

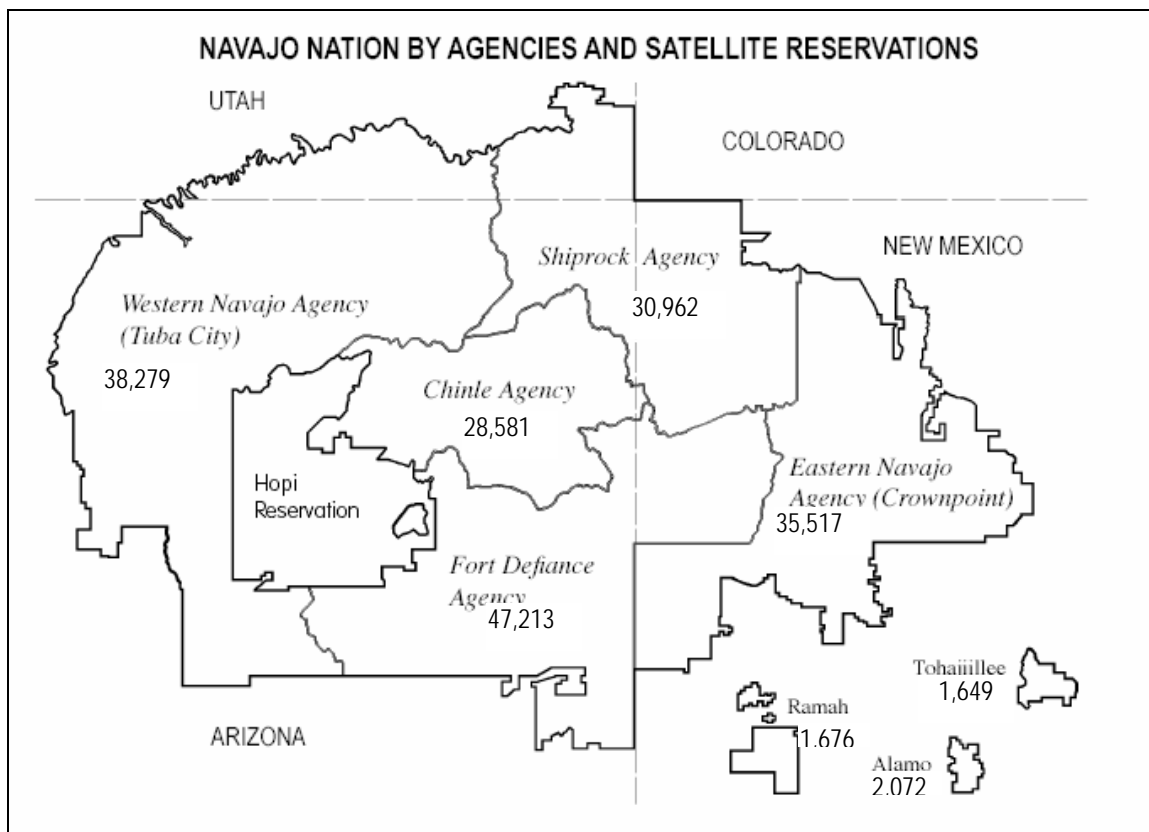
PROJECT NARRATIVE

Introduction

Most real progress occurs when individuals take hold of the idea that there is a better, more humane, or a more just way. (Homan, 1999)

The Navajo Nation is an immense, sparsely populated region in which thousands of children with special health care needs and their families live in isolation and sometimes quiet desperation. Services are fragmented across local service providers and state, federal, and tribal agencies. The Navajo Nation is the largest federally recognized Indian tribe in the United States. According to the 2000 U.S. Census, 298,197 individuals claimed Navajo ethnicity. Of the 180,000 residents living on Navajo Nation tribal land, 168,000 are Navajo enrolled members; the remainder are non-members who reside and work on the Navajo Nation. Another 80,000 Navajos reside near or in "border towns" of the Navajo Nation. The remaining Navajos reside in metropolitan communities across the United States.¹ The median age is 24 years. The unemployment rate among those in the labor force is 11.2 percent (compared to 3.4 percent statewide in Arizona). The median family income is \$22,392 (vs. \$46,723 in Arizona); and 42.9 percent of families were below the poverty level in 2003. Among these, 42 percent had children under the age of 18, and 47 percent had children under the age of 5. Hence, the Nation has a relatively disproportionate large number of children and youth.

The Navajo Nation land base extends across Arizona, New Mexico and Utah and covers 26,649 square miles, including all or parts of 11 counties in those states. Tables 1 and 2 depict population characteristics and Navajo Nation facts.



Population Statistics, U.S. Census, 2000

The Indian Health Service (IHS) and the Bureau of Indian Affairs (BIA) are the two federal agencies that provide services to federally recognized tribes across Indian Country. The BIA was established in 1824 within the War Department. In 1849, Native American health was transferred from the War Department to the BIA which oversaw the use of congressional appropriations for the establishment of health programs for Native American health. The IHS is now a division of the Department of Health and Humans Services (DHHS).

Government responsibility for providing health and social services to Indian tribes dates back to negotiated treaties concerned with ceded Native American lands, settlements, agreements, and legislation. Significantly, the U.S. federal government and Indian tribes signed treaties in which Native American land and resources were exchanged for federal promises of health care and other services. The primary legislation authorizing federal funds for health services to Native American tribes is the Snyder Act of 1921. In ratifying the Snyder Act, the federal government intended to provide appropriations "for the benefit, care and assistance . . . and for the relief of distress and the conservation of health . . . for Indians tribes throughout the United States."

The BIA is divided into 5 agencies on the Navajo Nation (see above map). The IHS is divided into 7 service units. The Navajo people must navigate between these two entities as well as tribal government programs and community public education systems to receive services. Each unit has distinct responsibilities. The BIA's is responsible for providing social services, land management and some education. The IHS provides health care. Tribal government programs provide social services, administer mental health programs, and other direct services.

Despite the mandates of BIA, IHS, and tribal programs, as well as federal efforts to raise Native Americans' standards of living, Navajos and other Native Americans experience disproportionate disparities in health care, social services and other basic needs. Native Americans continue to suffer high rates of poverty, poor educational achievement, substandard housing, and high rates of disease and illness. Native Americans continue to rank at or near the bottom of nearly every social, health and economic indicator. ²

Table 1 and Table 2 summarize Navajo and US demographics

Table 1			Table 2	
POPULATION CHARACTERISTICS	NAVAJO	US	NAVAJO NATION FACTS	
Median Age (2000 Census)	24.1	35.3	298,197	People claiming Navajo ethnicity (USA)
Navajo Nation Per Capita Income	\$7,269	\$21,587	255,543	Are enrolled tribal members* (USA)
Household Medium Income	\$20,005	\$41,994	180,000	Reside on the Navajo Nation
Persons living below poverty level	42.9%	12.4%	118,197	Live in surrounding border towns.
Unemployment Rate	25.1%	5.8%		Remaining
Persons 25+ with High School Diploma	26.3%	75.2%	9,286	Live in metropolitan centers across the US
Navajo language spoken at home (NN)	74.0%		69,154	Miles of roads (78% are dirt or gravel roads) **
Navajo language spoken at home (USA)		<1%	15,279	Housing Units
			13,447	Homes that lack complete plumbing (31.9%)
				Homes lack complete kitchen facilities (28.1%)

Indian language spoken at home (USA)	15.7%	28,740	Homes lack telephone services (60.1%).
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Sources: U.S. Census 2000/Chapter

Images: 2004;

* Navajo Tribal Enrollment/638

BIA;

** Navajo Dept of

Transportation/638 BIA

Table 3:

NAVAJO HEALTH DISPARITIES		
Unfavorable compared to the US Population	% Navajo Area Rate (95%Navajo)/10,000	% US Rate/10,000
All Deaths	628.9	479.1
Diabetes Deaths	35.9	13.5
Cervical Cancer Deaths	4.6	2.5
Alcohol Related Deaths	49.8	6.3
Suicide Deaths	16.8	10.6
Homicide Deaths	19.7	8.0
Tuberculosis Deaths	2.4	0.3
Pneumonia/Influenza Deaths	30.8	12.9
Births	21.7	14.5
Teen Births (13-19yrs)	16.9	12.7
Prenatal Care in First Trimester	56.4	82.5
Infant Deaths (under 1 yr. of age)	8.2	7.2
Post Neonatal Deaths (28-360 days)	4.4	2.5

Source: Navajo Area Indian Health Service Profile; Sept 25, 2003

²U.S. Commission on Civil Rights, A Quiet Crisis, Federal Funding and Unmet Needs in Indian Country, July 2003

Navajo Beliefs

The Dine' believes there are two classes of beings: the Earth People and the Holy People. The Holy People are believed to have the power to aid or harm the Earth People. Since Earth People of the Dine' are an integral part of the universe, they must do everything they can to maintain harmony or balance on Mother Earth. The Navajo people, the Dine, passed through three different worlds before emerging into this world, The Fourth World, or Glittering World. It is believed that centuries ago the Holy People taught the Dine' how to live and to conduct their many acts of everyday life. They were taught to live in harmony with Mother Earth, Father Sky and the many other elements such as man, animals, plants, and insects. The Holy People put four sacred mountains in four different directions, Mt. Blanca to the east, Mt. Taylor to the south, the San Francisco Peaks to the west and Mt. Hesperus to the north, near Durango, Colorado, thus creating Navajoland. The four directions are represented by four colors: White Shell represents the east, Turquoise the south, Yellow Abalone the west, and Jet Black the north.

