FETAL ALCOHOL SYNDROME (FAS) PRIMARY PREVENTION THROUGH FAS DIAGNOSIS: I. IDENTIFICATION OF HIGH-RISK BIRTH MOTHERS THROUGH THE DIAGNOSIS OF THEIR CHILDREN

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Abstract - A 5-year, FAS primary prevention study was conducted in Washington State to: 1) assess the feasibility of using a FAS Diagnostic and Prevention Clinic as a center for identifying and targeting primary prevention intervention to high-risk women (namely, women who had given birth to a child with FAS), 2) generate a comprehensive, lifetime profile of these women and 3) identify factors that have enhanced and/or hindered their ability to achieve abstinence. The results of this study are presented in two parts: Objective 1 is summarized in Part I below; Objectives 2 and 3 are summarized in Part II, published separately. This project demonstrated that a multidisciplinary FAS Diagnostic and Prevention Clinic (FAS DPN) could successfully attract and meet the diagnostic and treatment planning needs of patients presenting with prenatal alcohol exposure. One out of every three patients evaluated in the FAS DPN clinics was diagnosed with FAS or static encephalopathy/alcohol exposed. The birth mothers of one out of every three of these children diagnosed with FAS or static encephalopathy/alcohol exposed could be located and directly contacted. Half of the birth mothers directly contacted were still at risk for producing more children damaged by prenatal alcohol exposure. Thus, one out of every 18 children evaluated in the FAS DPN clinics had a birth mother who could be found and was at risk for producing more children damaged by prenatal alcohol exposure. Primary prevention programs targeted to this high-risk population could lead to measurable, cost-effective reductions in the incidence of FAS. Using this approach, the cost of raising a child with FAS would be roughly thirty times the cost of preventing FAS in the child. The benefit to the children, their mothers and society would be immeasurable.

INTRODUCTION

The fetal alcohol syndrome (FAS) is a permanent birth defect caused by heavy maternal use of alcohol during pregnancy. FAS is characterized by pre- and/or postnatal growth deficiency, central nervous system dysfunction (CNS) and a unique cluster of minor facial anomalies (Clarren and Smith, 1978). The presentation of each individual feature of the syndrome may be variably expressed with age. Estimates of the incidence of FAS range broadly from 1 to 3/1,000 live births documented in epidemiological studies to 1/10,000 live births documented in birth defect registries (Stratton et al., 1996; Abel, 1998). FAS is one of the leading known, non-genetic causes of mental retardation in the Western World (Abel and Sokol, 1987).

Although FAS is entirely preventable, the factors associated with maternal alcohol use during pregnancy are complex and resistant to change (Beckman, 1984a). Maximizing primary prevention efforts will require targeting limited prevention resources to women at highest risk for producing children damaged by prenatal alcohol exposure. Primary prevention refers to preventing the birth of children damaged by prenatal alcohol exposure. One such population is women who have already given birth to a child with FAS. FAS studies consistently report that women who have had one child with FAS, and who continue to drink, have progressively more severely affected children with subsequent pregnancies (May *et al*., 1983; Davis and Lipson, 1984; Abel, 1988).

It is axiomatic that the evolution of effective prevention and treatment programs for nearly any medical condition rests on the identification of sufficient numbers of patients so that interventions that are hypothesized to be effective can be appropriately evaluated. The identification of "patients" is made more difficult than usual in conditions like FAS when both the child and the parent should each be appropriately identified as "the patient." Unfortunately, the diagnosis in the child often is made after the child is no longer in the birth mother's custody and the diagnosticians have no direct access to the birth mother or her records. FAS is vastly misdiagnosed (Cordero *et al*., 1994; Floyd *et al*., 1994) and the birth mothers of children with FAS are rarely if ever identified and targeted for primary prevention intervention. Failure to identify and intervene with these two populations results in primary and secondary disabilities that come at high cost to the child, mother and society (Beckman, 1984; Abel and Sokol, 1987; Streissguth and Kanton, 1997).

The failure to medically diagnose FAS has complex antecedents. Based on our interactions with thousands of families attending our FAS diagnostic clinics and hundreds of medical professionals attending our diagnostic training sessions, in our opinion, these antecedents include three apparently commonly held beliefs. First, some physicians remain ignorant of the existence of FAS or the diagnostic approach to this syndrome, or any syndrome. Second, many physicians believe that intervention programs are equally effective for individuals with any etiologic form of mental retardation or attention deficit disorder and they fail to recognize the more complex and subtle brain damage in alcohol affected individuals. They also fail to recognize their role in helping to identify the birth mother for future prevention efforts through recognition of FAS in the child. Third, patients with FAS and their families often need help with foster or adoption support services, educational interventions, alcohol treatment, vocational rehabilitation, and/or the criminal justice system. Most physicians are not trained to lead intervention programs

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in these these arenas, nor are they likely to have well-established referral linkages to professionals in these other firleds. Further, many physicians may believe these issues are truly outside of the appropriate purview of pediatrics and 'healthcare'. Putting these false beliefs into practice sets up a self-defeating cycle. When physicians fail to perceive that a diagnosis of FAS will benefit the patient, the birth mother, the family, and society, FAS remains under-diagnosed. When individuals are not diagnosed, it is not possible to demonstrate the benefits of diagnosis to the child or the parent, nor can surveillance be done accurately enough to monitor the success of prevention efforts.

Although physician attitudes and training limit the availability and accuracy of FAS diagnostic services, we have found tremendous interest by families and professionals from social service, educational, and correctional facilities to obtain diagnostic confirmation of CNS dysfunction among individuals with prenatal alcohol exposure. They have shared with us that these diagnoses facilitate their intervention efforts with these individuals.

The ideas that stimulated this prevention project in 1992 arose from our experiences in the 1980s. Increasing knowledge of FAS in the medical literature and public media, and countless medical trainings on the subject did not seem to be changing medical practice in diagnosing FAS. Rather, we felt that a new team approach to diagnosis and treatment planning was needed in clinics dedicated to FAS issues if the beliefs described above were to be effectively challenged.

We believed that clinics dedicated specifically to FAS were the critical missing step in helping to solve this problem (Clarren and Astley, 1998). First, FAS clinics could provide a mechanism for demonstration of community interest in the diagnosis of FAS and an opportunity to determine which professionals or social/health care systems seek consultation and what issues or problems drive those referrals. The clinics could accurately make FAS diagnosis using appropriate and consistent assessments of physical, cognitive, and behavioral abnormalities. The clinics could recommend treatment programs and over time determine if these programs were available and, if available, effective. The clinics would stimulate ideas for novel treatment modalities and would generate enough patients and sufficient linkage to treatment venues that implementation and assessment could be done.

Second, clinics would become a critical resource in public awareness - FAS prevention programs. As the general public is made aware of FAS and related conditions and warned to avoid alcohol use in pregnancy, families who have children who might have FAS are also made aware of the disorder and they often become concerned. These families deserve to have appropriate diagnostic facilities nearby to answer their questions and provide appropriate diagnosis and treatment planning.

Third, clinics would be necessary to support active screening of high-risk populations like foster care or juvenile rehabilitation. Patients who screened positive would require a resource for final accurate diagnosis and counseling which could only be reliably met through dedicated clinics.

Fourth, the clinics could be a critical tool for primary prevention. Not all women alcoholics appear to be at equal risk for having children with FAS (Abel, 1995). Although women who have one affected child often have more, to date there is no anticipatory biologic or sociologic markers that distinguish the mothers of children with FAS from other women who drink in pregnancy and bear normal or nearly normal children. Treatment of women for alcoholism during pregnancy probably comes too late to prevent brain damage in affected fetuses even if the correct high-risk, alcoholic women are selected for therapy. While it would be ideal to identify and treat all alcoholic women prior to pregnancy, resources for such an effort are not available. However, each patient with FAS (as identified through a FAS diagnostic clinic) has a mother who has a proven potential to give birth to a child damaged by prenatal alcohol exposure. Focusing prevention efforts on this select and high-risk group of women could reduce the incidence of FAS births dramatically without unduly overburdening the current health care and alcohol treatment systems.

A Cooperative Agreement with the Centers for Disease Control and Prevention (CDC) from 1992 to 1997 allowed for the development of an FAS Clinic at the University of Washington that could demonstrate our conviction that misdiagnosis of FAS was occurring and could be corrected, and that the birth mothers of the patients could be found. Once found, the mothers could be interviewed to generate comprehensive lifetime profiles which, in turn, could be used to develop intervention programs targeted to meet their needs.

The specific objectives of this FAS diagnostic and prevention effort were to: (1) To assess the feasibility of using a FAS Diagnostic Clinic as a center for identifying and targeting primary prevention intervention to high-risk women. Specifically: (a) to establish an FAS Diagnostic Clinic; (b) determine the rate at which individuals with FAS could be identified; (c) determine the feasibility of identifying their birth mothers. (2) To generate a comprehensive, lifetime profile of their birth mothers as a first step in the development of a FAS primary prevention program targeted to meet their needs. Specifically, administer a personal, structured interview to the birth mothers of children diagnosed with FAS to document their: (a) sociodemographic profile; (b) social/health care utilization patterns; (c) adverse social experiences; (d) social support networks; (e) intelligence quotients (IQ); (f) mental health profiles; (g) reproductive and family planning histories; (h) alcohol use and treatment histories. (3) To identify factors that have enhanced and/or hindered the birth mothers' ability to achieve abstinence.

This report represents the first in a series of two reports that present the methods and outcomes of this FAS diagnostic and prevention project. This first report presents the complete methodology for the project and summarizes the project's success at identifying high-risk birth mothers through the diagnosis of their children (Objective I). The second report presents a lifetime profile of 80 birth mothers who gave birth to a child with FAS and identifies factors that enhanced and hindered their ability to achieve abstinence and/or practice effective family planning (Objectives II and III) (Astley *et al*., 2000).

METHODS

Establishment of the University of Washington FAS Diagnostic and Prevention (FAS DPN) Clinic

The first step in meeting the objectives above was to establish a multidisciplinary FAS diagnostic and prevention clinic at the University of Washington. The ultimate purpose of the clinic was to identify and target primary prevention services to women who had given birth to a child with FAS. To achieve this goal, the clinic had to effectively attract patients with FAS. After 25 years of experience making diagnoses in a variety of clinical settings, it was clear that this could best be accomplished by establishing a multidisciplinary clinic prepared to meet not only the diagnostic needs, but also the social service, educational and behavior management needs of the patients and their caregivers. This multidisciplinary approach to FAS diagnosis and prevention is described in detail in separate publications (Clarren and Astley, 1997; Clarren et. al., 2000).

Sources of Patients

Two sources of patients with FAS were used to address Objectives 1 through 3: 1) patients diagnosed through the CDC-sponsored University of Washington FAS Clinic and 2) patients diagnosed through other University of Washington or Children's Hospital and Regional Medical Center neurodevelopmental and genetics clinics. The CDC-sponsored FAS Clinic opened in 1993. Patients were identified through this clinic prospectively at the time of their diagnostic evaluation. The University of Washington and Children's Hospital clinics opened in the 1970s and were operational throughout this study. Patients were identified through these clinics both retrospectively and prospectively through research and medical records. The diagnosis of FAS did not begin with the CDC-sponsored University of Washington FAS Clinic in 1993. The diagnosis of FAS has been actively made in these clinical systems since the early 1970s when David Smith, M.D. and his colleagues identified the first cases in the United States (Jones and Smith, 1973). Dr. Clarren has been actively making the FAS diagnosis, using the same criteria, since entering practice in 1978 (Jones and Smith, 1973; Clarren and Smith, 1978; Rossett, 1980; Sokol and Clarren, 1989).

To assess the feasibility of using a FAS Clinic as a center for identifying and targeting primary prevention services to high-risk women (Objective I), patients diagnosed with FAS prospectively in the CDC-sponsored University of Washington FAS Clinic were used. This single clinic expanded into the Washington State FAS Diagnostic and Prevention Network (FAS DPN) of seven clinics in the third year of the study to meet the ever-increasing demand for diagnosis. This expansion is described in more detail below.

To generate a lifetime profile of birth mothers of children with FAS and to identify factors that enhanced and hindered their ability to achieve abstinence (Objectives II and III), patients from both sources were used. The addition of this second source of patients served to increase the total number of birth mothers enrolled in the study and served to increase the maternal follow-up period of observation subsequent to the birth of the index child with FAS. The longer the period of follow-up on the birth mothers, the more meaningful the lifetime profiles and identification of factors that enhanced and hindered abstinence and family planning.

Diagnostic Criteria

The diagnoses of FAS and 'static encephalopathy/alcohol exposed' were made using the clinical gestalt guidelines published by Sokol and Clarren (1989) and the 4-Digit Diagnostic Code created by Astley and Clarren (1997, 1999, 2000). The diagnosis of FAS was accepted when Dr. Clarren made that diagnosis or when the diagnosis was made by another clinician and Dr. Clarren had reviewed the data and concurred.

In the last year of this project, a new, comprehensive, case-defined method for diagnosing FAS called the 4-Digit Diagnostic Code was established by the University of Washington FAS Clinic under a separate contract (Astley and Clarren, 1997, 1999, 2000). This new method was created in response to both the Institute of Medicine's recommendations that a more reliable and valid set of diagnostic definitions be adopted (Stratton *et. al.*, 1996) and our Washington State Senate's mandate that we assure diagnostic reproducibility among all Washington State FAS DPN clinics. This new diagnostic system documents the magnitude of expression of the four key components of the syndrome: 1) growth impairment, 2) the FAS facial phenotype, 3) evidence of brain damage and 4) prenatal alcohol exposure, on separate 4-point Likert scales (Astley and Clarren, 2000). Likert Rank 1 represents normal. Likert Rank 4 represents the most severe expression of the feature. Generally speaking, a diagnosis of FAS requires ranks of 3 or 4 in all four categories. This new system of diagnosis was implemented in the U.W. FAS Clinic during the last six months of this project.

Maternal Study Population

The target population for this prevention project was initially birth mothers of children who received a gestalt diagnosis of FAS. Implementation of the 4-Digit Code method of diagnosis in the last six months of the project allowed us to expand the maternal target population to all women who gave birth to infants with documented brain dysfunction and prenatal alcohol exposure, not just the subset who gave birth to children with FAS. One of the many benefits of the 4-Digit Code is that is clearly differentiates patients with organic brain damage and prenatal alcohol exposure from the much larger and heterogeneous group previously labeled through the gestalt method of diagnosis as possible fetal alcohol effects (PFAE). With the implementation of the 4-Digit Code, the diagnostic criteria were expanded to include all children who received a diagnosis of static encephalopathy (4-Digit brain Likert ranks of 3 or 4) and confirmed prenatal alcohol exposure (4-Digit alcohol Likert ranks of 3 or 4) with or without the FAS facial phenotype or growth deficiency. Children who also presented with the FAS facial phenotype and growth deficiency were the subset of children with static encephalopathy who met the criteria for a diagnosis of FAS. To obtain a 4-Digit brain rank of 3 or 4, a patient must present with microcephaly, a seizure disorder, an abnormal CT or MRI, a full scale IQ < 60, or performance of greater than two standard deviations below the norm across three or more of the following domains in a psychometric assessment battery (intelligence, achievement,

adaptation, neuropsychology and language). This expanded target population reflects a very high-risk group of women (Abel, 1988), who are not only uniquely and conveniently identifiable through a FAS Diagnostic Clinic, but ideally targeted for primary prevention intervention. Women who were eligible to enroll in this study met the following criteria:(1) they gave birth to at least one child with a medical diagnosis of FAS or static encephalopathy/alcohol exposed rendered or confirmed by SKC following the clinical guidelines of Sokol and Clarren (1989) or Astley and Clarren (1997, 1999, 2000); (2) they were of any age or race; (3) they were a resident of Washington State at the time of study enrollment; (4) they consented to participate in the study.

Identification, Location and Enrollment of Birth Mothers

This study was reviewed and approved by the University of Washington Human Subjects Review Board. The process for identifying individuals with FAS and identifying, locating and inviting their birth mothers to enroll in this study was done in compliance with medical and research policy for protecting patient confidentiality.

Birth mother identification, location and enrollment was conducted by a social worker over a 36-month period. Identification and location of the birth mothers was accomplished either through direct contact with them when they accompanied their child to the diagnostic examination, or through letters or phone calls of invitation delivered by family, friends and social/medical providers when they did not attend their child's diagnostic examination. Public records such as phone directories, driver's license bureaus, birth and death certificates and Department of Correction registries were used when necessary to identify and locate the women.

Birth mothers who attended their child's diagnostic evaluation in any clinic in which SKC was the diagnosing physician were invited to enroll in the study by SKC at the time of the diagnostic evaluation or through receipt of a letter from SKC. Women who did not attend their child's diagnostic evaluation, but whose names were documented in their child's diagnostic record received a letter of invitation from SKC as the child's treating physician. Women whose names were not known by the FAS DPN clinic were sent letters of invitation from SKC through a family member, friend or medical/social service professional that did know the women. This allowed the birth mother to be invited to learn more about the study without revealing her name or location to the FAS DPN study staff. If she was interested in participating, the letter of invitation included a stamped, response postcard, addressed to the FAS DPN, allowing her to contact us or give us permission to contact her.

Every effort was made to facilitate the woman's participation in the study. Offering child-care, transportation, flexible scheduling, and mobile interviewing were key in enrolling women. Additionally, as long as the parameters of the interview were maintained (private room, no interruptions), women were encouraged to choose the setting of the interview. Interviews took place in a variety of settings – public health centers, hospitals, community centers, treatment centers, libraries, correctional facilities, and homes – and at a time convenient to the women.

Maternal Interview

A four-hour structured personal interview was developed to generate a lifetime, comprehensive profile of each birth mother's sociodemographics, reproductive and family planning history, social and health care utilization patterns, adverse social experiences, social support network, alcohol use and treatment history, psychosocial profile and intelligence quotient. The interview included 2,044 questions. The questions focused on three time periods in the women's lives: (1) at the birth of the index child with FAS; (2) at the time of the interview; (3) over their lifetime. The interview included the following standardized (indicated by *) and non-standardized instruments: (1) Sociodemographic and Lifetime Social/Health Care Utilization Questionnaire; (2) Reproductive and Family Planning History Questionnaire; (3) Social Support Questionnaire (Short Version)* (Sarason *et al*.,1987); (4) Quick Diagnostic Interview Schedule III R* (Bucholz *et al*., 1996); (5) Shipley-Hartford Institute of Living Scale* (Shipley, 1967); (6) Alcohol Use and Treatment History Questionnaire.

