluntarily agreed to continue meeting as the FASIAWG in an effort to oversee the implementation of this interagency agreement: the FAS Family Resource Institute (FAS*FRI); the University of Washington Fetal Alcohol Syndrome Diagnostic and Prevention Network (FAS DPN); and the University of Washington Fetal Alcohol and Drug Unit (FADU), which now includes the Parent-Child Assistance Program (PCAP). The Division of Alcohol and Substance Abuse (DASA) has voluntarily served as program chair of the Fetal Alcohol Syndrome Interagency Workgroup (FASIAWG), since its inception

The first year, 1995, was spent creating the agreement. Representatives came together to coordinate the different viewpoints of state agencies, professionally run organizations (such as the March of Dimes) and representatives from FASD-specific family-run advocacy groups. The Interagency Agreement was completed and signed on December 28, 1995. In 1996, the FASIAWG reviewed and evaluated the practicality of implementing recommendations made to then Governor Mike Lowry from the Governor's Fetal Alcohol Syndrome Advisory Panel. A four point agenda from this report became the 1997-1999 charter for the FASIAWG:

- Establish an FAS Family Preservation Center.
- Support the FASDPN clinics.
- Support primary prevention efforts by replicating the PCAP, expanding outreach and treatment to women of childbearing age, and disseminating FAS information to college students.
- Provide training to professionals working in the systems of chemical dependency, mental health, developmental disability, vocational rehabilitation, health care, education, juvenile and adult criminal justice, and child welfare.

In the last few years, several organizations and agencies have joined the group, including: Office of Indian Policy and Support Services (IPSS); Governor's Office of Indian Affairs (GOIA); Fetal Alcohol Syndrome Information Services (FASIS); NOFAS Washington State; Valley Cities Counseling and Consultation; Skagit County Youth and Family Services; and the National Chapter of the Federation of Families/Spokane Advocacy Voice for Children with FASD and Mental Health Conditions. The FASIAWG represents a diverse spectrum of agencies and organizations, which provide programs designed for

FASD prevention and/or intervention, and support for individuals with FASD and their families. This network of educational, research, and clinical services responds to the legislative mandate to ensure coordination of identification, prevention, and intervention programs for children who have fetal alcohol spectrum disorders and for women at high risk of having children with fetal alcohol spectrum disorders.

The FASIAWG plans to continue meeting at least twice yearly by phone conference, as well as disseminate information through email and the Washington FASD website at www.fasdwa.org. This is the final annual report of the FASIAWG and the workgroup members will update their agency information at least once yearly on the Washington FASD website.

OVERVIEW FETAL ALCOHOL SPECTRUM DISORDERS PROGRAMS, PROJECTS, AND POLICIES IN WASHINGTON STATE

FASIAWG agencies continue to seek federal, state, and other options for funding. Funding will be used to develop and implement services and programs designed to address the needs of infants, children, adolescents, and adults with FASD and their families. Program design and implementation will result from the coordinated efforts of a team of deeply committed representatives from state agencies, professional organizations and family-run advocacy groups, who are experienced in the treatment and care of people with FASD. Since FASIAWG's inception in 1995, the following multidisciplinary collaborations have been developed between FASIAWG agencies and groups:

- FAS DPN provides diagnostic evaluations of FADU research subjects and clients suspected of having FASD.
- FAS DPN works with the Children Administration (CA) Foster Care Passport Program (FCPP) to screen foster children in King County for FAS.
- FADU contracted with DASA to exchange program data on PCAP and Safe Babies Safe Moms in order to improve process outcomes.
- FAS*FRI and FADU are working together to increase eligibility for individuals with FASD in the disability and mental heath systems.
- FAS and Partial FAS were added to the list of notifiable conditions in 2004. DOH has been working with FAS DPN on identifying which cases to focus in on and how to train providers in the identification and reporting of cases. FAS DPN works with the DOH Birth Defects Surveillance Program on reporting issues.
- FAS DPN, FASIS, and NOFAS Washington are working together to disseminate information to families and professionals on the topics of FASD and effective advocacy.
- FAS DPN and NOFAS Washington are working together to provide families with advocacy and to provide FASD training and education to families and professionals.
- FADU and FAS DPN cooperate to provide annual 3-day training for Native American service providers.
- FAS*FRI has taken the lead with DASA and other FASIAWG agencies and groups to implement statewide FASD conferences.
- FADU contracted with the March of Dimes to develop a program for PCAP mothers with FASD, and FAS*FRI provided training to PCAP staff for this program.
- NOFAS Washington collaborates with the FAS DPN, DASA, and other state and federal agencies to operate an annual FASD Family Summer Camp, FAStFriends family and community support network, an annual Winter Retreat for Families, monthly social skills group for teens affected by prenatal alcohol exposure, quarterly family activities, and parent retreats.
- FAS*FRI continues to work together with DASA, DDD, and MHD to gather information and provide their workforces with sole source training and educational materials based on the FASD Collective Family Experience with the purposes of preventing FASD, reducing secondary disabilities and preserving families raising children with FASD.
- Per FASIAWG workgroup recommendation and the requests of FAS*FRI and Skagit County stakeholders, 2006-2007 supplemental legislative funds were appropriated to expand the University of Washington Parent-Child Assistance Program (PCAP) to Skagit County.

- FAS DPN, FAS*FRI, and NOFAS work with Skagit County Youth and Family Services' FASD Project to provide FASD-specific training within the Juvenile Justice System, adjunctive services systems, and to the Skagit community.
- Carolyn Hartness, Suzie Kuerschner and FAS DPN have collaborated with Skagit County Youth and Family Services' FASD Project to provide FASD-specific training within Tribal Courts, services systems, and to the four Tribal communities represented within Skagit County.
- FAS DPN is working with the Skagit County Youth and Family Services' FASD Project through diagnostic clinic provision and in developing the project's programming.
- The FASIAWG workgroup worked together, with technical assistance from the University of Washington FAS DPN, to develop and implement the Washington State FASD Web site.
- DOH and FAS*FRI collaborated to develop terminology to request that the U.S. Congress mandate the development of diagnostic tests and guidelines for diagnosing the full range of FASD, including ARND. As a result, this charge was given to the Centers for Disease Control and Prevention (CDC), which is currently working on this process.
- GOIA assisted FAS*FRI by writing and distributing a press release about the regional FAS Town Hall Meeting in early 2002 and coordinated Native American representation at the meeting.
- FADU, PCAP, and FASDPN have formed the University of Washington FASD Alliance for the development of collaborative research ideas.
- FAS*FRI has worked to promote the expansion of PCAP to Skagit County and other underserved counties.
- FADU is working in the Seattle area criminal justice system to identify those with FASD and assist the courts in planning for these individuals.
- FAS*FRI collaborated with the Divisions of Alcohol and Substance Abuse, Mental Health, and Developmental Disabilities and the Department of Health to produce and facilitate a parent retreat in August 2005.
- FAS*FRI hosted a legislative reception in collaboration with FADU in the state Capitol in January 2006 and 2007 to increase public and legislative awareness in honor of the success of the PCAP program in preventing FASD by educating, treating and supporting chemically dependent pregnant and parenting women.
- FAS*FRI collaborated with the Children's Administration, the Division of Mental Health and other consumer and family-run advocacy groups to develop a family-friendly screening tool (called the Evidenced-Based Matching Tool). This tool helps to determine which one of five programs in the Children's Mental Health Initiative might benefit youths and their families who are in need of family preservation services. Due to FAS*FRI's involvement, FASD is specifically included in the screening process.
- FAS*FRI is dedicated to leading cutting-edge efforts in collaboration with DASA, MHD, DDD and the Washington State Mental Health Transformation Workgroup to distinguish between FASD and co-occurring conditions. The first consult on this topic is planned for September 24-26, 2007.

Divisions of the Department of Social and Health Services

The **Division of Alcohol and Substance Abuse (DASA)** supports innovative programs that serve individuals and families with FASD. DASA strives to educate key stakeholders regarding the nature of addiction and the recovery process, and to promote understanding of the alcohol and drug use by pregnant and parenting women as a public health issue. A prime opportunity to intervene with substance-abusing women is during pregnancy. Early intervention during the prenatal period increases the likelihood a woman will successfully recover from her substance abuse. Comprehensive programs addressing multiple treatment needs have demonstrated effectiveness; such programs include assertive outreach to engage and treat women prior to the development of problems such as loss of child custody, and case management to coordinate wraparound services. Additional challenges include coordinating treatment with prenatal and other medical appointments, providing childcare for infants and older children, and offering parenting support and training. Length of involvement in both residential and outpatient chemical dependency treatment is associated with better birth outcomes.

DASA has voluntarily served as program chair of the FASIAWG since its inception in 1995, and ensures continued development and implementation of services targeted at identification, prevention, and

intervention with children, adults, and families suffering from this disability. DASA contributes considerable funding to the FASDPN, the Fetal Alcohol and Drug Unit (FADU) at the University of Washington, FAS*FRI, and Iceberg, an educational newsletter for people concerned with FASD.

Health Recovery Services Administration (HRSA) and DASA: A comprehensive program became a reality in January 2000 in Benton/Franklin, Whatcom, and Snohomish Counties. Since January 2000, program sites in these three counties served hundreds of women and their children through the provision of intensive, targeted case management, residential and outpatient chemical dependency treatment services and transitional housing support services. Safe Babies Safe Moms (formerly known as the Comprehensive Program Evaluation Project or CPEP) is a program designed to meet the needs of pregnant or parenting substance abusing women with children under the age of three. The goal of the Safe Babies Safe Moms program is to stabilize women and their young children, identify and provide necessary interventions, and assist women as they transition from public assistance to employment and greater self-sufficiency. Safe Babies Safe Moms seeks to improve the health and welfare of substance abusing mothers and their young children through early identification of pregnant substance abusers, improved access to health care coordinated with chemical dependency treatment, and family-focused early interventions services for mothers and children. Pregnant and parenting women are offered a variety of services including targeted intensive case management, a continuum of residential and outpatient chemical dependency treatment services, transitional housing, behavioral health services, child development screening and activities, parenting education and family planning. The project is a collaborative effort between the Department of Social and Health Services (DSHS) - DASA, HRSA, Economic Services Administration (ESA), Research and Data Analysis (RDA), Children's Administration (CA), and DOH. Early outcomes (January 2004) of the women and families involved in Safe Babies Save Moms include:

- The low birth weight rate for infants born after program entry decreased by 66%, compared to those born before program entry.
- The rate of accepted CPS referrals during the first year of life decreased by 35% for infants whose mothers enrolled in Safe Babies Safe Moms before delivery compared to those enrolled after delivery.
- Criminal justice involvement of Safe Babies Safe Moms clients is extensive, with an average of 1.5 arrests per woman in the two years before program entry. A decrease of more than 50% in the arrest rate was observed for clients with chemical dependency treatment.
- Two-thirds of Safe Babies Safe Moms clients (67.5%) received at least one Medicaid-paid family planning method in the year after enrollment. At one year follow-up, one-third (34%) received non-reversible or more effective methods.

The **Division of Developmental Disabilities** (**DDD**) The Division of Developmental Disabilities (DDD) has approximately 32,000 adult and children enrolled as eligible clients. To be a client of DDD requires a determination of eligibility per RCW 71A.10.020(3) and, as of July 1, 2005, WAC 388-823. RCW defines developmental disability as mental retardation, cerebral palsy, autism, epilepsy, another neurological or other condition similar to mental retardation or requiring the same treatment. The condition must originate before age 18, be expected to continue indefinitely, and result in substantial limitations. WAC 388-823 defines the diagnostic criteria and other evidence required to meet both the definition of an eligible condition and a substantial limitation. Children under age 10 may be eligible under "other condition" without a specific diagnosis if there is evidence of developmental delays. Children under age three need one developmental delay to quality for child development services through DDD and/or Individuals with Disabilities Education Act (IDEA), Part C. Children with FAS may quality at age six or older with a diagnosis of Mental Retardation. A Full Scale IQ of less than 70 will quality under Mental Retardation. Children or adults with a diagnosis of FAS and an IQ of 70 or higher may quality under "Other condition" if there is evidence of academic delays and a qualifying score in a Vineland Adaptive Behavioral Scale (VABS), Scales of Independent Behavior - Revised (SIB-R), or Inventory for Client and Agency Planning (ICAP). Being determined eligible for DDD does not guarantee paid services. Access to paid services is determined by an assessment, eligibility for the service, and available funding, unless the service is Medicaid Personal Care or the person is currently a Waiver recipient. DDD provides in-

home supports; out-of-home residential services; employment programs for adults; family support services; Medicaid personal care; therapies; Home and Community Based Waiver services.

Children's Administration (CA) provides comprehensive services to protect approximately 12,500 children from abuse and neglect in any given month. Alcohol and substance abuse is a major risk factor impacting at least two thirds of the families served.

Within CA, the Office of Foster Care Licensing has developed an award winning series of videos to provide education and prevention on FAS entitled, "Journey through the Healing Circle." The series employs a Native American format using animal characters to explain the effects of alcohol on behavior. The four videos are age-specific and weave the issues of guilt, support group, foster care, adoption, cross-cultural placements, peer impact, lack of attention, behavior principles, etc., into stories about animals of the forest. The first video "Little Fox" has won the Emerald City award for outstanding video; the Neil Shipman award for editing; and the prestigious "Telly" for excellence in video production. National and international inquiries and requests for copies have been received. This video series has also been nominated for an Emmy. In August 2002, the series was compacted for the use of public television stations. To date, it has aired on stations throughout Washington, Alaska and several Canadian provinces.

Additionally, the CA Foster Parent Training Program has posted a workshop on its training website (http://www1.dshs.wa.gov/ca/fosterparents/index.asp) that allows foster parents to receive training from the convenience of their homes. The presenters are Carolyn Hartness (co-author of "Journey Through the Healing Circle") and Julie Gelo, foster and adoptive parent of 6 children with Fetal Alcohol Syndrome.

CA Region 4 continues to collaborate with the UW FAS DPN to provide photographic screening for children in out-of-home placement within the Foster Care Passport Program (FCPP). Children referred to the UW FAS DPN have all results and recommendations incorporated into their Passport information. Possibilities for expansion of this model to other areas of the state are being explored.

In 2004, the Children's Administration began a joint DASA/CA Substance Abuse Services Initiative. A Memorandum of Understanding guides the Initiative between the two agencies. A number of changes are underway because of the Initiative, including screening families for substance abuse problems, better coordination between the treatment field and the child welfare system, and focus on the damage done to children by parental substance abuse and alcohol abuse.