When Navajos experience problems, such as an illness, medicine men use herbs, prayers, songs and ceremonies to help cure them. Some tribal members choose to be receive medical services at hospitals on the Navajo Nation. Others seek the assistance of a traditional Navajo medicine man. Navajos believe that a qualified medicine man is a unique individual bestowed with supernatural powers to diagnose a person's problem and to heal or cure an illness and restore harmony to the patient. The Navajo culture has more than 50 different kinds of ceremonies - each performed for a specific reason. Some ceremonies last several hours, while others may last as long as nine days.

Navajo Facts

- The Navajo Nation has its own government with an elected President, Vice-President and council members (110). Local governments known as "Chapters" elect representatives to the Navajo Nation Council
- Navajo Nation is comprised of geographic 5 agencies: Tuba City/Western Agency, Chinle, Fort Defiance, Shiprock and Crownpoint/Eastern Agency which are the largest population centers/communities on the Nation
- Navajo is the primary language. English is the secondary language. The Navajo language is based on descriptive observations therefore there may not be direct translations for every English word.
- The quest to preserve the Navajo way of life, culture and language is represented in government policy and programs across the Nation
- The IHS is the principle Federal health care provider and health advocate for Indian people. Navajo people receive health care from the IHS
- Tribal income is currently derived from gas, oil, and coal leases as well as federal dollars. However, coal leases are rapidly declining, which will lead to increased unemployment
- The Navajo Tribe currently is not involved in casino gambling.

In general, Navajos do not live in villages, and primary population centers are sparsely populated. Shiprock is the largest community with approximately 9,000 residents. There are <7.5 Navajos per square miles. The Navajo traditionally banded together in small groups, often near a source of water. Their wide dispersion across the reservation is due in part to the limited amount of grazing land, and the limited availability of water.

Traditionally, the Navajos are a matriarchal society, with descent and inheritance determined through one's mother. Navajo women have traditionally owned the bulk of resources and property, such as livestock. In cases of marital separation, women retain the property and children. In cases of maternal death children are sent to live with their mother's family. Traditional Navajo have a strong sense of family allegiance and obligation. One of the most significant attributes of Navajo family structure is its dependence on extended family as caregivers to children. In general, relationships with aunts and uncles are much more important in the Navajo family than it is in the mainstream American family. A great deal more responsibility is given to other members of the extended family, and there is considerable attachment of the child to the entire group. Today, Navajos are faced with large unemployment rates, and "acculturation" to a more nuclear family structure similar to Anglos in the U.S. is increasingly the case. The Navajo Nation is a culture in transition, and its traditional lifestyle is under substantial stress because of rapid changes in their society.

In addition to the stresses that stem from poverty and societal changes, thousands of Navajo parents of children and youth with special health care needs have increased stress due to their need for medical, social and educational services related to their children's conditions. **Because the Navajo Nation currently does not have valid or reliable data on early screening, access to medical home, cultural competency, transition to adulthood, levels of family participation or access to services in general, it**

is not possible to accurately describe the Navajo Nation's compliance with the MCHB 6 Core Performance Indicators. For example, while the reported incidence of disability among Navajo children is significantly lower (5.7%) than that of the rest of the United States, Navajo children experience several risk factors (e.g., poverty, limited education, physical isolation, limited access to resources) that suggest this figure is a gross underestimate of the number of children with special needs.

DOC Goal

The primary **goal** of the Dine' For Our Children (DOC) project is to reduce health disparities by improving Navajo families of CYSHCN access to integrated services. The DOC project is different from other efforts to improve Navajo living conditions because it will be family-centered, and focused on grass roots community involvement in reaching project goals. The methodology will focus on developing teams of families, youth, and service providers at local levels who will identify existing services and gaps in the service system. These groups will articulate their needs and determine how services should be organized so that they are responsive to families needs within Navajo traditions and western medical care and related services.

Overview of Objectives

In order to accomplish this goal the following **objectives** are proposed.

1. Teams of parents, youth, and providers in each of the five BIA Agencies will be established to serve as the backbone of the project. The teams will be coached by project staff who will empower them to:
 - a. Assess the needs of their respective communities using a reliable and valid tool that produces an electronic database as well as a local map of services and related information;
 - b. Examine Navajo/BIA/IHS progress toward meeting the MCHB performance indicators by conducting a modified version of the National Survey of Children with Special Health Care Needs within each agency;
 - c. Identify barriers that hinder performance in the areas of family-professional partnerships, medical home, equitable insurance, early screening and detection, access to services, and transition to adulthood;
 - d. Use community based participatory research (CBPR) to develop strategies within each community to overcome these barriers;
 - e. Share successes and difficulties with the other teams quarterly;
 - f. Expand the network and opportunities for leadership and parent professional partnerships to new families.
2. A Navajo Nation-wide steering committee will be developed with a broad representation of parents, youth, IHS physicians and related service providers, social service and health administrators, tribal council representatives, educators in early childhood, elementary and secondary education, Navajo Workforce Initiative representatives who assist adolescents in transition, representatives from Utah, AZ, and NM Title V offices who will open communications between the Nation and state Medicaid programs in order to examine issues around insurance for CYSCHN
3. A Navajo Youth Action Council (NYAC AZ) of teens and young adults with special health care needs will be recruited. The team will inform Navajo tribal leadership of the unique needs and perspectives of Navajo YSHN, network with YSHN in other communities, and serve as models and consultants to other Native American communities wishing to promote YSHN transition to adulthood.

4. Increase the number of culturally competent social workers available to the Navajo Nation, through a partnership with the New Mexico Title V Office for Children with Special Health Care Needs

The DOC project has 4 Phases designed to be completed in three years.

Phase 1, Year One: (a) teams in each of the five BIA service areas will be established and coached to conduct a local resources/needs assessment. Parents in each community have agreed to participate, as have IHS service providers, public school faculty, and early intervention providers. Sites for meetings and interpreters for Navajo speaking members have been secured as donations to the project. Coaching includes developing a consensually agreed upon mission, and learning about the network of CYSCHN resources across the U.S, how to identify resources within their communities, how to advocate for CYSCHN, and how to collaborate with the steering committee. The major activity during Phase 1 is to conduct a local resource/needs assessment which will map resources within each Agency. Teams will use the SWift® Resources tool to input resources so that there is a current digital/web archive of resources. Each Chapter House across the Nation is equipped with computers and internet access so that families can access the information they need. In addition, a paper version, SWift Map of local resources, will be printed and made available in each Agency.

The second component of Phase 1 focuses on establishing a Navajo Nation-wide steering committee. The committee will be made up of designees of the 5 Agency teams as well as administrators from the executive branch of Tribal government, IHS, BIA, Title V Offices in AZ, NM, and UT. The purpose of the committee is to examine data generated by the Agency teams and make recommendations to tribal government, IHS, BIA, and state agencies for sustaining gains made and disseminating findings to state and national organizations. The steering committee will meet quarterly for half days in areas around the Nation (Window Rock, Tuba City, Shiprock, Chinle, Eastern).

