

## *Forming a Diagnostic Team – an example of an ongoing process*

### **NPAIHB**

### **FASD Diagnostic Project**

### **Overview**

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Development of the diagnostic project generates from within the context of the collaborative circles of care model and exists as a part of the continuum of service and support to Northwest tribal families affected by an FASD. It should be understood philosophically and conceptually that its purpose is to increase application of information in a process that that will result in positive outcomes for clients, family and communities. It should "help"; it should never "hurt." The diagnostic project ideally is derived from a multigenerational family focus that draws on the strengths and identity of the family within its cultural and community landscape. The traditions, values and beliefs of the client and family should inform the process, shape the pre and post diagnostic procedures and protocol.

Prior to entering the diagnostic project process, elders, family and advocates need to be identified to serve as primary support people who will serve to navigate systems of services, and who will help to process and relay information in a positive, concrete manner that is structured, functional and culturally appropriate.

## **A Proposed Diagnostic Project**

### ❖ Objective

- To provide culturally congruent assessment and comprehensive diagnostic services with follow up delivery of support services informed by the norms, values and strengths of the community

### ❖ Goals for Diagnostic Project

- To support and extend current attitudes and practices, recognizing the pervasive impact of FASD on all aspects of community life
- To demonstrate that community specific diagnostic services can be delivered and received as a component of service and a part of the collaborative circles of care that will promote “healthy families and healthy futures”
- To create understanding and demonstrate that diagnosis is for accessing information and identifying solutions rather than for labeling
- To recognize and identify “subset” of women of childbearing age who may themselves have an FASD and increased risk for producing a child with an FASD
- To diminish the incidence of secondary characteristics as they relate to the absence or lack of diagnosis
- To use an identified four digit medical diagnostic code in concert with other evaluative and interview findings to create individualized client/family plans
- To continue to move focus from morphologic understanding of FASD to cognitive and behavioral understanding (“it is not the face we are treating”)
- To form foundations for future longitudinal study, exploration and subsequent delivery of services, identifying best practices based on evidence and indigenous knowledge; attention is given to
  - Outcomes for mothers with an FASD with and without appropriate intervention
  - Effects of early intervention and diminished presence of secondary characteristics
  - Possible increased risk for post-partum depression among women who may have an FASD
  - Strategies addressing maternal bonding and attachment issues impacted by an FASD
- To model respect and compassion throughout all components and methodologies of the diagnostic processes by observing and responding to family's communication style (including the pace of that communication), tailoring an individual diagnostic plan for each client
- To create an understanding of the potential for “diagnosis as prevention”

### ❖ Approach (values and principles)

- Elders, family and community traditions, beliefs, norms and values are embedded throughout the diagnostic process
- Diagnostic team members promote a climate conducive to positive experience and relationships with families, i.e., feel no judgment and feel they are driving the process
- Points of entry are linked and coordinated

- Basic conditions for positive evaluation experience include:
  - Freedom from fear of failure
  - Encouragement and positive behavioral mapping
- Diagnostic policies, protocols and procedures are cooperative and based on community assessments of strengths, needs and resources
- Families feel equal in relationships and as participants (delivery is not done “to” but designed “with” and participation in their lives is understood as a privilege by diagnostic team members)
- All practice is embedded in a culturally congruent context that is neither stigmatic or punitive in response to need or delivery of support
- Ensure volitional willingness of participants
- Services are driven from perspective that all inquiry and information on FASD should “help” not “hurt”
- Effort is family focused and multigenerational with extended family strengths identified and used as the foundation for future holistic interventions
- All diagnostic team members and participants are knowledgeable about the special parenting challenges of parents who themselves may have special needs, i.e., FASD
  - Seamless fit with existing services
- Efforts are driven from a perspective of “family wellness“ and co-located in the ecologic context of natural community and family resource settings (i.e., health clinic, early childhood settings, etc.)
  - Utilizes case coordinated care model from NPAIHB FASD Tribal Project (see forms)
- Successful community mentors are paired with the client and family as on-going partners for support

