NPAIHB Tribal FASD Project

❖ Overview of FAS and FASD

Syndromes describe a set of specifically defined and clinically documented characteristics. Fetal Alcohol Syndrome describes a specific pattern of morphologic abnormalities observed in children and adults who have been prenatally (in utero) exposed to alcohol. FASD, according to the FASD Center for Excellence, is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

Diagnostic, protocols and definitions change; however, what remains consistent within the context of diagnostic criteria are the following four criteria for an FAS diagnosis:

- ❖ History of maternal alcohol use during pregnancy
- ❖ Particular facial or morphologic features
- ❖ Growth deficiency
- ❖ Central nervous system abnormalities

Some but not all of the primary diagnostic criteria for FAS can lead to the following diagnoses: Alcohol Related Neurodevelopmental Disorder (ARND), Fetal Alcohol Related Conditions (FARC), Alcohol Related Birth Defects (ARBD). Alcohol is a teratogen (toxin) that affects fetal development when a woman drinks. Whether or not her child has the specific physical characteristics of FAS depends on when she drinks.

Fetal Alcohol Spectrum Disorder (FASD) refers to the range of behavioral, physical and cognitive (intellectual or learning) disabilities resulting from prenatal exposure to alcohol. FASD is not a diagnosis but rather a descriptive umbrella of manifestations. FASD identifies not only the physical, cognitive and social/emotional impact of alcohol, but often also reveals the complicated and significant impairment resulting in mild to severe mental health issues. As these children age mental illness can become apparent and already complex treatment plans may become less effective because of lack of services and co-morbidities. The incidence of these secondary characteristics and co-occurring disorders can be diminished by early intervention. (Ann Streissguth).

The toxic potential of alcohol on the fetus has been recognized for over 30 years, yet alcohol continues to be one of the most commonly ingested teratogens. (Randall, CL J Study Alcohol 62:2001). Alcohol using (prenatal exposure to alcohol) during pregnancy is a significant public health problem, despite prevention efforts over the past twenty years. Prenatal exposure to alcohol is one of the leading causes of preventable birth defects and developmental disabilities. Fetal alcohol spectrum disorders (F.A.S.D.) are caused by the effects of maternal alcohol consumption during pregnancy. (Wattendorf, DJ Am Fam Physician, 2005 2(2)) Exposure to alcohol can have numerous adverse effects on the developing fetus, including structural, neurocognitive and behavioral disabilities. (Manning, MA, Neurosci Biobehav Rev, 2007) Diagnosis of an F.A.S.D. is

difficult, awareness and understanding of the disorders remains lower than optimum. (Caprara, DL Neurosci Biobehav Rev, 2007, Ryan, DM, AJPH 12/2006). F.A.S.D. is a large and rapidly increasing public health problem worldwide (Calhoun, R, Ann 1st super Sanita, 2006).

It is important to remember how young we are in our knowledge before we can begin any definitive description or identification of what characteristics constitute a diagnosis of Fetal Alcohol Syndrome or what behaviors suggest fetal alcohol exposure. In a sense, we are in the youthful stage of both clinical and practical, theoretical and functional, inquiry. FAS is not yet 40 years old in its existence as a defined syndrome; we have only to look at Down's Syndrome and Autism to realize how much evolution is ahead of us both clinically and practically.

When we have the privilege as caregivers or providers to work with people with challenges or disabilities, it is good to be humbled by the thought that "this is what we think we know so far."

According to the birth defects monitoring program, F.A.S. rates among American Indians are 3.0 per 1000 live births compared to a rate of 0.6 per 1000 live births among Blacks and 0.1 per 1000 live births among Whites.

Fetal Alcohol Syndrome (FAS) and the related conditions of Fetal Alcohol Spectrum Disorder have produced some of the most devastating effects impacting Native peoples within the twenty-first century. Producing a spectrum of issues ranging from infant death to developmental, physical, cognitive and emotional delays that may be manifested in low self-esteem, learning difficulties, physical anomalies, impulsivity and poor judgment, FAS and related conditions are 100 percent preventable.

American Indian and Alaska Natives (AI/AN) have high rates of alcohol use, frequency of use and increased rates of F.A.S.D., compared with other ethnic groups (J. Hishnanick, 1992, PA May 1996, and JM Wallace, et al, 2003). Native studies reveal that many communities have a high incidence of FASD producing devastating affects with a global impact on all aspects of community life. Central to understanding the multigenerational and multidisciplinary aspects of fetal alcohol is recognition of this comprehensive impact on all facets of service delivery.

Indian Country has led the response to this issue by developing the majority of prevention and intervention curricula. However, just imparting this knowledge is not enough. We know so much. We have collected a large amount of information about the problem. We even know the solution. What we lack are the appropriate vehicles to get us to, or even effectively facilitate, interventions. We must create an awareness that re-teaches and reinforces the knowledge taught by our ancestors that a child is a sacred gift. We must recognize that there are many among us whose lives are already impacted and for whom interventions will result in prevention for future generations. For our children and the parents of our children who are already affected, we must move beyond blame and gloom and doom to demonstrate interventions that successfully utilize the strengths of these

individuals. We must also promote holistic healing through traditional and developmentally appropriate techniques that address the physical, intellectual, emotional, and spiritual needs of individuals affected by an FASD, integrating service provider and "natural helper community systems". In this way, we must integrate traditional and clinical knowledge, filling our basket with tools of help of past and present generations.

❖ Project Information

The global impact of F.A.S.D. within Native communities has served to inform the design and delivery of the Northwest Tribal Fetal Alcohol Spectrum Disorders Project. Driven from a comprehensive, holistic approach, the N.P.A.I.H.B. F.A.S.D. project understands the potentially stigmatic nature inherent in addressing F.A.S.D. and believes that community readiness merits careful and respectful attention resulting in increased awareness and information that is "helpful" and never "hurts". This premise promote methodologies that are culturally congruent with a process orientation that engages all community stake holders and solicits community member response in identifying strengths that reveal commonly held community norms, values and beliefs, and identifying needs that reveal goals barriered by both gaps in services and lack of integrated delivery. Such a comprehensive approach further informs the need for multigenerational support that serves not only an individual with an F.A.S.D. but the entire family through out the lifespan. F.A.S.D. produces life long consequences.

The Northwest Tribal Fetal Alcohol Spectrum Disorders Project incorporates this multigenerational family focus that draws on the strengths and identity of the family within the context of their culture and community landscape. The traditions, values and beliefs of the client and their community inform the process and shape the procedures and protocols generated by the project mission to deliver prevention and intervention strategies to pre-conceptual through elder American Indian/Alaska Native populations that will diminish the prevalence of pre-natal exposure to alcohol, the occurrence and incidence of the secondary characteristics and co-occurring disorders associated with an F.A.S.D. Tribal communities are supported in creating and growing a readiness and delivery model from the context of their own identified attitudes, needs and resources.

❖ Mission

The Northwest Portland Indian Health Board Tribal FASD Project seeks to reduce the incidence of prenatal exposure to alcohol and to diminish the consequence of secondary characteristics of FASD among American Indian families and tribal communities.

❖ Goals

- To diminish the incidence of pre-natal exposure to alcohol
- To diminish the incidence of multiple F.A.S.D. births by one mother and address the risk of mothers of child bearing age who themselves may have an F.A.S.D.
- To diminish the consequence of secondary characteristics and co-morbidities

- To model respect and compassion throughout all components and methodologies of F.A.S.D. training and technical assistance such that denial of its prevalence is diminished and receptive readiness for understanding its pervasive impact upon all aspects of community life is increased
- To develop diagnostic pre and post protocols that demonstrate that diagnosis is for identifying solutions rather than labeling; and that community specific services can be delivered as part of a collaborate circle of care promoting "healthy families and healthy futures"
- To engage all community members in addressing the presence of F.A.S.D. from a multi- and intergenerational culturally congruent context
- To increase successful educational and career outcomes for individuals with an F.A.S.D.
- To provide technical assistance facilitating appropriate cognitive re-tailoring of educational and behavioral health strategies

❖ Project History

History and Background

- The project has assisted tribes in developing prevention and intervention strategies to create an awareness of the spectrum of impact to individuals, families and communities, disseminates information, assists in the creation of FASD community task forces and diagnostic clinics, and offers technical assistance and training.
- Community assessments identified broad themes and needs common to sites.
  - Twenty out of twenty tribes expressed or reported:
    - The impact of grief and denial on provider-family relationships as a major inhibitor to successful prevention and intervention strategies.
    - That families have difficulty accessing useful information and resources regarding-FASD.
    - That health clinics, educational programs, and social services within the community vary in their knowledge, access and delivery of FASD information.
    - Difficult or no access to medical identification and diagnosis.
    - That family and community denial and grief result sometimes from stigmatic approaches or inadequate support.
    - A generalized resistance to *counts, and studies* in the absence of effective help on the subject.
    - The need for more training specific to each service, as well as trainings that involve all providers and families as a consortium.
  - Nineteen out of twenty tribes reported:
    - That the transition and change of providers produced little continuity of care or sustainable approach to FASD programming.
    - Little real collaboration among services.
  - Eighteen out of twenty tribes reported:
    - That there was a need for all programs to tailor their parenting and substance abuse programs to meet the learning styles of alcohol-affected populations.

- Seventeen out of twenty tribes reported:
    - A need for intervention strategies that recognize the multigenerational aspects of FASD and its impact on parents and grandparents.
- Fifteen out of twenty tribes reported:
    - Infrequent integration of elders and community members in prevention and intervention strategies.
    - Little knowledge of how to use educational mandates to identify and map intervention strategies.
- Four out of twenty tribes reported:
    - Concern about the occurrence of multiple births of children affected by alcohol exposure in utero by the same mother.
    - That these mothers may possibly be alcohol affected themselves.

While this data reveals the initial assessments, successive periodic assessments have been conducted, indicating that communities have become more successful in decreasing stigma and increasing awareness. One community, having developed a diagnostic clinic through the project, reports receiving more family and community referrals for diagnosis than from providers.

❖ Scope of Work

The most successful collaborative circle of care approach seems to be one that acknowledges the grief of the past and moves forward, without judgment of shame and blame, to proactive strengths-based strategies…the proverbial mapping of the positive, in terms of the individual, the family and the community. For the community response to be effective it must have prevention, intervention and after care treatment systems that are seamless in their ability to provide from little to intensive care. Services within these systems should truly circle the need with coordinated levels of care that draw on multigenerational and multi-skilled (volunteers, mentors, professionals) community members. Such an integrated delivery insures the benefits of the reciprocal nature of prevention, intervention and after care.

Respect for each other's place in the solution drives collaborative strategies that increase the frequency and duration of support for the individual and their family. Simply, what this means is that all people within the community recognize their talents and skills that contribute to community healing through proud and productive use of these strengths in a manner that reflects community culture.

These strengths, skills and talents may reflect teachers, builders, mechanics, artists, beaders, drummers, musicians, trappers, hunters, storytellers, counselors, etc. which can be matched to community development objectives. A community inventory of resources and goals is a prerequisite to determining this match and its direction towards community vision. If the objective is to eliminate alcohol and drug use, it is

best understood from the context of the goal to achieve community health. Orienting the perspective to what you are building toward reinforces the concept and process of "putting something in place" rather than "taking something away."

- Project offers:
  - Trainings and technical assistance, developing integrated systems and Collaborative Circles of Care for families impacted by FASD.
    - Trainings and technical assistance include:
      Community
      - Early Childhood Education/Early Intervention
      - Education
      - Behavioral Health
      - Social Services
      - Justice and Corrections
    - Promoting and assisting community "Task Force" "or (consortium) development, facilitating Community Readiness Assessment and development of community approach
    - Facilitation and development of tribal community diagnostic clinics with pre and post services integrated within service delivery
    - Increased pre through post natal clinic support strategies developed in partnership with the health clinics
    - Partnerships including the Substance Abuse and Mental Health Administration and the University of Washington Fetal Alcohol and Drug Unit and PCAP programs
    - Recommendations for a tribal community approach to FASD with examples of community specific process models

❖ **Model Sequence**

- Community Steps
    - Create coalition or task force of community and service providers
    - Develop mission and design initial goals
    - Conduct community assessment of attitudes, strengths, needs and resources relating to FASD
    - Seek Council Resolution
    - Provide trainings across all disciplines, departments and provider settings, inclusive of community gatherings, activities and media promoting proactive awareness
    - Provide technical assistance facilitating program development and delivery including treatment planning, IFSP, IEP and Corrections Transitions Plans
    - Develop community diagnostic team following the Collaborative Circle of Care model with its pre- and post-methodology as described in the NPAIHB Tribal FASD Project Diagnostic Model

NOTE: The second, third and fourth steps are most successful when in concert, simultaneously serving to support and inform each other's process.

- **Project Stakeholders**

  - Educators
    - Healthy Start
    - Early Intervention
    - Early Childhood
    - Head Start
    - Special Education
    - Elementary through High School
    - Post Secondary/College
  - Behavioral Health
    - Mental Health Providers
    - Drug and Alcohol Treatment Counselors
    - Parent Educators
  - Public Health Providers
    - C.H.R.s
    - M.P.H.
    - W.I.C. staff
    - Medical staff: doctors and nurses
  - Indian Child Welfare
  - Vocational and Career Development Counselors
  - Corrections providers
    - Juvenile Services
    - Adult Corrections
    - Probation Officers
  - Families affected by fetal alcohol
    - Biologic
    - Adoptive
    - Foster
  - Middle and high school students
  - Community leaders/tribal council members
  - Elders
  - Spiritual advisers and religious leaders (relevant to community context)
  - Tribal and economic development staff
  - Tribal and community recreation development staff
  - Housing Providers

- **Activities**

  - Facilitate mapping of positive prevention strategies that draw on the strengths of the specific tribe or nation
  - Review existing prevention materials and strategies

- Involve consortium members in designing appropriate prevention strategies utilizing all aspects of community systems and activities
- Use opportunities for prevention messages in community activities, (i.e., canoe building, elder home visits, prenatal services and home visits, recreation programs, etc.)
  - Create bi-weekly cradle board making group for tangible reminder of "invitation to sacred gift".
- Identify the levels (primary, secondary, and tertiary) of prevention and their reciprocal relationship with all intervention strategies
- Develop a community-specific model and plan for addressing denial, grief, and shame
- Help communities define effective ways to use elders and extended families within prevention and intervention strategies to extend the frequency and duration of support services
- Help communities identify diversity of cultural and spiritual strengths and their appropriate integration within prevention and intervention strategies
- Construct collaborative consortium of community and providers to design strategies to address these issues
- Acknowledge and address community provider family relations
- Help communities build flexible, collaborative models that integrate all service providers and community members. This includes the following steps:
  - Provide educational opportunities and trainings that involve all providers and community members (specifically including affected families) in a developmental training and discussion of primary and secondary characteristics and appropriate preventions and interventions
  - Train, facilitate and provide ongoing technical assistance throughout all services so that all community systems and structures are knowledgeable about the cognitive learning and behavioral manifestations of an FASD. Insure they receive consistent support in designing individual and family intervention plans such as IFSPs, IEPs, Court Orders and Dispositions, and Treatment Plans
  - Create models for single source case coordination with each family
    - <u>Example</u> methodology:
      - Using concept of kinship networks/clan systems as model, identify strong extended family member for support and sustainability of prevention plan and "care coordination"
      - Identify elder and community volunteer mentors as traditional "helpers" to extend frequency and duration of client contact and support
      - Provide pregnant mother a minimum of one home visit per week for positive support and reinforcement of concept of "invitation to sacred child" using storytelling
      - Create monthly structure of "success markers" or "celebrations" at frequent intervals to honor pregnant mother's prevention plan successes and to map positive behavior

    - ♦ Examples could include: "Salmon Feast" for honoring; "Giveaway for gratitude, etc.
- Create pregnant mother's weekly "Talking Circle" support group (inclusive of both those not at risk and those at risk)
    - ♦ Provide non-didactic weekly gathering that includes traditional helpers, elders, birth mother advocates and support videos

❖ Funding and Program Contacts

The Northwest Tribal Fetal Alcohol Spectrum Disorders Project is funded by the Indian Heath Service. The Project has benefitted from it's partnership with the University of Washington FAS/FAE Legal Issues Resource Center, Fetal Alcohol & Drug Unit, and Fetal Alcohol Diagnostic and Prevention Network.

Administrative Officer:
Jacqueline Left Hand Bull (jlefthandbull@npapihb.org)
(503) 416-3258
Consultant:
Suzie Kuerschner (suziekuerschner@gmail.com) (503) 622-3973.

❖ Supportive Project Documents and Curricula (link to documents)

- Document Links
    - Building a Sustainable Coalition
    - Coalition or Task Force Potential Team Members
    - Community Assessment
    - Diagnostic Model
    - Proctor Model
    - Juvenile Justice: an opportunity
    - Guiding Principals for Transitional Programming
    - Intervention Mapping
    - Building Blocks for Successful Prevention & Intervention Strategies
    - Overlapping Behavioral Characteristics & Related Mental Health Diagnoses in Children
    - "Weaving a Resilient Basket of Hope; Filling with Tools of Help" A Developmental Manual
    - Journey to Self Reliance
    - Holistic Logic Model
    - Playgroup Model for an Early Childhood Education Approach
    - Project Template Forms
        - Vision, Mission and Values
        - Memorandum of Agreement
        - Family Coordination Service Plan
        - Transitional Work Plan

- I'm pregnant… I am an elder with an FASD