The Sociodemographic and Lifetime Social/Health Care Utilization Questionnaire was constructed to document lifetime education, employment, physical and social home environment, social/health care utilization patterns, and adverse social experiences. The Reproductive and Family Planning History Questionnaire was constructed to document: 1) for all conceptions (mother's age, birth outcome, form of birth control used, planfulness of conception and alcohol exposure) and for all types of birth control available (age when used, ever failed, currently using, if stopped using-why and if available at no cost-would she use it now). The Alcohol Use and Treatment History Questionnaire documented lifetime drug and alcohol use and all concerted efforts to reduce alcohol use. The women were first asked to list all concerted efforts to reduce intake by date and then to provide the following details on three specific efforts; the most successful, the least successful and the effort closet to the birth of the index child with FAS. For each of these three efforts they were asked to report: (1) their level of alcohol use; (2) reasons for attempting to reduce their intake; (3) pertinent sociodemographics; (4) alcohol treatment program parameters; (5) family support; (6) need and access to social/educational/medical services during their treatment; (7) their perceived level of success or failure in reducing their alcohol use; (8) reasons they attributed to their success or failure. This questionnaire was designed to address many of the issues raised by Beckman and Braiker on the treatment needs of women alcoholics and the structural, personal and environmental barriers to treatment (Beckman, 1980, 1984, 1984a; Beckman and Amaro, 1984; Braiker, 1984). It also incorporated questions that addressed key findings of a 1993 Seattle-based survey of chemical dependency treatment programs serving women (Seattle-King County Task Force for Chemically Dependent Women, 1993). The Short Social Support Questionnaire is a standardized instrument of twelve questions (Sarason *et al*., 1987). The respondent is asked to list the number of people they can depend on to provide them with help or support (e.g., "Whom can you count on to console you when you are very upset?") and to rank their level of satisfaction with the support they receive on a six-point scale. The Shipley-Hartford Institute of Living Scale is a standardized instrument of 60 self-administered questions used to derive an

estimate of the WAIS-R full-scale intelligence quotient (I.Q.) (Shipley, 1967). The National Institute of Mental Health Quick DIS-III-R is a computerized interview used to diagnose lifetime psychiatric disorders in accordance with DSM-III-R criteria for positive symptoms (Busholz *et al*., 1996). The following components were administered by the trained interviewer: demographics, panic disorder, generalized anxiety disorder, agoraphobia, social phobia, simple phobia, post-traumatic stress disorder, major depressive episode, manic episode/bipolar disorder, schizophrenia/schizophreniform, anorexia, bulimia, alcohol disorder and antisocial personality. The computer program reports the diagnostic outcome (+/-) for each disorder and the age at onset of symptoms.

At the completion of the 4-hour study interview, the women received $75 and referrals to services specific to their needs. The interview was constructed through a collaborative effort between medical and social service providers at the University of Washington, Washington State Department of Public Health, Seattle/King County Department of Public Health and the CDC. The interview was administered by a single registered nurse with a master's degree in addictions nursing.

Analysis

t-tests, Mann-Whitney Rank Sum tests and chi-square (or Fisher Exact) tests were used to compare outcomes between two independent groups when the outcomes were measured on continuous, ordinal or nominal scales respectively.

RESULTS

Establishment of the FAS Diagnostic Clinic

The UW FAS Clinic opened in January 1993. The format and function of the clinic are described in full in Clarren and Astley (1997) and Clarren et. al (2000). Briefly, the clinic at the University of Washington was and continues to be held one day per week and sees two to four patients and their caregivers per day. A multidisciplinary team that includes a pediatrician (SKC), educational and clinical psychologists, an occupational therapist, a speech language pathologist, maternal advocate and a family advocate staff the clinic. Applications for appointments are taken over a telephone hotline. Patients seek their own appointment or are seen on referral. Referrals come primarily from social service agencies, educational facilities, the criminal justice system and rarely from physicians or other health care providers. All persons who call are sent a New Patient Information Form to complete. The form documents the patient's physical and developmental history, gestational exposures and caregiver's concerns. The completed and returned forms are reviewed and prioritized based on the urgency of the request. Caregivers are asked to bring copies of previous school, medical and psychological evaluations to clinic on the day of their appointment. The caregivers are interviewed jointly by the pediatrician and psychologist, and the patient is examined to determine if he/she has the physical features of FAS. The patient also receives brief language, neurologic and psychometric assessments. After the interview and clinical examination, the clinic team completes the FAS Diagnostic Evaluation Form (Astley and Clarren, 1997) derives a 4-Digit diagnosis and generates a referral plan for treatment and services for the patient, their family and the birth mother if appropriate. The caregivers then meet with the Clinic team to discuss the diagnosis and referrals. The caregivers receive a complete medical summary within three weeks after their clinic visit.

The clinic was so successful in meeting the diagnostic needs of families, as demonstrated by the patient satisfaction surveys presented above, that it was unable to deal with the very large demand for services. Working first with the Western Washington Chapter of the March of Dimes Birth Defects Foundation and then with the Washington State Legislature, a law was passed in 1995 which directed us to develop community-based clinics like the one at the University throughout the state. This was the beginning of the Washington State FAS Diagnostic and Prevention Network (FAS DPN). The FAS DPN is a consortium of six community-based clinics located at major population centers around Washington State led by the core diagnostic and training clinic at the University of Washington. While this was not a specific objective of this CDC cooperative agreement, ensuring the continuation of this project through other forms of support beyond the 5-year Cooperative Agreement was certainly a positive outcome. It also led to an increased capacity to identify birth mothers in the last two years of this study.

The mission of the FAS DPN is primary and secondary prevention of FAS through clinical screening, diagnosis, research and training. To accomplish this mission, comprehensive, case-defined methods for FAS screening (Astley and Clarren, 1996) and diagnosis (Astley and Clarren, 1997, 1999, 2000; Astley *et al*., 1999) were developed and implemented. A clinical training program was established at the University of Washington core site to provide FAS training to local community professionals and multidisciplinary clinical teams worldwide. The screening, diagnostic and training tools were all developed from the FAS DPN clinical database. This database also serves as a confidential registry of over 1,200 consistently diagnosed patients eligible to enroll in ongoing prevention/intervention research. The FAS DPN clinics are unique from other genetic and neurodevelopmental programs that typically provide services to these children in three fundamental ways: 1) The FAS DPN clinics all follow the same comprehensive, case-defined method for diagnosis (Astley and Clarren, 1997, 1999, 2000), 2) the clinics provide a multidisciplinary approach to diagnosis and treatment planning (Clarren and Astley, 1997; Clarren et. al., 2000) and 3) the clinics focus their intervention efforts on both the child and the birth mother (diagnosis and treatment planning for the child with primary prevention intervention for the child's birth mother). The patient satisfaction survey presented to all patients seen in the FAS DPN revealed that 87% of patients felt they had received services they were unable to obtain anywhere else. Ninety-nine percent reported they would recommend the clinic to families in similar need. The Network is currently funded through multiple sources including in-kind support, fee for service, and specific grants and contracts to provide targeted services within the community.

Proportion of Patients Receiving a FAS Diagnosis in the FAS DPN Clinics

The FAS DPN clinics received 3,002 requests for diagnostic evaluations in its first five years of operation (1993

through 1997). Operating at capacity, the clinic conducted 811 diagnostic evaluations.

Gestalt Method. The first 454 patients evaluated in the FAS Clinic were diagnosed using the gestalt method. Of the 454 patients, 110 (24.2%) received a gestalt diagnosis of FAS or atypical FAS (AFAS) and 344 (75.8%) received a gestalt diagnosis of PFAE. AFAS is FAS without the growth deficiency. Using the gestalt method, one out of every four patients received a diagnosis of FAS/AFAS.

4-Digit Code Method: Patients 455 through 811 were diagnosed using the 4-Digit Diagnostic Code method. All 454 patients diagnosed prior to implementation of the new diagnostic method had their gestalt diagnostic outcomes converted over to the new, more stringently case-defined 4-Digit Code. Thus, of all 811 patients evaluated at the FAS DPN, 39 (4.8 %) received a 4-Digit diagnosis of FAS/AFAS (Diagnostic Categories A-C) and 559 (68.9 %) received a 4-Digit diagnosis (Diagnostic Categories E-I) comparable to the gestalt diagnosis of PFAE. Using the 4-Digit Code method, one out of every 21 patients evaluated in the FAS DPN Clinics received a 4-Digit diagnosis of FAS/AFAS. A lower proportion of patients were diagnosed with FAS using the 4-Digit Code relative to the gestalt method because the 4-Digit Diagnostic system demands more stringent adherence to the diagnostic criteria of FAS through the use of specific case definitions (Astley and Clarren, 2000).

Impact of the 4-Digit Code on Identifying High-Risk Mothers

In contrast to the maternal population initially targeted in this study through their child's gestalt diagnosis of FAS, the 4-Digit diagnostic system allowed a much broader and more appropriate maternal population to be accurately identified and targeted for primary prevention. In other words, rather than target the birth mothers of just the children with FAS/AFAS, the birth mothers of all children receiving a 4-Digit diagnosis ending in 33, 34, 43, or 44 could and should be targeted. These codes reflect strong evidence of organic brain damage (static encephalopathy) and a confirmed history of maternal alcohol exposure. Of the 811 patients evaluated at the FAS DPN, 238 (29 %) received a diagnosis of static encephalopathy/alcohol exposed. Thirty-nine of these 238 patients (16.4%) also presented with growth deficiency and the FAS facial phenotype and thus received a 4-Digit diagnosis of FAS/AFAS. Thus one out of every three patients evaluated in the FAS DPN Clinics received a 4-Digit diagnosis of static encephalopathy, alcohol exposed. This is the maternal population currently being targeted for primary prevention intervention in the FAS DPN clinics.

Identification and Enrollment of Birth Mothers

A total of 257 women who had given birth to one or more children with a gestalt diagnosis of FAS (Sokol and Clarren, 1989) or a 4-Digit diagnosis of FAS or static encephalopathy (Astley and Clarren, 1997, 1999, 2000) were identified as potentially eligible to enroll in this study (Table 1). One hundred and forty-seven (57%) were identified prospectively from the FAS DPN clinics and 110 (43%) were identified both retrospectively and prospectively from other clinics. Of the 257 mothers, 92 were confirmed to be eligible to enroll in this study, 58 were confirmed to be ineligible and the eligibility of the remaining 107 remained unknown. Of the 92 mothers confirmed to be eligible, 80 (87%) were enrolled and interviewed. Of the 58 women who were deemed ineligible, 31 no longer lived in Washington State and 27 were deceased. Of the 107 women whose eligibility status could not be determined, 97 were identified by name, but none of them could be located.

Key challenges to locating the birth mothers included: 1) 80% of the children were no longer in the custody of their birth mothers at the time of the child's diagnosis, and 2) medical confidentiality limited the exchange of patient/birth mother information between our study staff and outside agencies who could be instrumental in assisting us. It required, on average, 6.7 (range = 1 to 36) attempts to contact each of the 80 women over an average of 3.8 months (range = 0 to 36 months) per woman to identify, locate and enroll them into the study. We found that public health and social service providers were very willing to help locate the women when they could. Most often, they would telephone or forward letters of invitation from us to the eligible women.

Success at identifying, locating and enrolling women was comparable between the two clinical sources (Table 1). The majority of the children diagnosed with static encephalopathy/alcohol exposed came from the FAS DPN clinics because the majority of children diagnosed in the other clinics were diagnosed before the 4-Digit Code was created and only children seen by SKC in the other clinics were diagnosed using the 4-Digit Code. The patient population at the FAS DPN also had a slightly higher proportion of Caucasians than the patient populations identified through the other clinics.

Representativeness of the Maternal and Patient Study Populations

The maternal population that the FAS DPN clinics will target for primary prevention efforts are the birth mothers of children with FAS and static encephalopathy who can be identified and located with reasonable effort and live within Washington State where they are eligible to receive social and health care services. This target population is defined by the eligibility criteria presented above for this study. Eighty (87%) of the 92 women confirmed to be eligible to enroll in this study were enrolled and interviewed (Table 1). Of the 12 eligible women who did not enroll, six were identified by name and location, but could not be reached directly to invite into the study. Of the six women who were contacted, but declined to interview, five of them had given birth to the index child with FAS over 17 years ago and one had given birth to the index child with FAS only four months ago. Two of these six patients had been diagnosed over ten years ago. Four of these women said they were too old or unhealthy to participate, one said that she was too busy, and one did not provide a reason. Based on the percent of eligible women interviewed (87%), this study population should be reasonably representative of the target population. Although the primary objective of this

Table 1. Summary of maternal identification, location and enrollment stratified by whether the child was identified prospectively in a FAS Diagnostic & Prevention Network clinic (FAS DPN) or retrospectively/prospectively in another clinic.

Characteristic	Source of Patient with FAS or Static Encephalopathy: Prospective FAS DPN Clinics n	(%)	Retrospective/Prospective Other Clinics n	(%)	Total n	(%)
Birth mothers of children diagnosed with FAS or static encephalopathy	147		110		257	
Maternal interview status						
Interviews completed	46	(31.3)	34	(30.9)	80	(31.1)
Interview not completed	101	(68.7)	76	(69.1)	177	(68.9)
Reasons interview not completed:	(Among 101)		(Among 76)		(Among 177)	
Not eligible	32	(31.7)	26	(34.2)	58	(32.8)
Did not live in WA State	20		11		31	
Deceased	12		15		27	
Eligibility Unknown	63	(62.4)	44	(57.9)	107	(60.5)
Identified but not located	55		42		97	
Not identified or located	8		2		10	
Eligible, but:	6	(5.9)	6	(7.9)	12	(6.7)
No direct contact achieved	5		1		6	
Declined to interview	1		5		6	
Identification and location success	(Among 147)		(Among 110)		(Among 257)	
Identified by name	139	(94.6)	108	(98.2)	247	(96.1)
Identified by name and located	84	(57.1)	66	(60.0)	150	(58.4)
Identified by name but not located	55	(37.4)	42	(38.2)	97	(37.3)
Not identified by name or located	8	(5.5)	2	(1.8)	10	(3.9)
Child's diagnosis -- method of diagnosis **						
FAS: Gestalt or 4-Digit	119	(80.9)	106	(97.2)	225	(87.9)
Static encephalopathy: 4-Digit	28	(19.1)	3	(2.8)	31	(12.1)
Child's race *						
Caucasian 93	(67.4)	51	(56.0)	144	(62.9)	
African American	11	(8.0)	8	(8.8)	19	(8.3)
Native Amer., Alaskan or Canadian	25	(18.1)	30	(33.0)	55	(24.0)
All others	9	(6.5)	2	(2.2)	11	(4.8)

* P < 0.05; ** P < 0.01.

prevention project was to demonstrate the feasibility of targeting primary prevention services to birth mothers identified prospectively through the FAS DPN clinics; women identified from other diagnostic clinics were also enrolled to increase the sample size and duration of follow-up. Inclusion of women from outside the FAS DPN did not appear to impact the overall maternal profile. The sociodemographic profiles of the two clinical populations were very comparable. The 46 mother/child pairs identified through the FAS DPN and the 34 mother/child pairs identified through the other clinics did not differ significantly in maternal race, maternal education level, maternal age at the time of the child's birth, maternal age at the child's diagnosis, maternal age at the time of the interview; child's race, child's gender or the child's age at the time of the maternal interview. The mean age of the patients diagnosed in the FAS DPN clinics was older than the patients diagnosed in the other clinics (9.4 ± 6.2 compared to 5.7 ± 4.8; $t = 2.8$, $p = 0.006$) because the FAS DPN clinics see both children and adults. The other clinics were all pediatric clinics. Patients identified through the other clinics had been diagnosed longer ago relative to the patients identified through the FAS DPN (4.8 ± 4.2 years compared to 1.4 ± 1.1 years; $t = 4.4$, $p = 0.000$), which was expected since the other clinics opened in the 1970s. The magnitude of these two contrasts is not likely to have a meaningful impact on the overall profile of the maternal target population.

One additional contrast that will be of interest to some is a comparison of the 80 women who were enrolled versus the remaining 177 who were identified as having given birth to a child with FAS or static encephalopathy, but were not enrolled. The following sociodemographic characteristics were comparable between the two groups: the child's diagnosis, mother's race, mother's age at the child's birth, mother's age at the child's diagnosis and mother's age at the time she was identified as potentially eligible to be enrolled in the study. A complete sociodemographic profile of the 80 women enrolled in the study can be found in Table 1 in Part II of this series (Astley *et al*., 2000). The children of the mothers who were not enrolled were on average three years older at the time of their diagnosis (10 ± 9 compared to 8 ± 6; $t = 2.6$, $p = 0.01$), were more likely to be female (45% compared to 31%; chi-square = 4.2; $P = 0.04$) and were diagnosed 1 year earlier (4.4 ± 4.3 compared to 3.5 ± 3.0; $t = 3.6$, $P = 0.000$) than children of the women enrolled. Again, it would appear that the maternal

Table 2. Selected characteristics of the 80 children whose birth mothers were interviewed.

Characteristic	mean	(S.D.)	min. - max.	n	(valid %)
Age (years) at time of diagnosis					
0.0 to 5.9				37	(46.3)
6.0 to 10.9				18	(22.5)
11.0 to 15.9				20	(25.0)
16.0 +				5	(6.2)
Mean	7.8	(5.9)	0.1 - 24.2	80	
Age (years) at time of interview	10.5	(6.2)	0.6 - 25.5	80	
Gender, male:female (% female)				55:25	(31.3)
Race					
Caucasian				51	(63.8)
African American				8	(10.0)
Native American, Alaskan or Canadian				19	(23.7)
Hispanic				2	(2.5)
Primary caregiver at the time of the child's diagnosis					
Birth mother with or without birth father				38	(47.5)
Birth father only				3	(3.7)
Other family members				10	(12.5)
Adoptive/foster parent				24	(30.0)
Other (group home, therapeutic center, juvenile detention)				5	(6.3)
Clinical source for patient identification					
FAS DPN clinics (1993 to 1997)				46	(57.5)
Other clinics				34	(23.5)
Diagnosed by author (SKC)				72	(90.0)
Child's Diagnosis for Maternal Enrollment: Method of Diagnosis					
FAS: Gestalt or 4-Digit Code				70	(87.5)
Static encephalopathy: 4-Digit Code				10	(12.5)
Child's Diagnosis transformed into 4-Digit Diagnostic Code					
FAS/AFAS (Diagnostic Categories A, B, or C)				23	(30.3)
Static Encephalopathy, alcohol exposed					
With or without sentinel physical findings				32	(42.1)
Neurobehavioral Disorder, alcohol exposed					
With or without sentinel physical findings				21	(27.6)
Sufficient data not available to generate Code				4	(---)

population enrolled is reasonably representative of the population of all mothers identified through the diagnosis of their children.

Profile of the 80 Children whose Mothers were Enrolled.

A profile of the 80 children whose mothers were enrolled in the study is presented in Table 2. They were predominantly Caucasian, 7.8 years of age at the time of their diagnosis with over half no longer living with their birth mother at the time of the diagnosis. The racial distribution was comparable to the racial distribution in WA State with the exception of a slight over representation of Native Americans. Eighty-nine percent had a gestalt or 4-Digit diagnosis of FAS, the remaining 11% had a 4-Digit diagnosis of static encephalopathy/alcohol exposed without the full FAS facial phenotype.

DISCUSSION

This project demonstrated that the multidisciplinary FAS DPN of clinics could successfully attract and meet the diagnostic and treatment planning needs of patients presenting with prenatal alcohol exposure. The clinical database generated from this patient population allowed for the development of screening and diagnostic tools that, in turn, allowed the clinic and its diagnostic method to be replicated statewide and nationally. The FAS DPN was successful at attracting a patient population at high risk for organic brain damage and prenatal alcohol exposure. Using the original gestalt method of diagnosis, one out of every four patients evaluated received a diagnosis of FAS. Using the 4-Digit Diagnostic Code method of diagnosis that demands more stringent adherence to strict diagnostic criteria, 238 (29 %) of the 811 patients evaluated through the FAS DPN Clinics received a diagnosis of static encephalopathy/alcohol exposed. Thirty-nine of these 238 patients (16.4%) also presented with growth deficiency and the FAS facial phenotype and thus received a 4-digit diagnosis of FAS/AFAS. Thus one out of every three patients evaluated in the FAS DPN clinics received a 4-Digit diagnosis of static encephalopathy, alcohol exposed. The birth mothers of these children with documented organic brain damage and prenatal alcohol exposure represent the FAS

DPN's current target population for primary prevention intervention. While only 20 % of the patients evaluated in the FAS DPN clinics are accompanied by their birth mother, the clinic was able to identify 95% and locate 57% of them. Forty-six percent of the 80 women interviewed in this study were still at risk for producing alcohol-damaged children at the time the index child received a diagnosis of FAS or static encephalopathy. They were at risk because they were still fertile and either actively drinking or at risk of drinking. Thirty-five had given birth to 61 additional children in the years following the index child's diagnosis. Seventy-five percent of the 61 children were exposed to alcohol in utero. Thus, based on what we have learned from this study: 1) that these women are at high risk for producing more children damaged by alcohol exposure, 2) that they, themselves, are often facing serious adverse social, mental and physical health issues, and 3) that some are often just a few phone calls away, one could argue that it would be unethical to ignore their existence and ignore the opportunity to provide them with advocacy support and primary prevention intervention (Astley *et al*., 2000).

Current Status of the Washington State FAS DPN Primary Prevention Program

The Washington State FAS DPN meets monthly with pertinent state agencies and programs (Department of Health, Department of Social and Health Services, Department of Corrections, Office of Public Instruction, Medical Assistance Administration, Family Advocacy, Western Washington March of Dimes and the University of Washington Fetal Alcohol and Drug Unit) to facilitate efficient and effective provision of FAS screening, diagnostic, prevention and educational services statewide. The FAS DPN is currently working with the State to facilitate referral of high-risk women identified through the FAS DPN to appropriate primary prevention intervention services. One state-supported service that provides very high-risk mother/infant pairs with home-based paraprofessional advocacy from birth to three years of age is the Washington State Parent-Child Assistance Program (P-CAP) directed by Therese Grant, Ph.D., at the University of Washington. P-CAP has proven to be highly effective and efficient at leading women into sobriety and effective family planning (Grant *et al*., 1999, Ernst *et al*., 1999). When the FAS DPN of clinics first opened in 1995, P-CAP had only one site in Seattle, Washington and enrolled only women who were in their last trimester of pregnancy with chronic alcohol and/or drug use during pregnancy. In 1999, the Washington State legislature supported the expansion of P-CAP into four of the six major metropolitan areas of Washington State where FAS DPN clinics exist and expanded the enrollment criteria to include birth mothers of children diagnosed with FAS or static encephalopathy through the FAS DPN clinics. While not all birthmothers targeted for primary prevention through the FAS DPN clinics need the intense services of P-CAP, those that do are well held.

Rate of Identification of Children and Mothers and Cost of FAS Prevention

Based on the results of this study, one out of every three patients evaluated in the FAS DPN clinics is diagnosed with FAS or static encephalopathy/alcohol exposed. The birth mothers of one out of every three of these children diagnosed with FAS or static encephalopathy/alcohol exposed can be directly contacted. Half of the birth mothers directly contacted will still be at risk for producing more children damaged by prenatal alcohol exposure. Thus one out of every 18 children evaluated in the FAS DPN clinics has a birth mother who can be found and is at risk for producing more children damaged by prenatal alcohol exposure.

Providing diagnostic and intervention services to both mother and child through a FAS Diagnostic Clinic not only benefits the mother and child, but has the potential of being a very cost effective approach to FAS primary prevention. The cost to society to raise a child with FAS is estimated to be $1,000,000 (Abel and Sokol, 1987). A diagnostic evaluation for a child through a FAS DPN clinic costs approximately $1,200. Providing effective intervention to the highest risk birth mothers through the Parent-Child Assistance Program costs $3,800 per year per woman for three years (Grant *et al*., 1999). If, on average, 18 children must be diagnosed to identify and intervene with one high-risk mother, the approximate cost to find and provide effective intervention services to the birth mother would be $33,000 ($22,600 to diagnose 18 children and $11,400 to provide three years of advocacy services to the mother through the P-CAP program). Thus, the cost of raising a child with FAS would be roughly thirty times the cost of preventing FAS in the child. The benefit to the mothers, their children and society would be immeasurable.

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REFERENCES

Abel, E.L. (1988) Fetal alcohol syndrome in families (Commentary). *Neurotoxicology and Teratology* **10**:12.

Abel, E.L. (1995) An update on incidence of FAS: FAS is not an equal opportunity birth defect. Neurotoxicology and Teratology **17**:437-443.

Abel, E.L. (1998) The American Paradox In: *Fetal Alcohol Abuse Syndrome*. pp. 139-157. Plenum Press, New York.

Abel, E.L. and Sokol, R.J. (1987) Incidence of fetal alcohol syndrome and economic impact of FAS-related anomalies. *Drug and Alcohol Dependence*, **19**:51-70.

Astley, S.J., Bailey, D., Talbot, C. and Clarren, S.K. (2000) FAS Primary Prevention through FAS Diagnosis: Part II. A

comprehensive profile of 80 birth mothers of children with FAS. *Alcohol and Alcoholism*, <*recommended for publication*>.

Astley, S.J. and Clarren, S.K. (1996) A case definition and photographic screening tool for the facial phenotype of fetal alcohol syndrome. *Journal Pediatrics* **129**:33-41.

Astley, S.J. and Clarren, S.K. (1997) *Diagnostic Guide for Fetal Alcohol Syndrome and Related Conditions: The 4-Digit Diagnostic Code*. pp. 1-93, University of Washington Publication Services, Seattle.

Astley, S.J. and Clarren, S.K. (1999) *Diagnostic Guide for Fetal Alcohol Syndrome and Related Conditions: The 4-Digit Diagnostic Code*. 2nd Edition, pp. 1-111, University of Washington Publication Services, Seattle.

Astley, S.J. and Clarren, S.K. (2000) Diagnosing FAS: Introducing the 4-Digit Diagnostic Code. *Alcohol and Alcoholism*, <*recommended for publication*>.

Beckman, L.J. (1980) Perceived antecedents and effects of alcohol consumption in women. *Journal Studies on Alcohol* **41(5)**:518-530.

Beckman, L.J. and Amaro, H. (1984) Patterns of Women's Use of Alcohol Treatment Agencies. In: Wilsnack, S.C. and Beckman, L.J. eds, *Alcohol Problems in Women, Antecedents, Consequences and Intervention*, pp. 319-348, Guilford Press, New York.

Beckman, L.J. (1984) Treatment needs of women alcoholics. *Alcoholism Treatment Quarterly* **12**:101-112.

Beckman, L.J. (1984a) Analysis of suitability of alcohol treatment resources for women. *Substance and Alcohol Abuse/Misuse* **5**:21-27.

Braiker, H.B. (1984) Therapeutic issues in the treatment of alcoholic women. In: Wilsnack, S.C. and Beckman, L.J. eds, *Alcohol Problems in Women, Antecedents, Consequences and Intervention.* pp. 349-368, Guilford Press, New York.

Bucholz, K.K., Marion, S.L., Shayka, J.J., Marcus, S.C., and Robins, L.N. (1996) A short computer interview for obtaining psychiatric diagnoses. Psychiatric Services Mar; **47**(3): 293-297.

Clarren, S.K. and Astley, S.J. (1997) The development of the fetal alcohol syndrome diagnostic and prevention network in Washington State. In: Streissguth, A. and Kanter, J. eds,. *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities.* pp. 40-51, University of Washington Press, Seattle.

Clarren, S.K. and Astley, S.J. (1998) Identification of children with fetal alcohol syndrome and an opportunity for referral of their mothers for primary prevention-Washington, 1993-97. *Morbidity and Mortality Weekly Report*, **47**(40):861-864.

Clarren, S.K., Carmichael Olson, H., Clarren, S.G.B., and Astley S.J. (2000) A child with fetal alcohol syndrome. In: Guralnick, M.J. ed. *Interdisciplinary Clinical Assessment of Young Children with Developmental Disabilities*. pp. 307-326, Paul H. Brookes Publishing Co., Baltimore.

Clarren, S.K. and Smith, D.W. (1978) The fetal alcohol syndrome. *New England Journal of Medicine* **298**:1063-1067.

Cordero, J.F., Floyd, R.L., Martin, M.L., Davis, M. and Hymbaugh, K. (1994) Tracking the prevalence of FAS. *Alcohol Health Research World* **18(1)**:82-85.

Davis, A. and Lipson, A. A (1984) challenge in managing a family with fetal alcohol syndrome. *Clinical Pediatrics* **23**:304.

Ernst, C.C., Grant, T.M., Streissguth, A.P. and Sampson, P.D. (1999) Intervention with high-risk alcohol and drug-abusing mothers: II. Three-year findings from the Seattle model of paraprofessional advocacy. *Journal Community Psychology* **27(1)**:19-38.

Floyd, R.L, Davis, M.K., Martin, M.L., Hungerford, D., and Hymbaugh, K.J. (1994) Fetal Alcohol Syndrome. In *From Data to Action*, Wilcox, L.S. and Marks, J.S. eds, pp. 343-350. U.S. Public Health Service. CDC Atlanta Georgia.

Grant, T.M, Ernst, C.C. and Streissguth, A.P. (1999) Intervention with high-risk alcohol and drug-abusing mothers: I. Administration strategies of the Seattle model of paraprofessional advocacy. *Journal Community Psychology* **27(1)**:1-18.

Jones, K.L. and Smith, D.W. (1973) Recognition of the fetal alcohol syndrome in early infancy. *Lancet* **2**:999-1001, 1973.

May, P.A., Hymbaugh, K.J., Aase,J.M. and Samet, J.M. (1983) Epidemiology of fetal alcohol syndrome among American Indians of the Southwest. *Social Biology* **30**:374-387.

National Institute on Alcohol Abuse and Alcoholism: Seventh Special Report to the U.S. Congress on Alcohol and Health. (1990) Washington (DC): U.S. Department of Health and Human Services, DHHS Pub. No. ADM (90-1656).

Sarason, I.G., Sarason, B.R., Shearin, E.N. and Pierce, G.R. (1987) A brief measure of social support: Practical and theoretical implications. *Journal Social and Personal Relationships*.**4**:497-510.

Seattle-King County Task Force for Chemically Dependent Women (1993) Chemical dependency treatment for women in Seattle and King County Washington. pp. 39.

Shipley, W.C. (1967) *Shipley-Institute of Living Scale.* Los Angeles, CA: Western Psychological Services, 1967.

Sokol, R.J. and Clarren, S.K. (1989) Guidelines for use of terminology describing the impact of prenatal alcohol on the offspring. *Alcoholism: Clinical and Experimental Research* **13(4)**:597-598.

Stratton, K., Howe, C. and Battaglia, F. eds, (1996) *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment* Institute of Medicine, National Academy Press, Washington D.C.

Streissguth, A. and Kanton, J. eds, (1997) *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities*. University of Washington Press, Seattle.