#### ❖ Barriers

- Functional
  - Geographic distance to appropriate diagnostic settings
  - Lack of sustained training and understanding of comprehensive impact of FASD
  - Lack of understanding of diagnosis as a tool of opportunity rather than a sentence or label
  - Sense of clinical interest limited to diagnosis but little care of follow up (stories of negative experience)
  - Lack of integrated service delivery
  - Turf issues/competition
  - Fear of change
  - Lack of funding for community specific diagnostic, assessment, and follow up services
- Conceptual
  - Absence of addressing community wide issues of grief, hopelessness, loss, shame, blame and denial related to the effects of alcohol on the fetus
  - Lack of collaborative models integrating all service providers and community members

- Uncomfortable diagnostic access and protocol
- Little understanding of FASD's relationship to other health, education and social issues
- Insufficient identification and incorporation of the spiritual and cultural strengths and diversity within each tribe
- Aversion to surveillance
- Fear of loss or misuse of confidentiality
- Inadequate follow up
- Overriding issues relating to both needs and barriers
  - Denial
  - Grief
  - Pain
  - Blame
  - Shame
  - Mistrust of institutionally driven services

❖ Methodology for Diagnostic Project Development:

- Identify Elders, grandmothers and grandfathers, family and community members that can serve as advocates and support during the diagnostic process (including pre and post)
- Continue to increase provider knowledge and skills inclusive of public health, private physicians, mental health and substance abuse, education, social services, justice and corrections
- Continue to train people responsible for referral in non-stigmatic delivery and strategies that are supportive and culturally congruent in their address of issues of denial and guilt
- Continue to train service providers and community in access and availability of intervention services provided by the tribe or mandated by Federal Education Acts (IDEA) and Human Services (SSI)
- Continue to promote community and provider understanding of diagnosis and surveillance from the context of providing successful intervention and prevention strategies
- Provide multiple points of entry to referral for assessment and diagnosis from community providers and services inclusive of family
- Identify site-specific diagnostic team members from the following:
  - Pediatricians, physicians, nurse practitioners, neurologists, speech pathologists, occupational therapists, physical therapists, educators, psychologists, learning specialists, social workers, mental health and substance abuse professionals, community members, elders, birth family representatives, and caregiver family advocates
- Diagnostic team and NPAIHB consultants co-present series of community trainings and gatherings on positive outcomes of screening and diagnosis (use training and storytelling models, demystifying morphologic understanding)
  - Individualized cognitive and behavioral interventions
  - Importance of early identification
  - Increased positive outcomes at all ages
- Present and use media to give voice to those with positive diagnostic experiences and services
- Establish diagnostic setting co-locating with positive non-stigmatic community resources

- Define appropriate diagnostic protocols and process from context of community values and culture. Include:
  - Screening and referral
  - Family interview and visit with team
  - Family home visits
  - Identify support person
- Map of diagnosis and evaluation process
  - Provides pre and post diagnostic consultation with family, advocates and clients to explain process and answer questions
  - Ensures that family has support system present if needed during interview and debriefing stages of diagnosis
  - Provides welcoming, non-judgmental initial contact at beginning of process with diagnostic team coordinator, who explains the proceedings
  - Provides non-stigmatic, non-judgmental, culturally appropriate interview techniques for interviewing Elders, parents, family, caregivers and clients
  - Utilizes diagnostic, interview and evaluation techniques recognized as meeting FASD diagnostic standards (includes four-digit medical code and appropriate spectrum of professionals representing all domains of development)
  - Diagnostic sequence reflects the values of community and family focus, and will be defined by the specific communities and the families they serve
- Evaluation findings and results shared with family and caregivers
- Framed from perspective that identifies strengths as well as needs
  - Individualized to support specific family and client strengths and needs
  - Framed in solutions and appropriate interventions
- Extended family and provider meeting
  - Identification of players and case coordination
  - Mapping of appropriate referrals and “follow through”
- Follow up assistance including:
  - Home visit for processing of information
  - Identify and establish family focused resources
    - Set up transition meetings with appropriate resources
- Evaluative component soliciting participant feedback (oral or written)

❖ Individual Care Methodology:

- **Pre-diagnosis**
  - Select Elder and/or family advocate
  - Meet and discuss with client, family and Elder support advocates to learn their knowledge and understanding of
  - Visit and share stories, videos, and materials, as well as children's curricula through "home visit" or "out of service site" model

- Meet with all participants (client, Elders, family and diagnostic team) to map pre through post diagnostic process; individualizing to meet their context
- Share stories and materials with client, family and support advocates, identifying the strengths of people with an FASD (art, music, beadwork, trapping, care giving, etc.).
- Help client, family and advocates understand their potential strengths in visual observation and expression, and compassion
  - Share concrete, clear descriptions and stories of the challenges with client and support advocates
  - Review with client, family and support advocates the diagnostic procedure; insuring that it is informed by respect and understood as a tool to create more successful plans and outcomes for the client...that it is never about being "smart" or "stupid"
  - Create individual diagnostic plan in collaboration with identified support team and client
- **Diagnosis**
  - Insure that transportation to, and participation in, the diagnosis includes at least one supportive family member, Elder or advocate
  - Demystify and de-stigmatize diagnostic process by engaging trust and comfort through an explanation of each step as described in the individualized diagnostic plan
  - Deliver four-digit diagnostic protocol as identified and delivered through the University of Washington Diagnostic Clinic
  - Review findings with all participants giving time and space for client and support advocates processing and response
  - Identify and honor client's strengths by making and giving them and their family and support advocates a list of these strengths, showing how they will apply to meet their needs. Honor the Elder's participation in this process
  - Send home (with support team) "care package" of appropriate stories, informational literature, toy (if child) and appropriate food (if long journey)
- **Post Diagnosis**
  - Continue Circle of Collaborative Care approach with team of client, family and support advocates through "home" or "off-site" and/or center visits, mapping positive interventions and identifying the appropriate resources for referral. Use natural helpers to extend frequency and duration
  - Accompany and facilitate (through support team) first visits to referred resources
  - Meet with all appropriate service and systems providers identified on individual Circle of Care plan, to train and develop successful, adaptive strategies and structured, positive interventions
  - Develop and identify components of Individual Transition Plan
  - Continue frequency and duration of Elder and family advocate support as identified in Individual Diagnostic Plan
  - Begin to involve client in Family Support Groups and Community

- **Awareness Campaigns when appropriate**
  - Map the positive, celebrate and honor with Elders and community!

### **History of NPAIHB FAS Tribal Project**

#### ❖ Community attitudes and services

- Findings from survey
  - NPAIHB community assessments identified broad themes and needs common to most 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 discipline, as well as trainings that involve all providers and families as a consortium
    - Nineteen out of twenty tribes expressed or reported:
      - That the transition and change of providers produced little continuity of care or sustainable approach to FASD programming
    - Eighteen out of twenty tribes expressed or felt:
      - There was a need for all programs to tailor their parenting and substance abuse programs to meet the learning disabilities of alcohol-affected populations
      - Seventeen out of twenty tribes expressed or felt:
        - A need for intervention strategies that recognize the multigenerational aspects of FASD and its impact on parents and grandparents
    - Fifteen out of twenty tribes expressed or felt:
      - 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 expressed or felt:
      - The need to discuss the occurrence of multiple births of children affected by alcohol exposure in utero by the same mother
      - The need to understand that these mothers may have an FASD themselves

- Scope of work
  - Six tribes in Idaho, Oregon, and Washington participated. Selection was based on the level of interest expressed and their ability to successfully complete the tasks. Each site received a minimum of four visits to address the five major issues listed above
  - Facilitated mapping of positive prevention strategies that draw on the strengths of the specific tribe or nation
  - Reviewed existing prevention materials and strategies
  - Involved consortium members in designing appropriate prevention strategies utilizing all aspects of community systems and activities
  - Used opportunities for prevention messages in community activities, i.e., canoe building, elder home visits
  - Identified the levels (primary, secondary, and tertiary) of prevention and their reciprocal relationship with all intervention strategies
  - Developed a community-specific model and plan for addressing denial, grief, and shame
  - Helped communities define effective ways to use elders and extended families within prevention and intervention strategies
  - Helped communities identify diversity of cultural and spiritual strengths and their appropriate integration within prevention and intervention strategies
  - Constructed collaborative consortium of community and providers to design strategies to address these issues
  - Acknowledged and addressed community provider family relations
  - Helped communities build flexible, circles of collaborative care models that integrate all service providers and community members. This included the following steps:
    - Provided educational opportunities and trainings that involved 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
    - Created models for single source case management for each family
    - Created an oversight team or consortium of providers and community members resulting in “Task Force” development

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**"Successful diagnostic protocol delivery is measured by family and community requests rather than by agency or systems referral"**



**Budget (2005)**

**One time diagnostic cost for training diagnostic teams**

Six team members @\$850.00.....\$ 5,100.00  
 One time FASD PN training cost for six sites.....\$30,600.00

**Diagnostic team and NPAIHB consultant quarterly community training**

Diagnostic team training @ 3 hours.....\$1,000.00  
 Total annual diagnostic team training cost.....\$4,000.00

**Direct diagnostic family service per family**

Pre-clinic family meetings (inclusive of home visit)

Social worker or mental health worker.....@ 2 hours @ \$60.00 \$120.00  
 Caregiver family advocate.....@ 2 hours @ \$25.00 \$ 50.00

Pre-clinic total \$170.00

Clinic

Pediatricians or physicians or nurse practitioners...@ 3 hours @ \$200.00 \$600.00  
 Neurologists.....@ 3 hours @ \$200.00 \$600.00  
 Speech pathologists.....@ 3 hours @ \$100.00 \$300.00  
 Occupational therapists.....@ 3 hours @ \$100.00 \$300.00  
 Physical therapists.....@ 3 hours @ \$100.00 \$300.00  
 Educators or learning specialists.....@ 3 hours @ \$ 60.00 \$180.00  
 Psychologists or mental health.....@ 3 hours @ \$100.00 \$300.00  
 Social workers.....@ 3 hours @ \$ 60.00 \$180.00  
 Substance abuse professionals.....@ 3 hours @ \$ 50.00 \$150.00  
 Community members.....@ 3 hours @ \$ 20.00 \$ 60.00  
 Elders.....@ 3 hours @ \$ 20.00 \$ 60.00  
 Birth family representatives.....@ 3 hours @ \$ 20.00 \$ 60.00  
 Caregiver family advocates.....@ 3 hours @ \$ 25.00 \$ 75.00

Clinic total \$3, 165.00

Post-clinic family meetings and transition to appropriate resources (inclusive of home visit and meetings with resources)

Educators or learning specialists.....@ 3 hours @ \$60.00 \$180.00  
 Social worker or mental health worker.....@ 3 hours @ \$60.00 \$180.00  
 Caregiver family advocate.....@ 3 hours @ \$25.00 \$ 75.00

Post-clinic total \$435.00

Total per family cost \$3,770.00

Annual cost for diagnostic service for ten families \$37,700.00



Total site diagnostic service cost  
 Total estimated annual cost per site for services \$41,700.00

**NPAIHB FASD consultant**

Quarterly community training.....@ 3 hours \$180.00  
 @ 4 times \$720.00

Participation in direct family diagnosis  
 @ 2 hrs pre clinic \$120.00  
 @ 3 hrs clinic \$180.00  
 @ 3 hrs post clinic \$180.00

Total NPAIHB consultant cost per family.....\$480.00

Total annual consultant cost for ten families.....\$4,800.00

Total annual consultant site cost..... \$5, 520.00

Total cost for six sites.....\$33,120.00

**Totals**

First Year

One time FASD PN diagnostic team training.....\$5,100.00

Quarterly community training.....\$4,000.00

Direct family diagnostic services..... \$37,700.00

NPAIHB total annual site cost.....\$5,520.00

Total first year per site services.....\$52,320.00

Second year

Direct family diagnostic services.....\$37,700.00

NPAIHB consultant services .....\$5,520.00

Total Second year per site services.....\$43,220.00

First Year total cost for six sites.....\$313,920.00

Second year total cost for six sites.....\$259,320.00