Phase 2, second six months of Year 1, focuses on establishing a data base on Navajo Nation progress in meeting MCH performance standards. The parents on the 5 Agency teams will be trained to administer a face-to-face survey which is a modified version of the NSCSHCN. The survey will be administered to a weighted sample of randomly selected families from Agency Chapter registries. Because a significant number of Navajo families do not have telephones, the only way to get a reasonably representative sample is through face-to-face interviews of families selected from the registries. The results will allow teams to determine local progress in meeting MCH performance indicators; i.e., strengths and weaknesses with respect to family partnerships, medical homes within IHS, insurance and the relationship with IHS, early screening and detection/immunization for young children, access to services for CYSCHN and, and transition to adulthood. Additionally, these data will serve as a baseline which the teams and steering committee can use to measure the progress of the DOC project.

Phase 3, a follow-up of Phases 1 and 2, extends across Years 2 and 3 of the Project. Each team will learn to use community-based participatory research (CBPR) to address a specific barrier, need or issue that they identified in either the local needs/resource assessment or the Navajo version of the NSCSHCN. Teams will develop a strategy based on empirical data from other projects that have addressed similar problems. For instance, if the teams identify a cultural mismatch between physicians and families that affects communication or treatment, the strategy might involve parents training IHS physicians on Native traditions and the role of Native Healers. The CBPR model has been highly effective in the Integrated Services project, Building Community Health across Arizona (BCHA) (as well as hundreds of other public health projects).

BCHA parents and project staff are committed to sharing the CBPR method with the DOC teams. Funds have been allocated to allow teams to develop and implement their CBPR projects. The role of project faculty and consultants is to initially facilitate these teams and as they become more independent, assist with the evaluation of project results.

Phase 4, Years 2 and 3, involves a collaboration with the New Mexico Title V Office for Children with Special Needs to establish a social work mentorship program with the schools of social work in Arizona, New Mexico and Utah. A major need identified prior to the DOC project is a dearth of social workers in communities across the nation who are educated and culturally competent to work with Navajo families of CSHCN. Ms. Lynn Christiansen, LMSW, Chief of NM Office for CSHCN will negotiate participation in the mentorship project at Shiprock on the Navajo Nation. Project Director Jenny Rodgers, MPH, will recruit Navajo social workers to mentor the participants. The DOC teams in Shiprock and Crownpoint will refine materials developed by the mentorship pilot project to be culturally appropriate and relevant to parents of CYSCHN. The team will collaborate with DOC project staff and NM Office for CSHCN to evaluate the efficacy of the project on measures of satisfaction, cultural competency, and improved access to service for CYSCHN.

Needs Assessment

It is in the nation’s interest to have healthy children. Healthy children are more ready to read and able to learn and in the long term are more likely to become healthy contributing members of their communities- *Nation Research Council, 2004.*

Preparation for the DOC project began 13 months prior to submission with a planning team of parents of CYSCHN, 2 youth with special health care needs, pediatric and administrative staff of Ft. Defiance Indian Medical Center, senior project staff of the Navajo Division of Social Service, early childhood educators from Growing in Beauty Navajo Early Intervention Services, staff of the recently completed Medical Home Project of New Mexico, staff from the Southwest Institute for Families and Children with Special Needs and senior project staff from the successful *Promoting Safe and Stable Families* Navajo mental health program. In addition, two focus group meetings were held with families and professionals to determine the priority of needs at the agency level. Participants reviewed the needs assessments prepared by NN Head Start and the Title V offices of New Mexico and Arizona. Additional information provided to the groups included the 2000 census data, 2005 Kids Count data and Chart Book, the results of the National Survey of Children with Special Health Care Needs (NSCSHCN). Both Arizona and New Mexico rely heavily on the NSCSHCN, which only provides data on children birth to 17.

The planning team and focus groups’ review of the extant data base found that, unfortunately, none of the studies related to CYSCHN have data regarding the incidence or prevalence of special health care needs among Navajo children or the service needs of their families. As a result of the geographic vastness of the Navajo Nation, the absence of a nationwide utility infrastructure (30% of homes lack electricity and or phone service), and the nomadic nature of many Navajo families, establishing accurate data has been elusive.¹ The largest and most comprehensive survey of children’s health, The National Survey of Children with Special Health Care Needs (NSCSHCN) was unable to report on demographic factors, or other key indicators as there were insufficient numbers of cases to determine prevalence in Native American populations². The NSCSHCN employed a telephone and random digit dialing to query 100,000 + households across the U.S. As a high number of Navajo families do not have phone service, a reliable sample was not obtained.

A second hindrance to accurate assessment is that IHS does not maintain an integrated data system across the nine medical service units on Navajo Nation. Data do not adequately follow patients when they are referred to specialty care or to service providers outside the IHS system. Moreover, Navajo children with multiple special health care needs are frequently seen in New Mexico, Arizona, and IHS medical centers as well as Title V funded clinics, and resultant hospitalizations in Utah, New Mexico and AZ.

The planning team and focus groups identified the following issues as priorities. This list covers most of the 6 MCHB Performance Indicators:

- 1- Children with special needs have never been perceived as a priority issue on the Navajo Nation. These children and their families need a clear and powerful voice to articulate their needs to the Tribal Council, BIA and IHS.
- 2- Navajo CYSHCN are at increased risk for abuse. The Nation needs increased methods of surveillance and improved methods of follow-up and treatment.
- 3- Families and youth across the Nation have no systematic way to find local resources. Services at the local level need to be organized in ways that are easier for families to locate and access. The Nation needs a flexible digest of resources that families can access at the local level.
- 4- Parents are accustomed to being recipients of services rather than partners, and their partnering in decision making is very minimal. Navajo families need strategies to become self-determined and advocates for their families, and to be able to evaluate the health services they receive.
- 5- Transition services for youth are non-existent. Youth need training tailored for youth, and opportunities for transition to all facets of adult life.
- 6- There is a significant dearth of related services for CYSHCN and their families on the Nation. The lack of physical, occupational, and speech therapists is exacerbated by a lack of culturally competent social workers to help coordinate care. The Nation needs to develop systematic recruitment efforts and strategies for maintaining the services of Native American professionals.

With respect to the remaining MCH Performance Indicators:

- All members of the Navajo Nation are eligible for a complete array of IHS medical services that includes early and periodic screening diagnosis and treatment (EPSDT), but services are not organized in ways that are easy for families, youth or children to use. Parents report that securing follow-up to Early Screening services is variable and sometimes difficult due to lack of resources, geographic locations, multiple service providers and lack of care coordination.
- Navajo families currently have adequate sources of health insurance because the IHS is required by law to provide complete medical care to all American Indians. A Certificate of Indian Blood (CIB) is required by IHS users. Currently, however, there is considerable controversy about responsibility for the extensive care/services required by CYSHCN.
- Health services are provided primarily through western medical techniques that fail to incorporate Navajo traditions and beliefs that are familiar to parents.
- Whether CYSHCN have a Medical Home depends on physicians' training prior to their joining the IHS. No systematic Medical Home physician training or Medical Home implementation has occurred in the IHS. However, the DOC partners in NM Title V and the Southwest Institute in AZ have had extensive Medical Home experience and are committed to sharing resources, tools, and coaching families and IHS physicians. Models of parent to physician education and cultural competence coaching will be integrated into development of DOC Medical Homes.
- No systematic archive of resources exists on the Nation nor is there a routine mechanism to access services.
- As noted, the services that youth need to transition to adulthood are not available, with the exception of some IDEA-related school transition activities.

A third planning group meeting was held with collaborative partners from the New Mexico Title V office, Family Voices, and Southwest Institute for Families and Children with Special Needs. Jenny Rodgers of NN Social Services described the focus group results process to the partners. The group discussed the relationship between Navajo Nation and the New Mexico Title V Office for Children with Special Health Care Needs. Director L. Christiansen indicated that there is much crossover between the needs of Navajo families and children and the service plans of her office. New Mexico remains concerned about the need for culturally effective methods to support Native American families. New Mexico has had demonstration programs on Medical Home and has much interest in sustaining these programs and sharing the results with Navajo Nation. Also in attendance was Karen Burstein, PhD, Vice President of the Southwest Institute for Families and Children with Special Needs (SWI). Across the past nine years, SWI has had four implementation and demonstration projects around CYSCHN, through which it has developed numerous tools for communities and families. These include the SWIFT Resource Mapping system, the Fast Track to Transition Curriculum for YSHN, and the Community Based Participatory Research Curriculum and Toolkit. These lessons and tools will be used in the DOC project. Trish Thomas, Training and Technical Assistance Specialist of Family Voices national office reported that there is a new and developing initiative around Native American health and transition of youth that closely aligns with the goals of the DOC project. The committee agreed that a community-based, family-centered model that integrates data-based decision making is most appropriate for reducing health disparities for CYSCHN and their families on the Navajo Nation. Each partner on the planning committee identified potential roles and contributions to the DOC's goal of improved access to services for families and youth with special health care needs. These are described in the Methodology and Organizational Capacity sections of this proposal.

General Information on Navajo Nation

The Navajo Nation has approximately 255,000 enrolled members, making it the largest federally recognized Indian tribe in the U.S. According to the 2000 Census, the total population residing on the reservation and on reservation trust lands was 180,462 (71%), (49 percent male, 51 percent female). Of those residing on the reservation or trust lands, 96.4 percent are American Indian, 2.4 percent are white, and less than 1 percent are more than one race. The median age is 24 years. The unemployment rate among those in the labor force is 11.2 percent (compared to 3.4 percent statewide in Arizona). The median family income is \$22,392 (vs. \$46,723 in Arizona). Furthermore, 40.1 percent of families were below the poverty level in 1999; of those, 42 percent had children under the age of 18, and 47 percent had children under the age of 5. The land is abundant with natural resources, including coal, natural gas, and oil. At the same time, the reservation is largely rural. More than 30% of homes lack plumbing, electricity, and telecommunications. Further, 77% of the roads within the reservation are dirt or gravel, making travel difficult during good weather and sometimes impossible during winter.

The enormous size of the Navajo Nation Reservation has created unique challenges for the tribe, particularly regarding social services delivery and administration and health care. Because the reservation lies within the boundaries of three different states (Utah, New Mexico, AZ), and each located within a different federal region, the Navajo Nation must coordinate with three different state governances, as well as three different federal regions. The sheer size of the reservation does not lend itself to centralization, rather five agencies have been established (Tuba City/Western, Chinle, Fort Defiance, Shiprock, Crownpoint). The tribal governance system is organized into three branches: executive, legislative and judicial. The capital of the Nation is Window Rock, AZ. The Executive Branch is headed by the president and vice president who are elected by popular vote and cannot serve more than 2 consecutive terms. There are 10 executive

departments including social services and health. Approximately 80% of the tribe’s annual budget is directed to administration and service delivery.

The legislative branch consists of the Navajo Nation Tribal Council, the governing body of the Nation. The council has 88 members, elected by popular vote and representing 110 local governments (chapters) of the reservation.

Health care is provided to all Native Americans by the U.S. Indian Health Service (IHS), a division of the Department of Health and Human Service. Members of federally recognized American Indian and Alaska Native (AI/AN) Tribes and their descendants are eligible for services provided by the IHS. The mission of the IHS, in partnership with AI/AN people, is to raise Navajo physical, mental, social, and spiritual health to the highest level. The IHS goal is to ensure that comprehensive, culturally acceptable personal and public health services are available and accessible to all AI/AN people. The IHS mission and goal are based on its foundation to uphold the Federal Government's obligation to promote healthy AI/AN people, communities, and cultures, and to honor and protect the inherent sovereign rights of Tribes.

In order to carry out its mission, attain its goal, and uphold its foundation, the IHS³:

1. Assists Tribes in developing their health programs through activities such as health management training, technical assistance, and human resource development;
2. Assists Tribes in coordinating health planning, in obtaining and using health resources available through Federal, State, and local programs, and in operating comprehensive health care services and health programs. The relationships between IHS and the health departments of AZ, New Mexico, and Utah differ as does the relationship between these entities and the Navajo Departments of Health and Social Services.
3. Provides comprehensive health care services, including hospital and ambulatory medical care, preventive and rehabilitative services, and development of community sanitation facilities.
4. Serves as the principal Federal advocate in the health field for Indians to ensure comprehensive health services for Indian people.

General Findings on Native American Health Status

Native American Mortality Rates

Indians/Alaska Natives have slightly lower mortality than whites. However, because deaths among American Indians are underestimated by more than 20 percent, primarily due to misclassification of race on death certificates,⁴ it is likely that the overall death rate for this group is actually higher than that for whites. Compared with whites, American Indians/Alaska Natives have higher reported morbidity and mortality for pneumonia/influenza, liver disease, obesity, pediatric tuberculosis, bronchiolitis⁵, diabetes, sudden infant death syndrome, diabetic kidney disease,^{6, 7} unintentional injuries, and homicide.^{8, 9, 10, 11} Racial/ethnic disparities in health outcomes likely result from the complex interaction between socioeconomic status (SES), insurance, racism, segregation, culture, and access to quality health care.^{12, 13} The leading causes of death for all racial/ethnic groups are similar although groups differ widely in absolute rates of death.

Rural and Urban Residents

Research on primary and specialty care for children with special health care needs and chronic conditions has generally be conducted in urban communities. However, a recent study evaluated the impact

of a medical home demonstration in a rural community. Results indicate that comprehensive, family-centered care can be provided in rural communities and that it is effective for CSHCN.¹⁵ Most urban-rural-suburban differences in health are attributable to differences in the socio-demographic characteristics of the respective populations. Rural residents often reside in medically underserved areas and often face geographic and other barriers to care¹⁴. The majority of Navajo families are rural residents who may have reduced geographic access to primary, tertiary, and mental health care. Even though the IHS has 9 service areas served by health clinics or hospitals, the low density distribution of families across the vast Navajo Nation continues to be problematic. It is the rule rather than the exception for Navajo families to live 50-100 miles from the nearest medical facility or 100+ miles to the nearest full-service hospital. Access to therapeutic services are often more difficult to access and are frequently provided on an ad-hoc basis.

Native American Children

Assessment of pediatric health care quality lags behind adult assessment. Various factors unique to child health care make quality measurement particularly challenging. These factors include a focus of pediatric care on not simply staying healthy, but also optimizing growth and development, differences in pediatric and adult disease patterns, and dependence of children on parents/caretakers. In addition, compared with the general population, children are disproportionately minority and poor¹⁴ and thus confront additional barriers to quality care. Although most pediatric health care focuses on health promotion and disease prevention, a sizable number of children suffer from chronic health care problems, some of which result in disability.

Abuse of Children and Youth

American Indians may represent the most traumatized segment of the American Population. A study by Manson, Beals, O’Neill, Piasecki, Bechtold, Keane, and Jones, (1996) revealed a high incidence of trauma exposure among American Indian adolescents. According to the Office of the Surgeon General, American Indians and Alaska Natives experience Post Traumatic Stress Disorder (PTSD) at almost three times the rate of the general population, 22% prevalence rate for AI/AN versus 8% for the general population (Office of the Surgeon General, 2001). The impact of trauma on brain development has profound relevance for those working with American Indian youth. In recent years, increased attention has been given to the link between childhood trauma and brain development. Does childhood trauma actually change how a child’s brain develops? How can an external event, like child abuse or neglect, actually change brain development? These questions have generated quite a bit of interest. An internet search using the keywords “brain, child, abuse” yielded 620 articles. One review article, “The Neurobiological Consequences of Early Stress and Childhood Maltreatment,” lists 193 references (Teicher, Andersen, Anderson, Navalta, & Kim, 2003). A few years ago, no one seemed to be thinking about whether child abuse and neglect, or other traumatic events such as exposure to domestic violence, can alter the actual, physical structure of the brain.

Persons with Disabilities and Special Health Care Needs

The prevalence and impact of various conditions and type of special care needed to treat these conditions frequently differ between groups. Children experience health care problems and have health care needs that differ from those of adults. Some of the health care needs of women require female-specific quality measures (gender-specific measures are also needed for men but the number of key male-specific conditions is lower). Low-income persons often become chronically ill or die at earlier ages than those with higher incomes. Poorer persons experience many access barriers to quality health care such as affordability of care and low health care literacy. Persons with chronic illnesses and disabilities have condition-specific health care needs that require specific quality measures; in addition, they may face barriers to health care access related to their disability.

As already noted, few data exist regarding the quantity and quality of care received by Navajos with disabilities or special health care needs. IHS records are generally incomplete and do not reflect longitudinal effects of care. Additionally, accurate estimates are hindered by lack of suitable measures. Nonetheless,

available evidence suggests that health care quality for this vulnerable population is substandard. Children and youth living with special health care needs often require ongoing medical management; yet sensory, mobility, or cognitive impairments often create barriers to care.

Causes of Racial and Ethnic Disparities in Health

Not all children are healthy. Twenty million children live with chronic conditions.¹⁵ The most frequent chronic conditions among children include asthma, allergies/sinusitis, atopic dermatitis, attention deficit disorder, and learning disorders. These conditions differ by race and ethnicity. For example, rates of asthma are higher among African Americans and certain Hispanic groups.¹⁶ Rates of disability and mortality for blacks with asthma are nearly double those for whites.^{17, 18, 19} Black children have higher death rates from congenital heart disease than white children.²⁰ Hispanic and Native American children have higher rates of dental caries and are at risk for behavioral and developmental disorders, diabetes, obesity, and asthma.²¹ Asian/Pacific Islanders also appear to have worse asthma outcomes than whites.²² Obesity rates are especially high among African American, Native American, and Mexican American children.²³

The prevalence of risk of obesity in children ages 2 to 5 years increased from 13.6% in 1993 to 15.4 % 2002. This increase was seen among all racial and ethnic groups. American Indian and Alaska Native Poverty among children is strongly linked to poorer mental health,²⁴ and minority and uninsured children have high unmet needs for mental health services.²⁵ Children with chronic conditions are twice as likely as other children to have had at least one unmet health care need, such as dental care, prescription medications, eyeglasses, and mental health services. They also were more likely to have been unable to get needed medical care or to have delayed obtaining medical care because of worry about its cost.²⁶ Children with chronic conditions were at greater risk for unmet needs than were children without conditions across all income levels.²⁶ Although most children are healthy, 4 million children suffer from chronic disabling conditions.²⁷ Children who are disabled and minority are more likely than white children to be without health insurance coverage, to be without usual sources of care, and to be unable to get needed medical care.²⁸ Minority children with special health care needs are less likely than whites to have seen a physician but more likely to be hospitalized during the past year.²⁸ Specific quality indicators are needed to monitor the care provided to children with special needs. Examples of these conditions include congenital heart disease, cerebral palsy, chronic renal failure, sickle cell anemia, cystic fibrosis, severe asthma, childhood cancer, major mental illness, severe developmental delay, and mental retardation. Much of the racial disparity in adult mortality,²⁹ but not infant mortality,^{13, 30} is explained by the lower socioeconomic status (SES) of African Americans. African Americans, Hispanics, American Indians/Alaska Natives, and members of certain Asian/Pacific Islander groups have higher rates of poverty, lower rates of high school graduation, and are more likely to reside in impoverished communities.³¹ Nonetheless, it is difficult to determine the reasons for racial or ethnic disparities in incidence, prevalence, or severity of disease because the exact causes of many of the diseases that disproportionately affect minorities are not known.³² It is likely that racial disparities result from the complex interaction between SES, racism, segregation, culture, and access to quality health care.^{12, 13} In the absence of clear understanding of how these factors interact, it is difficult to assess the contribution of specific factors to disparities. It is probably safe to speculate that the salience of these factors differs by condition and by racial/ethnic group.

Last, the demographic characteristics of children differ from those of adults. Until the development of the State Children's Health Insurance Program (SCHIP), children were more likely to confront more difficulties accessing health care than adults.³³ Children are more likely to be poor and minority, and minority children have lower rates of recommended well-child care than whites.³⁴ Differences in health by SES begin in childhood.³⁵

U.S. Census Data 2000

Child data taken from the 2000 U.S. Census, summarized in the Kids Count Chart Book⁴⁹ indicate that almost 50% of Navajo children reside in AZ, while 40% reside in New Mexico. The remaining 10% reside

in other western states. On key characteristics of Child Well Being, Navajo children fare poorer than other children in general: 41% or two and one half times as many Navajo children live in poverty; 7% more Navajo children live in single parent households; 5.5% more adolescents have dropped out of high school; and 8.5% of Navajo live in the care of their grandparents.

Arizona Title V Maternal and Child Health Needs Assessment 2005

Every three years, State Title V Offices are required to complete a Needs of Assessment. The AZ Office for Children with Special Health Care Needs attempted to integrate a variety of different data sources to evaluate the needs of children and youth with special health care needs throughout the state. Several reports issued by other agencies or community groups were utilized to enhance the picture of C/YSHCN throughout Arizona. The overall methodology of the Needs Assessment was to provide convergent data on factors that impeded achievement of the six National Performance Measures, to identify any specific unmet service needs, and as much as was feasible, to identify the reasons for the unmet needs. However, as the report relied heavily on the NSCSHCN, there is little information as to the needs of Navajo children and families especially those who reside on the reservation.

Table 4 illustrates the prevalence of children and youth with special health care needs in AZ between ages 0-17.

Table 4. Prevalence of Children and Youth with Special Health Care Needs in Arizona, 0-17 years old ¹¹⁰		
	State %	Nation %
Child-Level Prevalence		
Percentage of C/YSHCN, 0 - 17 yrs old	10.8	12.8
Household-Level Prevalence		
Percentage of households with children that have one or more SHCN, 0 - 17 yrs old	17.8	20.0
Prevalence by Age		
Children 0-5 years of age*	5.5	7.8
Children 6-11 years of age*	12.0	14.6
Children 12-17 years of age	15.0	15.8
Prevalence by Sex:		
Female*	8.4	10.5
Male*	13.1	15.0
Prevalence by Poverty Level:		
< 200% FPL*	9.1	13.6
200% – 300% FPL	13.0	12.8
> 300% FPL	12.3	13.6
Prevalence by Race/Ethnicity:		
Hispanic*	6.8	8.5
White (non-Hispanic)	13.8	14.2
Black (non-Hispanic)	16.0	13.0
Multi-racial (non-Hispanic)	17.8	15.1
Asian (non-Hispanic)	4.4
Native American/Alaskan Native (non-Hispanic)	5.7	16.6
Native Hawaiian/Pacific Islander (non-Hispanic)	9.6

Source: Title V Needs Assessment, Arizona Department of Health Services 2005
 +Weighted Estimates Prevalence data only available for States where this minority group makes up at least 5% of total population of children in the State. Estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than 30 percent. * Statistically significant from national data based on 95 percent Confidence Intervals.

No specific data are available that reflect the impact of special health needs on Navajo families. However, the information in Table 5 illustrates some key effects of special health care needs on child health and on families in Arizona as compared to the U.S.

Impact on Child Health:	State %	Nation %
Health conditions often greatly affect their daily activities.	22.8	23.2
More than 11 days of school absences due to illness.	15.2	15.8
Currently uninsured.	5.1	5.2
Currently insured with coverage that is not adequate.	30.4	33.8
Impact on Family:		
Families pay \$1,000 or more in medical expenses per year.	8.6	11.2
Families experienced financial problems due to child's health needs.	18.3	20.9
Families spend 11 or more hours per week providing and/or coordinating health care for child.	11.7	13.5
Family members had to cut back or stop working because of child’s health needs.	30.3	29.8

+ Weighted Estimates *Source: National Survey of Children with Special Health Care Needs*⁴⁸

While the overall birth defect rate has decreased in AZ newborns and the state has achieved the Healthy People 2010 Goal of 1.0 birth defects per 1,000 live births, a similar achievement has not been evidenced among Native Americans. In 2003 the overall birth defect rate for Native Americans was 2.3 per 1,000 live births, down from 2.9 in 1999, but not at the 2010 goal. Much of this difference is due to the rate of Fetal Alcohol Syndrome (FAS) among Native American children born in AZ. In 1999, the rate of FAS among all AZ live births was .01 decreasing 0.03 in 2002. Conversely, the rate of FAS among Native American live births was 0.6 in 1999, decreasing to only 0.36 in 2002. Specific rates for Navajo Nation are not currently available. Table 6 illustrates the rates of FAS and birth defects in AZ.

Table 6. Rate of Fetal Alcohol Syndrome and Birth Defects per

TABLE 6. FAS & BIRTH DEFECTS	1999	2000	2001	2002	2003
Native American FAS Rate	0.6	0.36	0.19	0.36	NA
All AZ FAS Rate	0.10	0.05	0.05	0.03	NA
Native American Birth Defect Rate	2.9	1.9	1.9	2.2	1.3
All AZ Birth Defect Rate	1.3	1.3	1.3	1.3	1.0

Source: Arizona Department of Health Services, Bureau of Public Health Statistics.

The AZ Title V Needs Assessment determined a set of priority needs for Arizona’s C/YSHCN through a group consensus of the Needs Assessment Planning Group after reviewing the data from the NSCSHCN, focus groups and the provider community. **It should be noted that no Navajo families participated in the development of the Needs Assessment.** The participants agreed there were many

specific service and coordination needs; however, there was very little OCSHCN that could do to directly impact these needs. It was decided that the State would address the needs from a systems approach that would focus interventions on education of providers as well as the families of C/YSHCN. The following three statements of need for C/YSHCN are the result of that consensus.

- 1- Increase the accessibility and availability of individualized health and wellness resources for C/YSHCN.
- 2- Increase the availability of a cohesive and stable continuum of resources within a medical home that includes an improved quality of life approach.
- 3- Increase the recognition of families as integral partners in the care of their child's health and wellbeing.

Finally, for the past 10 years, MCH has sponsored public health leadership planning conferences for the Rocky Mountain/Southwest States that revealed that many public health workers at both local and State levels did not have formal public health training and many hold at most an Associate Degree identified regional core public health competencies. 70% of the respondents believed there were insufficient program offerings and there was a desire to focus on both technical skills/training and public health concepts. The results indicated a critical need for accessible graduate level public health education training and continuing education (CE) opportunities for MCH workforce, including a bridge public health training program, a certificate program.

Methodology.

Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has. *Margaret Mead*

Dine' for Our Children: Target Population

The DOC project proposes to serve children and youth with special health care needs (C/YSHCN). C/YSHCN, the fastest growing segment of individuals served under the Individuals with Disabilities Education Act (IDEA) and Section (504) of the Rehabilitation Act, have been defined as those children or youth who are birth to 22 years old and have, or are at risk for, chronic physical developmental, behavioral, or emotional conditions and who require health and related services of a type and amount beyond that required by children generally, (McPherson et al, 1998). The C/YSHCN population shows increased incidence of severe chronic disorders such as genetic disorders, metabolic diseases, severe respiratory complications and orthopedic complications. These children are also at risk for learning disabilities, mental retardation, and social and emotional disorders. Many of these children have limitations in activity and frequent school absenteeism. Health problems affect all aspects of their lives. Given the broad nature of the federal definition of C/YSHCN coupled with dramatic increases in diabetes, asthma, and FAS among Navajo children and youth, it is reasonable to believe that there is a much higher prevalence of C/YSHCN on the Nation.

Recent recommendations by the National Research Council and the Institute of Medicine (2004) call for a new definition and framework for children's health based on the principles of rate and course of development; broad biological, behavioral, and environmental factors that affect child development; the cumulative effects and long term consequences of these factors; the shifting impact of influences and exposures across the life span of children; and finally the fundamental impact of children's health on the course of adult life. The joint committee recommends that children's health should be defined as the extent to which individual children or groups of children are able to a) develop and realize their potential b) satisfy their needs, and c) develop the capacities that allow them to interact successfully with their biological physical and social environments.

Dine' for Our Children: Conceptual Framework

The Navajo Nation's vision for social services "is for the Nation to work collectively, cooperatively and collaboratively with others to provide the services which strengthen the family's abilities to care for their children within their own communities." The main component of this vision is "to treat the Navajo family holistically, providing a programmatic continuum of care designed to be family focused, community based, comprehensive, coordinated and accessible." In keeping with this vision statement, NNDS also administers Financial and Family Support Services and Adult/Elderly Services as well as numerous other specialty services.

Based on this mission, and responding to a rash of child sexual abuse cases in Arizona and a federally legislated opportunity to craft tribal solutions, the Navajo Child Special Advocacy Program (NCSAP) was launched in 1990 to provide Western and Navajo therapy to children who have been sexually abused. With five offices on the reservation, the Program administers sand, art and play therapy, energy psychology and trauma reduction counseling, and provides services and referrals for traditional Navajo therapy. They also conduct forensic interviews. By effectively addressing a pressing but rarely discussed social problem, the Program is helping to create a safe environment that nurtures children and families' physical, mental and spiritual well being. The NCSAP is confronting and dealing with an extremely difficult, yet common, social problem in Native America. NCSAP's exemplary work provides much-needed treatment for Navajo society's most at-risk individuals and families, demonstrating that it is indeed possible to treat children with the protection, dignity and respect they deserve. It is a worthwhile example for other governments, Indian and non-Indian, to follow. The following are lessons learned from the NCSAP project that the DOC has built into its conceptual framework.

- Good governance mandates that Indian nations be responsive to compelling social problems, and often, the response requires coordination between tribal and federal agencies. Creating multidisciplinary teams, developing detailed protocols and working closely with other tribal and non-tribal agencies are several ways to craft effective institutional responses.
- Successful programmatic intervention begins with extensive data collection and information management. Maintaining clear records and detailed data enables tribal programs to track progress and tailor services to best meet community needs.
- Matching social services to community needs may require the integration of Western and indigenous practices. For example, Western therapy can be integrated with traditional approaches to healing.

Also compatible with the DOC conceptual framework is The New Freedom Initiative, a comprehensive plan to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives and participate fully in community life.

Building on the Navajo Nation's mission and The New Freedom Initiative, the proposed DOC project's conceptual framework is based on an ecological model designed to develop healthy communities. Several successful Navajo Nation projects provide lessons that support community based family-centered care as does the 2005 AZ Title V Needs Assessment. "Healthy communities tend to produce healthy people" ³⁹. Fostering healthy communities is fundamental to the DOC's approach to reducing health disparities in Navajo CYSHCN and their families. Strengthening communities promotes individual as well as group health. A healthy community sustains healthy connections among its members, as well as with other sources of strength within the community. Healthy communities provide ways for members not only to survive but also to grow; not only to receive but to contribute. Healthy communities are built from social capital, active engagement of individuals with others members of the community and with "community life." These engagements provide opportunities for affiliation among members and benefits to the community. "Social capital refers to the features of social organizations such as networks, norms, and social trust that facilitate

coordination and cooperation for mutual benefits”⁴⁰. The ultimate goal of all community development activities is to mobilize community resources, facilitate improved system service delivery, develop policies supportive of children, youth, and families, and enable full participation of citizens in the life of a community that nurtures and values all of its members.

The DOC methodology is an expansion of Bronfenbrenner’s⁴¹ Ecological Framework in which families are viewed from the perspective of their relationships with the community, the community from the perspective of its relationship with larger systems and the larger systems as a result of their relationships with governance. Key to Bronfenbrenner’s model is that the strength of relationships is dependent on proximity, i.e., adjacent spheres exert the greatest effect on one another, family to immediate community/microsystem to endosystem; community to system/endosystem to exosystem. Hence, non-adjacent systems exert little power on one another. An explanation of Bronfenbrenner’s model follows.

The **microsystem** includes families and CYSHCN needs within communities. Navajo families are unique as they frequently are comprised of a large extended family. The Navajo clan system confers relationships of ‘brother’, ‘sister’, ‘grandmother’, ‘grandfather’, ‘aunt’ and ‘uncle’ to individuals ‘related’ through clan affiliation but not necessarily by ‘blood’. Typically families are identified by their affiliation with members of the endo or exo systems such as their primary care physician, a school system, or other local entity. Because of the physical isolation of many Navajo families, many CYSCHN go unidentified and underserved.

The **endosystem**, or system within the community, is the community that surrounds the families. The endosystem is typically reflective of the demographic, cultural and political composition of the community. Within DOC, the endosystem refers to the 5 Agency teams of parents of CYSHCN (consumers), community physicians, ancillary health care providers, educators, and decision-makers at the local level. As communities differ on their demographics/cultural composition and current resources, the composition of these teams will differ by location. A significant strength of the Agency Teams is their ongoing outreach to existing families of CYSHCN and linkages to newly identified children, youth and families. The Teams will serve as the primary identifier of families within each community and resources, data collectors on surveys that establish community needs, and analyzers of issues within local areas. The Agency Teams will nominate members to the steering committee.

The **exosystem, or system outside of the community**, includes agencies statewide that support communities. Depending on the location, size, and level of community development, the exosystem may have branch offices/clinics of health, welfare, and education, as well as not for profit and profit organizations. The main exosystem structure within the DOC conceptual framework is the Navajo Nation steering committee. Membership includes parents and youth representatives from each of the 5 Agency Teams, Title V Office; Title XIX (Medicaid) representation from UT, AZ, and NM; Arizona Health Care Cost Containment System (AHCCCS); Behavioral Health Services; and Indian Health Services, Navajo Divisions of Social Service (DOSS), Education (DODE), Health (NDOH), BIA, representation of educational programs in the 5 Agencies; early childhood Part C programs in NM and AZ; and Navajo Behavioral Health. These organizations and agencies constitute the larger system of services available to families across the Navajo Nation. A task of DOC is to have each Agency Team identify/map their community’s exosystem.

Within the scope of the DOC project, the **macrosystem** is the Tribal Council and the U.S.HHS/ IHS, and the BIA, which promulgate policy and promote change across systems. Annually, the DOC steering committee will submit a report of activities, data, and recommendations to the Tribal Council through the Council’s Health Committee.

The ecological model contends that adjacent systems have the greatest impact on each other; therefore, natural patterns of communication emerge. Families articulate their needs to communities, communities collaborate directly with the infrastructure and the agencies within the infrastructure communicate with the

steering committee. The steering committee will be facilitated by the DOC project Director, Jenny Rodgers, MOH, who has longstanding positive relationships with all of the members. A listing of Task force members and letters of commitment are in Appendix.

Dine' for Our Children: Procedure

The methodology of the DOC project is Community-based Participatory Research, which yields empirical findings that serve as the strong base on which rural Navajo communities build or enhance service systems for CYSCHN and their families.

Community-based Participatory Research (CBPR) was developed as a method to translate the ecological model into reality. CBPR, which has historical roots in the social reform movements of the late 19th and early 20th centuries⁴², requires close collaboration among researchers, practitioners and citizens to foster constructive community development⁴³. CBPR is a collaborative approach that equitably involves community members in every aspect of the evaluation process. The partners contribute unique strengths and shared responsibilities to enhance understanding of a given phenomenon within the social and cultural dynamics of the community. CBPR reduces the typical long stretch of time between the production of new knowledge and translation of research into practice. CBPR can quickly bridge the gap by translating research into health interventions and science-based policies ^{44, 45}.

For immigrants and racial or ethnic minorities, historic mistrust of the health care system and research has compromised the ability of researchers and providers to identify and address their health needs⁴⁶. Given this challenge, CBPR has (re)emerged as an approach that builds the capacities of communities to function as co-investigators, which then yields commitment among all partners, and methodologies and results that are more likely to be culturally sensitive and socially valid. Thus CBPR has become a viable approach for academic and public health communities to address the persistent problem of disparities in the use of health care and health outcomes for several populations). What is distinctive about CBPR is not the methods employed, which may be either¹⁴ quantitative or qualitative, but the active involvement of the people whose lives are affected by the issue under study in every phase of the process⁴⁷, and an orientation toward a setting's strengths, competencies and potential promise rather than its weaknesses, deficits and problems ⁴³. The outcomes are relationships and continued communication long beyond the actual research project and richer validity of research outcomes⁴⁷. The DOC proposal was developed by a 'CBPR' team of professionals and families, primary health care providers, administrators, and researchers across the Navajo Nation. The CBPR methodology is described below.

The DOC will support parents financially and through technical assistance to function as community leaders. Parents will chair Agency Teams, a unique approach, and Agency Teams will include equal representation of parents and professionals. Agency Teams will prioritize and choose issues needing resolution, identify resources, plan activities, and take action, incorporating Community Development Techniques. Parents are no longer merely recipients of services, but collaborators in improving services and their communities. Through these efforts, parents, youth and Agency Teams, link with other teams and become respected and competent agents of change. They will present a strong unified voice for children and youth with special needs.

Dine' for Our Children: Goal

The scope and sequence of DOC objectives and activities are responsive to the ecocultural conceptual framework described above and the implementation of CBPR by teams of families, youth and professionals in 5 Agencies across the Navajo Nation. A secondary goal of each of the Objectives is to develop empirical evidence that can be translated to other communities on Navajo Nation or to other

American Indian communities. Hence, the following methodology describes each objective, its rationale, the method by which it will be evaluated and how the results will be disseminated.

The primary **goal** of the Dine' For Our Children (DOC) project is to reduce health disparities by improving Navajo families of CYSHCN access to integrated services. The DOC project is different from other efforts to improve Navajo living conditions because it will be family-centered, and focused on grass roots community involvement in reaching project goals. The methodology will focus on developing teams of families, youth, and service providers at local levels who will identify existing services and gaps in the service system. These groups will articulate their needs and determine how services should be organized so that they are responsive to families needs within Navajo traditions and western medical care and related services.

Rationale for DOC Goal: This goal is responsive to the President's New Freedom Initiative: State Implementation Grants for Integrated Community Systems for Children and Youth with Special Needs, the stated mission of the Navajo Division of Social Services, the needs articulated by the state of AZ and New Mexico Title V, the lesson learned by the Navajo Child Special Advocacy Program, and recommendations of the MCHB Rocky Mountain Task Force

Dine' for Our Children: Objectives and Activities

Objective 1. Establish Teams

Teams of parents, youth, and providers will be established in each of the five Agencies. The teams, coached by project staff, who take responsibility for the following:

- A. Assess the needs of their respective communities using a reliable and valid tool that produces an electronic database as well as a local map of services and related information;
- B. Examine Navajo/BIA/IHS progress toward meeting the MCHB performance indicators by conducting a modified version of the National Survey of Children with Special Health Care Needs within each agency;
- C. Identify barriers that hinder performance in the areas of family-professional partnerships, medical home, equitable insurance, early screening and detection, access to services, and transition to adulthood;
- D. Use community based participatory research (CBPR) to develop strategies within each community to overcome these barriers;
- E. Share successes and difficulties with the other teams quarterly; and expand the network and opportunities for leadership and parent professional partnerships to new families

Rationale. Developing teams of parents, youth with special needs, health and service providers, educators and community leaders at the local level creates an environment through which family-centered care, family/professional partnership, and cultural and linguistic competences can be integrated into all aspects of the project. These teams form networks and build relationships that identify issues, test solutions and give a clear voice to the issues of CYSCHN.

Activity 1.1. 'Who Should We Be Talking To?'

The objective is to constitute a team of approximately 10 individuals in each of the five Agencies. Each team will have a minimum of four parents; a youth with special needs, a physician or medical provider from the local IHS medical center, a member of the local public school system, and tribal governance (e.g., chapter president or vice president). Parents and service providers will be recruited from IHS primary care settings in which CYSCHN receive care, early intervention programs in which young children are enrolled, high school programs from which youth matriculate/transition to adulthood, public schools that children attend. Parents of residents of St. Michael's Children's Facility in Window Rock also will be invited to join. Paula Saenez, Director of the Growing in Beauty early intervention program will recruit parents of young children. Ms. Rosemary Silver will recruit through the public schools. Dr. Douglas Esposito, MD, MPH, FAAP, Director of IHS Community H, Ft. Defiance Area, has volunteered to recruit physicians in the IHS service areas. Jenny Rodgers, MPH, will recruit social service professionals in each community, and Youth will be recruited through their high school settings and recreation programs as well as the Navajo Workforce Initiative Act programs in Window Rock, Shiprock and Chinle. Additionally, YSHN enrolled in college at San Juan, Dine' and Highlands Colleges will be invited to join the teams. The remaining membership will depend on individuals the respective teams identify as important partners in their communities. A program to recruit these members will be initiated by press releases in the Navajo Times newspaper, on Navajo radio and on the website of the President of Navajo Nation. In addition, project flyers (see Appendix F) will be provided to the 110 Chapter Houses, the 7 major and 2 clinic IHS health facilities, special education departments of the public schools and early intervention programs.

Activity 1.1 Evaluation Benchmarks

- a. Press releases are developed and delivered to Navajo Times, Navajo Radio, and placed on the Navajo President's Website by 15 May 2006
- b. By 01 July 2006, all 5 Agencies will have teams of at least 10 members
- c. Each team will have at least 4 parents/family members and 1 YSHN

Activity 1.2. *'Many Voices-Many Styles'*

The Navajo Nation ONSat Department will develop the A DOC website that will be linked to the website of the Navajo President. ONSat is a freestanding department in the Nation that was funded by a multimillion dollar grant from the Bill and Melina Gates Foundation. The grant enabled internet connectivity among all of the 220 Chapter Houses (centers of local government across the Nation), Window Rock (the Navajo capital), and the Agencies and IHS health centers. Hence, residents who may lack infrastructure services such as electricity or telecommunication, can access the internet, connect through email, and conduct research for information online at local Chapter Houses. The DOC website will identify the Project, its goals and objectives and ongoing outcomes, its leadership and partners, the teams/memberships, their locations and meeting times, a calendar of the dates of steering committee meetings its accomplishments (future), team CBPR projects and their status, and future reports and findings of the DOC project. The website will also include a bulletin board for community members to post questions and comments to the project. Within the website will be nested a system called Team Talk®, a product of the Page Partners community team and SWI from the SWI Integrated Services Enhancement Grant (2001-2005). Team talk is used to electronically link members and groups together, facilitate sharing of information, provide organization of time and materials and is generally a virtual meeting platform. SWI contributes use of this state-of-the-art tool to the DOC project to facilitate seamless communication between team members and across teams. Team talk will serve as the primary digital link between members/teams. Team members

unable to access Team Talk from their homes will be able to access the system through their Chapter Houses and will be connected by face-to-face meetings, phone calls, and mail. Every avenue will be made to connect members by their chosen route.

Activity 1.2. Evaluation Benchmarks

- a. The website will be “live” by 01 June 2006.
- b. 100% of Chapter Houses will have received DOC website information announcing the website by 15 May 2006
- c. 100% of Team members and steering committee members will receive Team Talk logons and instructions by 01 July 2005

Activity 1.3. *‘Team Building’*

Agency Teams will be individually coached by Jenny Rodgers, Project Director and Lee Hunter, SWI, community development consultant, and Trish Thomas, training and technical assistance for Family Voices and the Laguna Pueblo to organize using the steps outlined in the SWI CBPR guide. At the initial meeting in each Agency, Navajo introductions and invocations will take place; the team will receive an overview of the DOC goal and objectives, the roles and compensation of family and youth team members, and organizational structure of the teams. It will be clear to all participants that families and youth leadership is central to meeting the goals of the DOC project. Families will complete the forms and paperwork necessary to receive stipends for interviewing, SWIfT coordination (see Activity 1.5), and CBPR projects (see Activity 1.6) as well as meeting attendance, fees and reimbursements for travel and other expenses incurred. The team will be assisted to nominate parent leaders, recruit NCHS interviewers (see Activity 1.4) and SWIfT Coordinators; and set up schedules that meet their respective needs. The team will discuss the activities that will occur at the next meeting, e.g., CBPR coaching. IHS has offered space in facilities across the nation for monthly meetings of the respective teams. Meetings typically last 2-3 hours. Free childcare for families will be provided at each location; travel/mileage will be paid at the time of the meeting; parents will receive stipends for meeting attendance; and refreshment will be served.

Activity 1.3. Evaluation Benchmarks:

- a. 100% of each team has received DOC overview by 15 August 2006
- b. 100% parents and youth on teams complete stipend and reimbursement forms
- c. Each team identifies a structure by which to conduct their meetings. At a minimum 1 parent will be identified to lead the meeting and 1 backup parent to assist, project staff will initially train parents on maintaining accurate records
- d. An agenda that includes planning for the Child Health Survey is developed by the team.

Activity 1.4. *‘In God We Trust, From Everyone Else We Expect Data’*

A central objective of the DOC project is to determine Navajo progress toward achieving the 6 MCHB Performance Indicators and to determine the incidence and prevalence of special health care needs in children and youth on the Navajo Nation. As indicated in the *Needs Assessment*, currently, no accurate data for the Navajo Nation are available. To accomplish these two tasks the DOC project will conduct a model of the NSCSHCN SLAITS. The results will then be compared to regional (neighboring states), and

national performance. Most importantly, the results will be used to inform Agency teams of their strengths and needs in the areas of 1) family/ professional partnerships, 2) early and continuous screening as well as follow-up that links to medical home as well as specialists, 3) medical homes that are comprehensive, family-centered, and culturally competent in which families traditions and beliefs are respected and integrated in the care plan; 4) adequacy of health insurance for Navajo people through HIS as well as Title V providers; 5) the ease of use and accessibility of systems of care on the Nation; and 6) the extent to which 1) Navajo and IHS systems of care are responsive to the Consensus Statement on HRTW, 2) the extent to which YSHN are prepared for adulthood across the areas of health, social service, vocational support, and long-term care, 3) the existence of a comprehensive system that supports YSHN and their families to accomplish transition goals effectively and serve as convergent data to support or refute the findings of local focus groups. Furthermore, these data will provide Title V offices in Utah, AZ, and New Mexico with data about the children, youth and families who reside on the Navajo Nation lands that cross their state boundaries. The DOC model, Navajo Child Health Survey, will be based on the *SLAITS NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS 2 CATI SPECIFICATIONS* July 6, 2005.

The following process will be used to conduct the Navajo Survey of Children with Special Needs:

- A total of 770 surveys will be collected during the period of 01 July 2006 and 30 October 2006.
- The major problem encountered by the original SLAITS was that it depended on people having telephones. The Navajo Children’s Health Survey’s NSCSHCN (modified SLAITS), will use the same questions but be conducted face-to-face by trained members of the Agency teams.
- There are 110 Chapters within the Nation. Each is relatively similar in population size. From these chapters representatives are elected to the Tribal Council. Chapters maintain accurate records of residents and residences. The DOC will gain permission from the Navajo Health Board to randomly draw the names of 7 residences in each chapter, which will yield a sample of 770 families across the nation. This approximates the sample size from each state in the original SLAITS (2000). A benefit of this method is that only residences (vs. business/commercial) will be selected.
- A modified version of the SLAITS NSCSHCN will be used. The Survey will be reformatted so that it is easy to read. Responses will be entered on the interview protocol. Individuals collecting data will be trained the same way as SLAITS interviewers, with the following changes- 1) training on face-to-face interviewing, 2) a simplified coding sheet, and 3) deletion of “Callback Scripts” and “Answering machine conversations.” Modified protocols will not list respondents’ names. However, Chapter names will be listed.
- Training will take place after the second meeting of Agency Teams at times determined by interviewers and evaluator. Training will be supervised by the project evaluator K. Burstein and delivered by project director, J. Rodgers, and consultants T. Thomas, L. Hunter, and T. Bryan. Instruction on surveys will be delivered at the local Agencies.
- The interviewer pool will consist of a minimum of four parents and one youth from each of the Agency Teams (N=>25). Other team members may also will agree to participate. Chapters will be divided by Chapter affiliation or physical proximity. Each interviewer will be asked to administer approximately 30 surveys across a 16-week period. Interviewers will be paid \$20 per survey collected and interviewees will be paid \$15 for completing the survey. The majority of the surveys will be collected at the Chapter Houses when residents come to conduct routine business. Other surveys will be conducted in the homes of the residents.
- Weekly, Interviewers will submit completed surveys to the DOC Administrative Assistant who will issue a check to families interviewed. Data will be entered into an SAS (2004) dataset by the project

administrative staff, trained by Burstein. Burstein will check data for accuracy by conducting reliability checks on 5% of the protocols. Interviewers will be paid bi-weekly for completed surveys.

- Initially, data will be analyzed so that comparisons can be drawn to other populations.
- Further, the Agency Teams and the steering committee will pose questions of the data set in order to develop hypotheses and to construct measurement of DOC progress.
- The same method of data collection will be used at the conclusion of the project to measure project outcomes especially around Easy Access to Service Systems.
- Data will be archived in Navajo systems and secured using high quality encryption systems. Access to these data will be determined by the Project Director, Evaluator and Steering Committee.
- Data will be analyzed and reported in ways that approximate the data reported by the SLAITS, 2005 reports.

Activity 1.4. Evaluation Benchmarks:

- a. Modified version of SLAITS (Navajo Child Health Survey) will be ready by 01 July 2006
- b. >26 interviewers are trained and achieve >.90 inter-rater reliability on mock interviews
- c. 770 randomly selected residences are contacted and interviewed by 30 October 2006
- d. Data will be entered and have 100% input accuracy
- e. By 30 December 2006, descriptive data on survey will be delivered to respective Agency Teams and the Steering Committee
- f. By 15 June 2007 a report of the Navajo Child Health Survey findings will be provided to the Agency Teams, Steering Committee, Navajo Health Board, IHS administration, Tribal Council and the Title V Offices in AZ, New Mexico, and Utah (in time for inclusion in their respective MCHB Block Grant Applications)

Activity 1.5 'Hidden Treasures' Mapping Community Resources : *SWift® Resources*

Before accurate determinations of need can be made at the community level, each team will begin the process of mapping the skills, talents and services that exist in each Agency catchment area. