VI. Developing a Multidisciplinary Team Approach for Cases Involving Persons with FAS/ARND

Learning Objectives and Activities
• *Define "multidisciplinary team" and how it may be applied to the issues of FAS/ ARND in Indian Country* • *Define the team players and their roles* • *Develop a plan for creating a local FAS/ARND multidisciplinary team*
Presenters and Materials
• *Curriculum, chapter VI.* • *FAS/ARND MDT Planning Worksheet*

Pros and Cons for Developing a Tribally Controlled Program

There are many obstacles to developing new local programs even where the resources for such programs may already be available. This portion of the curriculum suggests some strategies for planning and development of an FAS/ARND multidisciplinary team with achievable goals and objectives.

Pros:

- Exercises in tribal sovereignty
- Creates culturally appropriate services
- Gives tribe flexibility in design
- Tribe determines the service area and the population served
- Offers services that are close to the people who use them
- Services may be for tribal members only
- Tribe determines eligibility criteria, including time limits, for services

Cons:

- Time needed to develop the program's infrastructure is often limited
- Grant-funded programs are subject to the same data collection and reporting requirements as state programs
- Granted tribes are ineligible for bonus or contingency funds
- Tribal politics
- Information sharing between government agencies can be time-consuming and bureaucratic

Potential Funding Sources

The following is a list of some federal funding sources for substance abuse and maternal/infant health programs that are available to tribes, as well as examples of projects that have been funded. Although some projects may be outdated, they provide an idea of the past and current projects funded by federal agencies. See appendices for contact information.

Bureau of Indian Affairs (BIA)

- BIA schools receive Chapter 1 funding and special education funding. Children with FAS/ARND who fit the criteria for these schools may attend.
- The Drug-Free Schools and Communities Act sets aside 1% of available funds for BIA schools to address drug and alcohol issues.
- The Office of Indian Education sponsors an "FAS Awareness Week" for all BIA personnel and a one-month calendar of activities based on FAS for BIA-funded schools.

Indian Health Service (IHS)

- The "Early Childhood and Maternal Health Care Project" operates out of six IHS facilities. It provides general information on nutrition and health education, including the dangers of drinking during pregnancy.
- Public Law 100-713 (Indian Health Care Amendments of 1988) funded the development of a service plan, the goal of which was to reduce the rate of FAS among Native Americans served by IHS facilities to 1 case per 1,000 live births.
- IHS is currently developing a national computer registry that will list children with special needs. It is hoped that this database will enhance the tracking of services to children with disabilities.
- Specific area offices (Alaska, Nashville) have funded a number of local pilot projects addressing ARND.
- IHS has established prevention programs; case management programs; training and technical assistance; and group homes for pregnant alcoholic women.
- Some offices have allocated funds to develop culturally-specific FAS educational materials.
- $18.7 million was used in FY 1989 to establish youth inpatient alcohol and substance abuse treatment centers in eleven IHS service areas, as well as FAS/ARND

education programs for all employees in all service areas.

- The Office of Alcoholism has funded residential treatment centers, halfway houses, outpatient sites, and prevention programs.
- $1.132 million of IHS funding for FY 1990 was spent on various programs designed specifically to address FAS.
- $250,000 was spent in FY 1988 to provide a training workshop for individuals working with FAS in tribal communities.
- $220 million is allocated annually to programs designed to reduce infant mortality (including FAS-induced fetal death).

Administration on Developmental Disabilities

- University-affiliated programs are designed for the purpose of developing interdisciplinary training programs for persons concerned with developmental disabilities. Three universities focus on FAS: South Dakota, Tennessee, and Utah (which focuses specifically on FAS within the Navajo Nation).

Other Department of Health and Human Services Agencies or Departments

- The Anti-Drug Abuse Act (1988) authorized the Pregnant and Postpartum Women and Their Infants Initiative, which funds the development of "innovative, community-based models of prevention, education, and treatment."
- The Maternal and Child Health Bureau of the Health Resource and Service Administration also funds pilot projects.
- In July 1991 the National Center on Child Abuse and Neglect announced $18 million available for approximately 20 three-year demonstration projects relating to children whose parents were substance abusers.
- Administration for Native Americans (ANA) funded 14 projects in FY 1987-88 that focused on developing comprehensive strategies to reduce alcohol and substance abuse in Native communities.
- Numerous bills have been introduced to Congress which specifically address FAS, but very few have passed as of yet (see Appendix D).
- The National Institute of Child Health and Development funds research projects.
- The Centers for Disease Control and Prevention (CDC) has a Fetal Alcohol Syndrome Team.

- Since 1983 Congress has set aside $100,000 per year for the University of Washington's FAS research efforts.
- In January 1993 the University of Washington established a FAS diagnostic clinic with funding from the CDC.
- In 1990 California Governor Pete Wilson pledged $23 million to be spent on programs relating to substance-abusing pregnant and parenting women and their children.

A SAMPLE OUTLINE FOR A MULTIDISCIPLINARY SERVICE APPROACH

Once a tribe has decided to develop a comprehensive program that addresses ARND, it is necessary to develop a program outline that is inclusive of all the issues and needs that have been identified in the prospective service population. The model should be adaptable to specific tribal groups, multidimensional in its design, interdisciplinary in its approach, and have a long-term goal of community healing. Based on the "Model of Care" designed by Soman et al. (1992), as well as other pilot projects, the following is a sample outline for a comprehensive tribal health program:

I. Design a "Tribal Action Plan"

A. Concerned members of the community should create a multidisciplinary committee/or task force to address FAS/ARND. The task force should include members from the tribal governing body and the tribal court system (if one exists), a social worker or community advocate (tribal member), an educator, and other members of the community.

B. Caseworker interaction should follow a circular chain: client and family—caseworker assessment—panel of multidisciplinary experts—special needs (obstetric, pediatric, mental health, etc.)—caseworker—home of client and family.

II. Establish a philosophy and obtainable objectives for your program

A. Identify the principles the program is founded upon (for example: "the program will be family-centered, comprehensive, and coordinated").

B. Have a uniform and well-defined vocabulary; use inclusive terms such as FAS/ARND.

C. Delegate specific areas of focus for committee members.

III. Apply for block grants from multiple agencies

A. Decide on the preferred avenue for funding by surveying available resources (tribal, state, federal, private, etc.).

B. Utilize legislation such as P.L. 99-570 (The Indian Alcohol and Substance Abuse Prevention and Treatment Act [1986]), which provides funding and guidelines for tribal action plans, housing, and treatment facilities available specifically to tribes.

IV. Perform a risk assessment of the specific needs of the community

A. Assess at-risk behaviors and populations to determine their specific needs.

B. Consider the relationship between alcohol abuse and other social issues such as housing, employment, education, child care, and transportation.

V. Develop a directory of tribal, county, state, and federal resources available to tribal members with ARND

A. Establish a specific contact person at each location.

B. Set up a referral system that is part of a comprehensive service model.

VI. Begin a community education campaign

A. Assess community FAS/ARND awareness needs to determine priority and scope of community outreach and education.

B. Create tribe-specific appeals to the community at large.

C. Utilize radio, television, council meetings, and any public/social engagements possible, such as pow wows or traditional dances.

D. Include information about FAS/ARND in discussions of traditional child-rearing beliefs and practices.

E. Give audio-visual presentations on FAS/ARND at local junior high and high schools.

F. Create community pledges or compacts and have inter-community signature drives.

VII. Provide alcohol and drug treatment services or referrals

A. Devise programs that meet the specific needs of Indian women who drink and that address psychosocial issues such as physical, emotional, and sexual abuse; domestic violence; self-esteem; identity issues; unemployment; and education.

B. Provide clients with child care; residential facilities should provide room for children.

VIII. Prenatal care

A. Practice anonymous, universal toxicology screening, including a drinking assessment interview.

B. Do not criminalize prenatal alcohol consumption, but emphasize the risks associated with drinking while pregnant.

C. A woman's appetite for alcohol may naturally decrease when she begins gestation; utilize this ideal time for intervention strategies.[65]

IX. Parenting classes/Family training

A. Offer both pre- and post-natal parenting classes.

1. emphasize traditional tribal parenting skills where applicable
2. introduce parents to frustration and anger management
3. help families to understand the limitations and abilities of children/adults with ARND, including parental strategies for teaching social and sexual boundaries

B. Define "family" broadly.

1. recognize and support the significant role a woman's partner plays in her drug use and recovery
2. recognize nontraditional families, including same-sex partners

X. Case management

A. Assign a caseworker to each family with an FAS/ARND infant.

B. Caseworkers should:

1. visit the home, talk with the extended family, and explain implications of any further alcohol abuse.
2. work toward treating the infant, the mother, and the family.
3. determine whether or not the infant should remain in the home.
4. facilitate communication by understanding that:
    a. most interviews are uncomplicated
    b. a positive attitude is necessary
    c. caseworkers cannot control or teach control

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65. Little et al., 121. While only 45% of women abstain from alcohol consumption before pregnancy, 61% of women abstain throughout pregnancy (National Institute on Alcohol Abuse and Alcoholism, 12).

d. family issues are the focus in interviewing (caseworkers should not react to denial or to adolescent "acting out")

XI. Medical referral services

A. Work toward early diagnosis of ARND afflicted individuals.

B. Provide individual and family counseling.

C. Know your area health workers and available services.

D. Be aware of local/county policies regarding substance abuse and child removal policies.

XII. Educational programs

A. Where possible, work with special education programs to define and design appropriate curricula to match the needs of and to satisfy individuals with FAS.

1. stress accomplishable skills
2. teach traditional tasks that are useful to the community such as pottery, beadwork, animal care, land cultivation, etc.[66]

B. Utilize "Head Start" programs.

C. Practice FAS/ARND sensitive parenting and teaching strategies:[67]

1. have well-defined areas and images
2. provide pictorial representations of lessons
3. limit the number of displays in the room at one time
4. give preferential seating to FAS/ARND children
5. break up work into small accomplishable tasks
6. give direct instruction and emphasize thinking skills
7. use earphones for concentration work
8. give only literal translations
9. provide lesson outlines
10. demand random participation
11. use visual aids for taking turns
12. protect from over-stimulation
13. reduce lag time

66. Ann Streissguth et al., "Primary and Secondary Disabilities in FAS," in *The Challenge of Fetal Alcohol Syndrome* (Ann Streissguth and Jonathan Kanter, eds., University of Washington Press, 1997), 33-34.
67. For more information, see "Strategies for Parents and Caregivers" by Patricia Tanner-Halverson, Ph.D., http://www.nofas.org/main/strategy.htm.

14. use positive reinforcements
15. repeat and restructure

XIII. The criminal justice system

A. Develop a tribal ordinance which formally states the tribe's position on the consumption of alcohol during pregnancy and possibly mandates some form of rehabilitative treatment.

B. Provide educational training workshops for tribal officials, health-workers, and other interested individuals on issues relating to ARND.

C. Develop a model rehabilitative sentence to be used instead of potential jail time or fines which can be used as an outline in tribal court cases in which an ARND individual is the offending party.

D. Coordinate community advocates (similar to ICWA advocates) to work with ARND tribal members on their cases in state and federal courts.

XIV. Develop a checklist of each component of your program and conduct regular follow-up assessments of your services

The following description of the Fairbanks Fetal Alcohol Community Evaluation Services (FACES) is provided as an example of multi-jurisdictional and multidisciplinary approach to addressing FAS/ARND in tribal communities.

Team Name:	**Fairbanks Fetal Alcohol Community Evaluation Services (FACES)**
Service Area:	**Fairbanks North Star Borough**
Referral Criteria:	**Ages 5-14 years**
Approximate Wait Time*:	**2-4 months**
Contact Person:	**Sheree Dohner**
	Fairbanks Regional Public Health Center
	1025 W. Barnette Street
	Fairbanks, Alaska 99701
	(907) 451-1636
	Fax: (907) 451-1611
	sheree_dohner@health.state.ak.us

*wait time refers to the time it will take upon submission of all paperwork to the time of first scheduled appointment.

The mission of the Fairbanks Fetal Alcohol Community Evaluation Services (FACES) Team is to facilitate the referral, screening, assessment and diagnosis of children experiencing difficulties related to prenatal exposure to alcohol. The team also offers information and training to community agencies and providers. The team plans to link children and their families with resources and advocate for services. The team vision is to improve the quality of life for individuals and their families, as well as to reduce the occurrence and impact of secondary disabilities.

The diagnostic process involves medical, psychological, occupational therapy and speech pathology assessments which look at the child's ability to function in the home, community and school. The team reviews referrals, confers with clients, collects records and coordinates assessments helpful for the diagnosis. Using information from these assessments, the team evaluates and makes recommendations for care.

Members of the Fairbanks FACES include: Michelle Arnold, LCSW; LuJuan Gibson, ED., D.; Marvin Bergeson, M.D; Sue Guinn, SLP; Nanette Britten, PHN Aide; Kris Hammargren, SLP; Mary Lou Canney, Parent Advocate; Maureen Harwood, Graduate Student; Sheree Dohner, PHN; Vickie Horodyski, Parent Advocate; Joan Franz, OTR/L; Mary MacFarlane, M.D.; and Jackie Sunnyboy, Parent Advocate .

These providers are from both private, non-profit and community agencies. The Fairbanks FACES is partially funded by a 5 year grant from the statewide FAS office, in the Department of Health and Social Services. Some assessments are funded through third party payment. Several agencies provide in-kind services; however, the team evaluation is accomplished through the volunteer efforts of providers on the team.

The FACES Team is initially targeting children between the ages of five and twelve. For children outside this age group, we discuss assessment options, provide referral assistance and advocate for resources and support services.