The Children's Administration, as part of the Child and Family Services Review done by the Feds in 2004, has developed strategies for addressing the well-being of children in foster care. All children in foster care 30 days or longer will receive a initial health screening as part of the Child Health and Education Tracking (CHET) program. The CHET program helps to identify a child's on-going needs in five "domains" - physical and dental health, emotional behavioral health, education, developmental and connections the child has with their community (i.e. family, peers, and organizations). Children identified as having unaddressed issues such as FAS/E will be forwarded to a public health nurse (formerly Passport Nurse) assigned to CA to gather a comprehensive health history and recommend referrals to be made by the child's social worker to appropriate treatment services.

Office of Superintendent of Public Instruction

The **Office of Superintendent of Public Instruction (OSPI)** is the state office of kindergarten-12th grade public education. The agency's association with the Fetal Alcohol Syndrome Interagency Work Group in the past has been dissemination of prevention information.

Three materials are available from OSPI:

- *Educating Children Prenatally Exposed to Alcohol and Other Drugs* sponsored by Washington State Legislature, Fetal Alcohol and Drug Unit- University of Washington
- Department of Social and Health Services set of four CDs of stories portraying animals with FAS and their challenges

- *The Little Fox* birth-5 year olds
- *The Little Mask* 6-11 year olds
- *Sees No Danger and Wanders Afar* 12-17 year olds
- *Travels in Circles* 18-22 year olds

- *The Washington State Fetal Alcohol Resource Tools for Prevention and Information Guide* produced by Comprehensive Health Education Foundation

The plan for OSPI's involvement with FASIAWG is to make connections with other agencies and events that promote awareness and instructional information about children with FASD in school systems.

Department of Health

Department of Health (DOH) Maternal and Child Health (MCH) Office's mission is to promote a community that supports the health of women, especially pregnant women, infants, children, adolescents, and children with special health care needs. MCH recognizes that substance abuse during pregnancy has a major impact on the health outcomes for both mothers and babies.

DOH/HRSA has contributed to the following legislative, preventive education, capacity building, research, and technical assistance efforts in the area of FAS from 1998 – 2004.

Legislation:
HB 3103: An act relating to prenatal screening for exposure to drugs (including alcohol) was passed and signed into law by Governor Gary Locke in early 1998. As a result, DOH was directed to:

- Develop screening criteria for identifying pregnant and lactating women at risk of producing a drug affected baby;
- Develop training protocols for medical professionals related to the identification and screening of women at risk of producing a drug-affected baby;
- Investigate the feasibility of developing medical protocols for laboratory testing or other screening of newborn infants for exposure to alcohol and drugs.

A summary of these efforts is described in the HB 3103 report, which was completed in January 1999.

RCW 13.34.803: Required DOH and the DSHS to design a comprehensive program for Medicaid eligible women who gave birth to a drug or alcohol exposed infant. A report "A Comprehensive Program for Alcohol and Drug Abusing Mothers and their Young Children" was completed in January 1999. DOH continues to participate at the state and local level in the implementation and evaluation of Safe Babies, Safe Moms Project.

Education:
Public Health, Seattle-King County provides FAS education to health care professionals, social service professionals, and other who work with children and adults affected by alcohol in utero. DOH facilitated the production of Carolyn Hartness' *FAS Train the Trainers* curriculum, through a CDC cooperative agreement, which continues to be distributed, as well as posted on the Washington State Department of Health, Genetic Services Section website: http://mchneighborhood.ichp.edu/wagenetics/index.html. Annually, DOH distributes approximately 5,000 FAS Prevention Brochures to individuals requesting information on pregnancy through Within Reach (formerly *Healthy Mothers Healthy Babies).*

Quality Improvement
DOH continues to work to establish universal screening by interview, observation and self-report as the standard of prenatal/postpartum care in Washington State. Additionally, DOH seeks to improve provider screening skill and effectiveness, and increase the number of women identified and women who enter treatment. These goals are being addressed by the Maternity Support Service Program, development and dissemination of best practice materials and collaboration with the Comprehensive Pilot Programs for Drug and Alcohol using Women and their Children, (Safe Babies, Safe Moms).

Perinatal programs outreach and education activities: 2000-2004**:** Funding of $170,000.00 per year was divided among the four Regional Perinatal Programs to provide professional education and training to prenatal care providers with an emphasis on physicians, nurse practitioners, and midwives. The Regional Perinatal Programs used a variety of approaches such as conferences, professional educational website, grand rounds, hospital and residency program in-services, and individual OB practice office educational sessions to provide the training. Trainers used the best practice materials developed by DOH. Total health care professionals trained January 2000 – June 2004: 5462. Of this number, 1217 were physicians and midwives. This is approx. 61% of providers who deliver babies in Washington State. This program ended June 2004.

DOH continues to update and disseminate several professional educational materials related to substance abuse during pregnancy. These include clinician pocket cards with screening questions on the front and referral information on the back, and a best practice guide, "Substance Abuse During Pregnancy: Guidelines for Screening". The best practice guide includes information on skill building techniques, testing consent issues, basic prenatal management, new programs, and other resources. Distribution includes dissemination to OB providers, other health care professionals at First Steps trainings and regional meetings and MCH Local Health Jurisdiction regional meetings. Professional materials are available in hard copy or electronically from the DOH website and are included in DOH exhibits at professional meetings and conferences: Washington State Obstetrical Association, Reproductive Health Update, Primary Care Update, Washington Academy of Family Physicians, and others. These materials were developed with input from DSHS, Perinatal Advisory Committee, and other community experts. In 2007, DOH disseminated "Drinking and Reproductive Health: A Fetal Alcohol Spectrum Disorders Prevention Tool Kit to MSS staff and obstetric providers. This tool kit is a continuing medical education activity sponsored by the American College of Obstetricians and Gynecologists.

DOH continues to monitor alcohol use and provider screening for alcohol use during pregnancy using the Pregnancy Risk Monitoring Surveillance System (PRAMS) data. PRAMS is a on-going population based surveillance system sponsored by CDC that surveys new mothers who are representative of all registered births to WA State residents. WA DOH collecting PRAMS since 1993. More info: www.doh.wa.gov/cfh/prams.

Family Support
DOH provides several direct supports to families and individuals, including those affected by FASD. DOH supports public health nursing visits to extremely high-risk families to provide parenting education and information on infant development, facilitate referrals, and provide parental support. DOH supports adolescent development programs for at-risk youth, which include peer support groups, art, sports and career development activities, and parent education. DOH supports a system of Regional Genetic Clinics where at-risk individuals can be assessed and diagnosed. DOH supports the Family Health Hotline, formerly *Healthy Mothers, Healthy Babies Hotline,* which provides referral information for families, including the *ASK Line* that directs families to specific resources for children with special health care needs, such as the Children with Special Health Care Needs coordinators in each county and Parent-to-Parent of Washington. Families affected by alcohol related birth defects have access to and can receive these services.

Technical Assistance: Technical assistance is provided to the Solutions Workgroup, a committee who is proactive in their advocacy for women and children's services. DOH staff attends FASIAWG meetings and actively participates in coordinating efforts among state agencies involved in providing services for individuals who have FASD.

The department works with key professional organizations to develop and maintain this standard of care, identifies, and works with physicians who are interested in this area and will work to change peer practice.

FAS and ARBD were added to the list of notifiable conditions in 2004. DOH has been working with FAS DPN on identifying which cases to focus in on and how to train providers in the identification and reporting of cases.

Department of Corrections

Alcohol and substance abuse is a major factor in the criminality of women and impacts approximately 80-85% of all women in the criminal justice system. The **Department of Corrections (DOC)** houses approximately 1,340 women offenders at three facilities in Washington – Washington Correction Center for Women at Gig Harbor, Mission Creek Correction Center for Women at Belfair, and Pine Lodge Correction Center for Women at Medical Lake. At the correction center in Gig Harbor the DOC manages a Residential Parenting Program for eligible offenders who will give birth during the term of their incarceration. These women can keep their child with them for 30 months whenever the mother reaches the end of her sentence, whichever comes first.

At this time there are no educational services offered to these and countless other incarcerated women who are of child-bearing age and are unaware of the consequences of alcohol use on their unborn child.

The DOC is currently in the planning stages of providing the opportunity to offer FASD education to women offenders and the professional staff that work directly with them.

Governor's Office of Indian Affairs

The **Governor's Office of Indian Affairs** (**GOIA**), recognizing the importance of sovereignty and affirming the government-to-government relationship and principles identified in the Centennial Accord, has lead several activities that have promoted FASD awareness and prevention among the 29 federally recognized tribes.

In addition to staffing the Fetal Alcohol Syndrome Inter-Agency Workgroup (FASIWG), in the past, GOIA has been funded by the Division of Alcohol and Substance Abuse to provide one-day FAS training for each tribe in the state. GOIA has contracted Carolyn Hartness, Eastern Band Cherokee, a well-known consultant and trainer, to provide the training. She is also working with the Northwest Portland Area Indian Health Board and GOIA on the Northwest Tribal Fetal Alcohol Syndrome Project.

In June 2001, GOIA held a two-day conference for Native Americans on FAS at Daybreak Star in Seattle. Last fall, GOIA drafted a proclamation that was signed by Governor Gary Locke declaring September "Fetal Alcohol Syndrome Awareness Month." The proclamation, and accompanying press release, stated "prevention and treatment of FAS requires development of collaborative relationships between courts, schools, vocational centers, therapeutic childcare centers, health care providers, researchers, and local, tribal and state agencies."

GOIA assisted the FAS Family Resource Institute by writing and distributing a press release about the Regional FAS Town Hall Meeting, and coordinating Native American representation. In April 2002, the agency dedicated an entire page about FAS in Indian Country in its inaugural edition of "The Talking Stick" newspaper.

Schools within the University of Washington

The **Fetal Alcohol Syndrome Diagnostic and Prevention Network, (FASDPN)** is a statewide network of five interdisciplinary clinical sites, (located in Spokane, Yakima, Pullman, Federal Way, and Everett), with a core clinical/research/training site located at the Center on Human Development and Disability at the University of Washington (UW) in Seattle. Susan J. Astley, Ph.D., Professor of Epidemiology in the School of Public Health and Community Medicine, serves as the Director of the FAS DPN. The FAS DPN originated as a single FAS Clinic at the UW in 1993, and was sponsored by the Center for Disease Control and Prevention (CDC). Statewide demand for clinical services rapidly exceeded the capacity of the clinic. In 1995, through SSB 5688 and the private foundation support of the March of Dimes, the single clinic was expanded into a statewide network of clinics named the FAS DPN. An overview of the efforts and accomplishments of the FAS DPN clinical/research/training program over the past 30 years can be found on its website (http://depts.washington.edu/fasdpn).

Website: www.fasdpn.org

The mission of FAS DPN is to:

- Provide diagnostic and treatment referral services to individuals of all ages with fetal alcohol exposure;
- Conduct FAS screening and surveillance of high-risk populations;
- Identify and refer high risk women to primary prevention and intervention programs;
- Provide FASD training and education to professionals worldwide;
- Create state-of-the-art screening, diagnostic and surveillance tools, and
- Conduct research that will advance FASD diagnostic, intervention and prevention efforts.

Accomplishments to date include:

(1981-1991) Laboratory-based research documenting the teratogenicity of prenatal alcohol exposure.

(1992) Creation of the first interdisciplinary FASD Diagnostic Clinic at the University of Washington.

(1995) Expansion of the University of Washington FAS Clinic into a statewide network of clinics (Washington State FAS Diagnostic & Prevention Network). This interdisciplinary model for diagnosis of FASD using the FASD 4-Digit Diagnostic Code has been replicated worldwide.

(1997) Creation of the Diagnostic Guide for FASD: The 4-Digit Diagnostic Code. This comprehensive method of diagnosis is used worldwide. Over 500 copies of the Guide are downloaded monthly from the FAS DPN website.

(1998) Creation of FAS Facial Photographic Analysis Software for accurately screening and diagnosing the facial features of FAS. This software is distributed at cost to clinics worldwide.

(1998) Establishment of interdisciplinary FASD training programs that have:
- Trained several thousand Washington State medical, social service, and educational providers and,
- Trained over 80 FAS DPN multidisciplinary clinical teams across the U.S. and Canada.

(1999) Establishment of the King County Foster Care FAS Screening/Diagnostic/Surveillance Program that has screened over 2,000 children in King County Foster Care. The program has confirmed:
- The prevalence of FAS is 10-15 times higher in King County foster care than in the general population and,
- The prevalence of FAS has declined significantly from 1993-98 with the significant decline in maternal drinking during pregnancy from 1993-1998 documented by Washington State PRAMS data.

(2004) Creation of an Online Course to instruct professionals on how to screen and diagnose FASD using the 4-Digit Code. This course provides training accreditation for professionals worldwide.

Creation of a clinical research database of over 2,000 patients with FASD. This database has supported over 15 years of clinical research by the FAS DPN including the following major projects.

(1992-97) An FAS prevention study, sponsored by the Centers for Disease Control (CDC), involved 80 women who had given birth to a child with FAS in Washington State. This study established the first ever lifetime profile of women who give birth to children with FAS, and

identified factors that enhanced and hindered their ability to successfully achieve abstinence and engage in effective family planning.

(2001-05) Two FASD intervention studies, sponsored by the Centers for Disease Control (CDC), that tested the effectiveness of 1) a home-based, 9-month, behavioral consultation intervention for families raising children with FASD & behavior problems and 2) a social communication intervention targeted to children with FASD in a classroom setting. The behavioral consultation intervention documented significant improvement in parenting sense of competence and a significant reduction in child disruptive behavior. The social communication study established an accurate method for documenting child behavior in a natural setting (the child's classroom) and documented significant impairment in social communication skills among children with FASD. Both of these studies provided free assessment and intervention to over 70 children with FASD and their families in Washington State.

(2002-06) A study, sponsored by the National Institute of Alcohol Abuse and Alcoholism (NIAAA), that assessed the diagnostic value of magnetic resonance imaging (MRI) to evaluate brain structure, chemistry, and function in individuals damaged by prenatal alcohol exposure. Eighty children were enrolled in the study (60 with FASD and 20 children with normal development and no alcohol exposure). This study documented significant structural, chemical, and functional impairment in the children with FASD. The National Institutes of Health are currently establishing developmental norms from birth to 18 years for brain structure, chemistry, and function as measured by MRI. With these norms, MR technology will greatly enhance the accuracy of FASD diagnostic evaluations. This study provided free comprehensive psychological evaluations and MRI exams for 80 children in Washington State.

(2005-10) The FASD Behavioral Consultation Intervention, originally funded by the CDC in 2001-2005, has received additional funding to integrate this intervention into the community continuum of care, and evaluate its efficacy. The proposed project will systematically adapt, implement, and test this evidence-based intervention based within a collaborating community agency (Institute of Family Development) that has capacity as a future training center. This study will provide free intervention for the families of 30 children with FASD.

The **Fetal Alcohol and Drug Unit (FADU)** is a research unit at the University of Washington, Department of Psychiatry and Behavioral Sciences. Dedicated to the prevention, intervention, and treatment of Fetal Alcohol Spectrum Disorders (FASD), it was founded in 1974 by Professor Ann Streissguth, Ph.D., and is now under the directorship of Associate Professor Therese Grant, Ph.D. The diverse staff of over forty individuals includes faculty, professional and classified staff, students, volunteers, visiting scholars, and consultants. FADU's work has focused on research to identify and examine the effects of prenatal alcohol and drug exposure across the life span, and on interventions with high-risk mothers who abuse alcohol and drugs. The unit provides staffing and curricula for workshops and trainings, invited lectures, and conferences on FASD at the local, regional, national and international level. The FADU website has received over 225,000 hits since 1998: http://depts.washington.edu/fadu.

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) has funded FADU since 1974 to conduct the "Seattle Longitudinal Prospective Study on Alcohol and Pregnancy" under the direction of Ann Streissguth, Ph.D. Currently, the study is analyzing data from the exams of 500 subjects collected at 25 years of age. Findings from the 25-year exam and earlier exams continue to show long-term effects from prenatal alcohol exposure. This study won a Merit Award from National Institutes of Health (NIH), and in 2004, a new 5-year component was funded to interview the subjects at 30 years of age; data collection is ongoing.

In 1979, the NIAAA funded FADU to run a two-year demonstration program to intervene in female alcohol abuse during pregnancy and prevent fetal alcohol syndrome. Important changes in public awareness and professional knowledge about alcohol and pregnancy were documented with pre/post community surveys of citizens and professionals; procedures were developed and initiated at several maternity

centers to screen for high risk pregnant women; 340 pregnant women with concerns about their drinking were served; and 151 children exposed to alcohol in utero were evaluated psychologically and referred for appropriate services.

Since 1983, the Indian Health Service has funded FADU to provide prevention, intervention, and research strategies and trainings on FASD to Native American service providers and communities. A manual on adolescents and adults with FASD with special reference to American Indians was produced and over 32,000 copies were distributed.

In 1991, FADU was funded by SAMHSA's Center for Substance Abuse Prevention (CSAP) to conduct a research demonstration project, the Parent-Child Assistance Program (PCAP), to test the efficacy of long-term home visitation/case management intervention for mothers who abuse alcohol and drugs during pregnancy. Therese Grant, Ph.D. has directed PCAP since its inception. The aim of the program is to prevent future births of alcohol and/or drug exposed births, and to help mothers build healthy, independent lives. The program is now funded through state legislative appropriation, with sites in 7 counties and a capacity to serve 540 families. The model has been implemented in Minnesota, Alaska, North Carolina, Texas, Nevada, Louisiana, Pennsylvania and in provinces funded by 'Health Canada.' PCAP has been awarded national recognition and outcomes have been published.

In 1992, the CDC funded FADU to study secondary disabilities associated with FASD, to determine risk and protective factors and to make recommendations for prevention and treatment. The four-year study culminated in an international conference and over 25,000 copies of the final report have been distributed. Study findings continue to inform public policy on prevention and treatment. In August 2004, the Journal of Developmental & Behavioral Pediatrics published an article describing two significant protective factors against the adverse life outcomes the study documented: 1) being raised in a stable, good quality home, and 2) having an early diagnosis of FASD.

In 1996, FADU began another NIAAA study to measure and study the association between neuroanatomic and neuropsychologic abnormalities in people FASD. Magnetic Resonance Imaging and neuropsychological testing were conducted on 180 subjects. Findings indicate striking differences in corpus callosum shape between exposed and unexposed brains and these differences correspond to specific neuropsychological deficits. In 2003, a continuation of this study began to examine other parts of the brain, including the cerebellum, and to develop a diagnostic protocol based on all of the imaging and behavior data.

In 2001, the FAS/FAE Legal Issues Resource Center was established at FADU with Kay Kelly as the Project Director. Funding by the Robert Wood Johnson Foundation began in January of 2003 with Dr. Ann Streissguth and Professor Eric Schnapper of the UW School of Law as Co-Principal Investigators. The grant was awarded to analyze the public policy questions raised by FASD legal issues. This included the development of a Legal Issues Web site within the FADU Web site. State and federal cases in which FASD was a factor have been summarized, their relevant legal issues identified, and the cases then categorized for quick access to case law by judges, attorneys, and others. Articles on FASD and criminal and juvenile justice, sexual deviancy, social security, and dependency issues are also included. The URL is: http://depts.washington.edu/fadu/legalissues/.

In 2001, FADU conducted a CSAP-sponsored research project, under the direction of Therese Grant, Ph.D., to screen postpartum women for alcohol use during pregnancy. A total of 3,142 women were screened at two major hospitals in Seattle and Tacoma. We used this data, along with data from two earlier FADU studies, to examine pregnancy alcohol use trends from 1989 through 2004. We found a substantial decrease in any alcohol use during pregnancy between 1989 and 2004 (from 30% to 12%), across all age, race, education, marital, parity, and smoking status categories. Pregnancy binge drinking rates were low (3% or less). Any alcohol use in the month before pregnancy changed little over the study years (slightly over 40%), but binge drinking in the month prior increased somewhat (9% to 14%). .

In 2001, FADU was funded by the March of Dimes to conduct a one-year pilot project under the direction of Therese Grant, Ph.D., to study the special problems and needs of 19 women who themselves have

FASD. Results indicate these women have high levels of psychiatric distress and behavioral problems, and poorer quality of life relative to other at-risk populations. The study also demonstrated a method for educating providers and providing individualized intervention resulting in clinically relevant outcomes. Two papers were published based on findings from the study.

In 2001, PCAP and Community Psychiatric Clinic (CPC) partnered to develop transitional housing for high-risk families. Over $3 million in funding was secured to build a new housing facility in south King County (The Willows) for 15 PCAP mothers and their children. This is the first such facility in the Seattle/King County area serving some of the region's most vulnerable citizens: single mothers with children, who have co-occurring disorders of mental illness and substance abuse. The Willows opened in May 2005, and is owned and operated by CPC with PCAP serving as a referral source and providing case management services to support residents.

In 2002, FADU was funded by NIAAA to conduct a research grant under the direction of Paul Connor, Ph.D., to investigate abnormalities in brain activity in 48 research subjects (FAS, FAE, and controls) using functional magnetic resonance imaging (fMRI). Preliminary findings were reported at the International Neuropsychological Society and National Academy of Neuropsychology annual meetings. Findings indicate that subjects with FAS/FAE demonstrate reduced brain activation relative to control subjects in brain regions associated with arithmetic functioning, working memory, and bilateral motor coordination.

In 2003, Ann Streissguth led a group of FADU scientists joining an NIAAA-sponsored colloquium for collaborative studies on FASD. Our component studied the possible use for FASD diagnosis of neonatal brain ultrasound, a standard clinical imaging mode hitherto used mainly for investigating the effects of prematurity on the baby brain. We found a very strong signal of prenatal alcohol damage, a specific deformity of the corpus callosum, in half of all the high-exposed babies that was not present in any of the unexposed babies whose images we measured. Our finding has appeared in two peer-reviewed publications and forms the basis of a proposal for extension to larger infant groups and to other drug exposures that is currently under review by NIH.

In October 2004, the Northrop Grumman FASD Center for Excellence awarded a ten-month subcontract to FADU with Dr. Ann Streissguth as Project Director and Kay Kelly as Project Manager. The initial year of the subcontract was used to plan the project to work within the Seattle-area criminal justice system to raise awareness of FASD, help the agencies identify this disability within their caseloads, and create more effective programming for those with FASD who are in trouble with the law. The planning year concluded on July 15, 2005, and the first of four implementation years began August 26, 2005. An advisory committee guides the project with Dr. Ann Streissguth and the Honorable Anthony Wartnik as Co-Chairs. Professor Eric Schnapper of the UW School of Law is the Legal Consultant. Kay Kelly is the Project Director for the implementation years.

In 2006, FADU was funded by SAMHSA to conduct a 3-year research grant under the direction of Therese Grant, Ph.D. The project, a partnership between the Parent-Child Assistance Program (PCAP) and the UW Center on Infant Mental Health and Development (CIMHD), pilots an innovative infant/mother mental health intervention with mothers who used methamphetamines during pregnancy and their children. The pilot will compare outcomes from the enhanced intervention group (N=40 infant/mother pairs) with data from a comparison group that receives standard PCAP intervention alone.

Fetal Alcohol Syndrome Family Resource Institute (FAS*FRI)

The **FAS Family Resource Institute (FAS*FRI)** is a non-profit educational 501 (C) 3 organization, which began in 1990, when Program Managers for the Washington State Adoption Support Program helped frustrated parents organize and gather the "Collective Family Experience" on behaviors observed in children and adolescents with FASD. Counselors and therapists, who were trying to help preserve families raising affected children, had read the scientific literature on FAS. But they still could not understand the core behavior traits of the disability, especially when the IQs of the affected individuals were in the normal range. FAS*FRI is a family-run organization; in fact, over 75 percent of its Board of Directors are either adults with an FASD or are birth, foster, step, adoptive or grandparents who have

raised at least one affected child. The programs and policies are based on the perspective that each child disabled by prenatal alcohol exposure is like an innocent snowflake. There is nothing more beautiful and fragile than this innocence; but nothing is more tragic than innocence betrayed by the public's lack of knowledge and fear. Therefore, in defense of innocence, it is the mission of FAS*FRI to help others identify, understand and care for children with FASD and their families and to prevent future generations from having to live with this disability.

When FAS*FRI was founded in the early 1990's, even the medical doctors who diagnosed FAS did not know what to tell parents about how to raise their children. As adoptions failed, children were being returned to foster care and/or families were being forced to relinquish custody of their children (many of whom had undiagnosed FASD and co-occurring conditions) in order to access residential treatment. Consequently, the foundational activity of FAS*FRI was to gather information and the wisdom of practice from parents of diagnosed children through personal interviews, surveys, and working retreats. This information was analyzed, organized and integrated with scientific data, which produced practical educational materials and seminars to fill the experience-based void in the field. As new stages of raising affected children came and new issues were discovered, FAS*FRI added to their body of knowledge. Once they identified what most families with diagnosed children were experiencing, they were able to begin serving as mentors for other parents, advisors to public policy makers and educators for professionals. The result of this ongoing effort is a sole source body of knowledge, the Collective Family Experience. FAS*FRI offers many sole source educational materials, trainings and programs, all based on the FASD Collective Family Experience.

In 1995, the Division of Alcohol and Substance Abuse (DASA) recognized the validity and importance of FAS*FRI's sole source information and began funding three of their products:

- *FAS Times*, a quarterly newsletter (circulation approx. 2,500) and other educational materials.
- Professional development seminars on FASD.
- Toll-free information, mentoring and referral phone line (800-999-3429).

Additional products and activities which FAS*FRI offers mostly on a volunteer basis are:

- Experienced-based mentoring for affected individuals, families and the professionals who serve them.
- Public advocacy (representing affected individuals and their families in public forums).
- Individual advocacy and representation to access appropriate services in all relevant systems of care.
- A Birth Mom Mentor Program.
- Website: wwww.fetalalcoholsyndrome.org.

In the last few years, the FASD Collective Family Experience (based on data and information gathered by FAS*FRI since1990) has been recognized and printed in the following publications.

- Early Childhood Neurobehavioral Assessment for the Differential Diagnosis of Fetal Alcohol Syndrome and Alcohol-Related Neurodevelopmental Disorder, a monograph of a meeting held in March 2000, sponsored by The Interagency Committee on Fetal Alcohol Syndrome and The National Institutes of Health (NIH) including the National Institute on Alcohol Abuse and Alcoholism (NIAAA) - article entitled, "Observations from the Collective Family Experience."
- *Addiction Biology* 2004. a scientific research journal - article entitled, "Fetal Alcohol Syndrome through the Eyes of Parents."
- *FAS Guidelines for Referral and Diagnosis* published by the Centers for Disease Control and Prevention (CDC) in 2004, pp. 13-20.

Since its origin in the early 1990's through June 2007, FAS*FRI has trained approximately 18,832 professionals and parents and handled over 35,243 (phone and internet) contacts for FASD information, referral, and mentoring. In addition, parent presenters trained by FAS*FRI have educated over 35,000 high school students with an FASD prevention program. In the same time period, FAS*FRI has developed and distributed over 97,000 copies of FASD-specific prevention, public awareness, and intervention brochures and over 5,580 copies of their four educational books.

In 2002-2003, FAS*FRI conducted twelve U.S. regional town hall meetings on FASD (including one in Washington State) and six U.S. regional seminars for the federally-funded (SAMHSA) FASD Center for Excellence. An additional town hall meeting and a seminar were conducted in 2004 as a result of a collaboration between FAS*FRI and the Centers for Disease Control and Prevention (CDC). As a result of those meetings held across the United States, FAS*FRI staff identified other family-run groups who were providing FASD advocacy, education, mentoring and support to affected individuals and their families. Noting that the family-run groups were the most helpful intervention mentioned in the parent testimonies at the Town Hall Meetings, FAS*FRI recognized the need to preserve their work, creativity and wisdom of experience. So they formed a collaboration of these groups, called the National Family Leadership Council, to provide a nation-wide public policy voice from the Collective Family Experience on FASD.

In the past fiscal year (2006-2007), FAS*FRI efforts have centered around creating an ever increasing public awareness presence among the state disability, mental health and substance abuse workforce on the necessity of identifying and diagnosing children and adults with FAS/ARND and co-occurring conditions. Major activities for this year included the following.

- Collaborated with the Governor's Mental Health Transformation Project and the Divisions of Alcohol and Substance Abuse, Mental Health, and Developmental Disabilities to plan and conduct the first ever consult on Separating FASD and Co-occurring Conditions (scheduled for September 2007). The product of the event will be a set of recommendations to present to the Governor's Mental Health Transformation Project.
- Distributed over 260 copies of Nurture: The Essence of Intervention for Individuals with FAS (photo book) 120 copies of Cheers! Here's to the Baby: A Birth Mom's Discovery of FAS. (Both books, written and produced by FAS*FRI, are unique to the field.)
- Distributed 355 posters for public awareness that not all individuals with FASD have the facial features of the full syndrome,
- Continued participation as a member of the Governor's workgroup to assess and transform the way mental health services are delivered in the state of Washington
- Distributed an FASD public service announcement for TV and radio that was recorded by Governor Gregoire.
- Continued collaboration with Dr. Glena Andrews at Northwest Nazarene University on the FASD Behavior Screening Tool (BeST) to field test it. It is now available online (www.nnu.edu/psych-research/) for use with children ages five through adults who have do not have the facial dysmorphology of FAS.

Fetal Alcohol Syndrome Information Services

The **Fetal Alcohol Syndrome Information Service (FASIS)** of Washington State will be publishing four issues of the newsletter ICEBERG this year. FASIS will be soliciting articles from around the world in an attempt to highlight the newest research results and the discovery of best practices leading to successful outcomes for individuals impacted by FASD and their families. Our board of directors will continue to edit by consensus with an emphasis on being accurate to the best of our ability.

ICEBERG was founded in 1991 by a group of parents and professionals in the Puget Sound area. To our knowledge, it was the first newsletter in the world devoted to FASD. The first parent support group in the United States was organized through a notice in the first ICEBERG, followed by a very well attended first meeting. The ICEBERG shares "how to's" for getting these groups started all over the country. We formed FASIS as a non-profit corporation to support the printing of ICEBERG, and we printed four volumes a year, mailing them around the United States and internationally on a subscription basis. At one time, we have well over a thousand subscriptions, with individuals asking for more and more information.

FASIS will continue attempting to reach more individuals by publishing a bookmark to be distributed at conferences and other places where FASD is a topic for consideration. This bookmark will include some basic information about FASD along with information about how to find the ICEBERG on the internet. We are also working toward making the ICEBERG an audio as well as a visual newsletter and continuing to

make sure that it is linked to as many other websites as possible. You can find the ICEBERG at http://fasiceberg.org/newsletter.htm.

NOFAS Washington/FASt Friends

The National Organization on Fetal Alcohol Syndrome Washington State (NOFAS WA), a nonprofit 501 (c) (3), is an alliance of families and professionals supporting individuals with Fetal Alcohol Spectrum Disorders, the families that care for them, and the systems that serve them, through prevention, education, intervention and advocacy.

NOFAS WA is the Washington State affiliate to the National Organization on Fetal Alcohol Syndrome. The volunteer Board of Directors that oversees this agency reflects the diverse population affected by FASD and includes; adoptive parents, birth mothers, a young adult with FASD, educators, researchers, a physician, a registered nurse, social workers and other community members.

NOFAS WA programs provide support, education, advocacy, and training on FASD. FASt Friends a program of NOFAS Washington provides a support network that includes quarterly planned family activities, a monthly support group in Everett for families and professionals, and a social skills group for teens affected by prenatal alcohol exposure. Volunteer psychologists experienced in the field of FASD facilitate the teen social skills group. In collaboration with the University of Washington Master's Degree Program of Occupational Therapy NOFAS Washington has developed and implemented a model for a friendship/social skills group for elementary-aged children who have been diagnosed with FASD. NOFAS WA also sponsors a list serve that provides a mechanism for daily education and support to families and professionals across the state of Washington, as well as having members from other states and Canada. Other on-going programs include an annual FASD Family Summer Camp and an annual FASD Family Winter Retreat. The Everett FAS Diagnostic Clinic is a program of NOFAS WA. All NOFAS WA programs and activities focus on strengthening and empowering children and families and increasing their capacity to succeed.

NOFAS Washington State works collaboratively with a number of local, state, and federal agencies to maximize their resources and increase their ability to provide new and innovative programs. The success of this agency is due largely to the cooperative relationship that has been established between NOFAS WA, families of children affected by FASD, the FAS DPN, FADU, DASA, Volunteers of America, Little Red School House/Children's Village, Substance Abuse and Mental Health Services Administration (SAMHSA), and the National Organization on Fetal Alcohol Syndrome and the FASD Center for Excellence. NOFAS Washington programs model the effectiveness of families and professionals working together.

NOFAS Washington is a project partner in the Families Moving Forward Project (FMF) which is an intervention research project exploring evidence-based services for children with fetal alcohol spectrum disorders (FASDs), their families, and the professionals who care for them. This is an intervention research design and model being conducted with collaboration between Center for Disease Control and Prevention, Children's Hospital, University of Washington FAS DPN, NOFAS Washington, and the Institute of Family Development.

NOFAS Washington, in collaboration with NOFAS Oregon and NOFAS Alaska, sponsored the 2006 Northwest Regional FASD Conference "Building Bridges to Success." The conference was wonderfully successful with attendance by over 350 participants, from as far away as Australia. The conference achieved its goals of providing information, resources, and interventions strategies to assist families and professionals move beyond diagnosis and find ways to bridge the gap to provide increasingly successful outcomes for individuals with Fetal Alcohol Spectrum Disorders, their families, and caregivers.

NOFAS Washington State recognizes that drinking alcohol during pregnancy causes a broad range of alcohol related disabilities. We envision the elimination of all future alcohol related disabilities, safe and enriching communities that embrace, honor, and empower individuals affected by prenatal alcohol exposure, and construction of unifying bridges built between professionals, individuals with FASD, community members, and families.

Skagit County Youth and Family Services – FASD Project

In September 2005, the federal Substance Abuse and Mental Health Services Administration funded the operation phase of the **Skagit County Youth and Family Services - FASD Project**. The development of this project was based upon a Needs Assessment completed during a planning phase that preceded operations.

The Skagit County Youth and Family Services FASD Project seeks to:

- Build the capacity of area Juvenile and Tribal Courts to identify and diagnose youth with FASD.
- Provide family support, liaisons to educational systems, and individualized services based on the circumstances faced by each youth and their family.
- Collaborate with area resources and community members to decrease the occurrence of FASD through education and prevention.
- Develop the local resources and expertise required to offer families, educators, health care professionals, and social service providers the tools necessary to reduce the impacts of FASD, so youth may become stable, clean and sober while reducing their vulnerability to delinquency.

Young people served by the project include:

- Youth under the supervision of the Skagit County Youth and Family Services.
- Youth involved in the four Tribal Courts represented within Skagit County, including Sauk-Suiattle Tribe, Swinomish Tribal Community, Samish Tribal Nation, and Upper Skagit Tribe.

Project goals:

The goals of this Project include reduced recidivism, decreased probation violations, and improved functioning for participating youth.

Services provided:

Screening – The Skagit County FASD Project will provide an educated referral process of Court involved youth by Juvenile Court and Tribal Court staff. The FASD Project and specified Tribal services staff will perform more intensive FASD Screening.

Diagnosis – Initially, the University of Washington's Fetal Alcohol Syndrome Diagnostic and Prevention Network (FAS DPN) will perform diagnostic assessments. It is hoped that such a team can be formed as a Skagit County diagnostic clinic to provide all FASD assessment functions locally. The Project will seek to recruit local practitioners who would be comprehensively trained by FAS DPN.

Services – Project staff will deliver intensive case management services. Simultaneously, local resources and expertise will be developed so families, educators, health care professionals, and social service providers receive the tools necessary to reduce the impacts of FASD. Ongoing training, support, advocacy, and evaluation of the effectiveness of services will achieve this change in multiple systems. The goal of systems change will prove to be a long-lasting, sustainable outcome demanding the ongoing commitment of multiple systems including Juvenile Justice, Tribal communities, ARIS, local schools, social service providers, the Division of Child and Family Services, and family representatives.

Federation of Families for Children's Mental Health/Spokane Advocacy Voice for Children

The objective of the **Spokane Advocacy Voice for Children** is to advance public awareness and education about the extreme distress children with FASD and mental health conditions experience on a daily basis. To accomplish our goal we conduct educational seminars, participate in community commissions, committees, and task force meetings, and advocate with local, state, and federal policy makers to develop appropriate services for these most vulnerable children in our state. We work closely with the FAS Family Resource Institute and are a chapter member of the national advocacy group, the Federation of Families for Children's Mental Health.

GOALS AND RECOMMENDED PRIORITIES FOR STATE FUNDING, LEGISLATION, AND POLICY
JULY 2007

Alcohol exposure is cited as the leading preventable cause of birth defects and developmental disabilities. Children exposed to alcohol during fetal development can suffer multiple effects. While the number and severity of negative effects can range from subtle to serious, the negative consequences are lifelong. Each year, approximately 12,000 infants are born in the United States with FASD, suffering irreversible life-long physical and mental damage. FASD are national problems that can impact any child, family, or community. The threat to American Indians and Alaska Natives is especially alarming in some Native American communities where alcohol dependency rates reach 50 percent and above. In such communities, the chances of a newborn suffering FASD are up to 30 times greater than the national average. [Congressional Record of the 105th Senate Bill 1875, Senator Tom Daschle (D, South Dakota)]. The rate of FAS and FAE combined in the Seattle area between 1975 and 1981 had been estimated at 9.1 per 1,000 live births, nearly one in every 100 (Sampson et al., Teratology, 1997).

Therefore, the members of FASIAWG support the exploration and implementation of the following recommendations. Note: the opinions stated in this report do not necessarily reflect those of the individual state agencies or the governor's office. *The order listed is not an indication of priority*:

1. Include FAS as an eligibility category of the Division of Developmental Disabilities (DDD) in Washington State, regardless of the IQ level of the affected individual. To accomplish this goal, additional resources would need to be allocated for DDD to provide services to this population, e.g., through an alcohol tax. We are grateful for the progress that was made during 2005 when DDD changed their criteria to additionally allow more inclusive behavioral assessments to be used as measures of eligibility, even for individuals with IQ levels above the previously allowed measurements. We would encourage DDD to continue to work with other state agencies to assure service delivery to all individuals disabled by prenatal alcohol exposure, who are found eligible for DDD services in the newly expanded criteria.
2. Continue and expand the Washington State FAS Diagnostic and Prevention Network (FAS DPN) of clinics. Provide fiscal support to each network clinic in order to support costs that the clinics have demonstrated cannot be obtained from fee-for-service, cost-shifting, and in-kind sources.
3. Continue and expand the University of Washington Parent-Child Assistance Program (PCAP), including supporting the development of child intervention components to address the needs of children prenatally exposed to alcohol/drugs.
4. Support the development and evaluation of a demonstration project to provide residential services and supports for young adults and adolescents with FASD.
5. Continue to support and encourage efforts by the FAS Family Resource Institute (FAS*FRI) to gather, analyze and disseminate the Collective Family Experience from parents raising children with FAS and ARND. The mission of FAS*FRI is to use this unique database to increase public awareness and provide education to parents and public agency workforces on how to identify, understand and care for affected children and adults.
6. Continue to support and expand NOFAS Washington's statewide efforts involving family advocacy, training for families and professionals, information dissemination, advocacy, summer camps, resource guides, educational advocacy, teen social skills groups, substance abuse prevention for children and teens affected by FASD.
7. Support FASD education and advocacy efforts provided by Spokane Advocacy Voice for Children with FASD and Mental Health Conditions.
8. Support Washington State Indian Tribes, native communities, migrant communities, and minority communities in their efforts to develop FASD prevention and intervention projects.
9. Continue to support annual FASIAWG conferences on FASD and other means of information dissemination through the FASIAWG.
10. Support and expand the FASD Washington State website: www.fasdwa.org.
11. Support DOH in their ongoing efforts to include children with FAS in the birth defects surveillance efforts.

12. Continue and expand, beyond King County, funding and coordination between the FAS DPN and Children Administration's Foster Care Comprehensive Health and Education Tracking (CHET) Program to provide FAS screening.
13. Actively promote primary prevention strategies and campaigns to inform and educate the citizens of the State of Washington about this fully preventable life-long disability and limit purchase of alcohol to underage drinkers. Campaigns may be media oriented or policy advocacy including labeling, signage, location of retail outlets, and establishment of a fund by the alcohol industry (either voluntarily or through legislative mandate or tax) for FASD prevention effective interventions and services for affected individuals and families.
14. Provide technical assistance to law enforcement for FASD training to their officers.
15. Encourage and support physicians and psychiatrists in Washington State who are working toward the inclusion of FAS/ARND in the next revision of the Diagnostic and Statistical Manual (DSM) for mental health professionals.
16. Support expansion of comprehensive services for substance abusing pregnant and parenting women and their children, such as Safe Babies Safe Moms and Parent Child Assistance Program.

The recommendations identified in this report reflect a majority vote of representatives from the following entities: DASA; FAS DPN and FADU (University of Washington); FAS*FRI; FASIS; NOFAS Washington; National Chapter of the Federation of Families/Spokane Advocacy Voice for Children with FASD and Mental Health Conditions; OSPI; DOC; DOH; Developmental Disabilities Council; DDD; MHD; CA; HRSA; JRA; IPSS; and GOIA. Each entity is given one vote, for a total of eighteen votes. Ground rules were established to formalize the voting process.

Ground Rules for Majority Vote:

1. *The group will strive for consensus.*
2. *If consensus is not reached, a majority vote will rule.*
3. *Majority rule is determined by the vote of group members present at the time of the vote. At least five voting members must be present for a vote to take place.*

CONCLUSION

FASD is the leading preventable cause of birth defects and developmental disabilities in the United States today. Widespread prevention, education, early identification, screening and diagnosis, expanded alcohol treatment for women of childbearing age, and support for families can reduce the suffering and expense associated with this birth defect. We must all become advocates in the fight against this preventable disability. To reduce the rate and impact of FASD, we must implement statutory changes, modifications in policy and practice, and identify additional funding. Cost offsets of this investment will result in a reduction in the use of multiple social service systems by individuals with FASD and their families, which include chemical dependency, mental health, developmental disability, health care, and criminal justice.

The FASIAWG wishes to thank the Governor's Council on Substance Abuse in advance for its consideration of these recommendations. Together we can prevent the far-reaching and costly effects of FASD. Your support will help individuals and families experience improvement in the quality of their lives, and help Washington State reduce the demand for social services.

The FASIAWG plans to continue meeting at least twice yearly by phone conference, as well as disseminate information through email and the Washington FASD website at www.fasdwa.org. This is the final annual report of the FASIAWG and the workgroup members will update their agency information at least once yearly on the Washington FASD website.

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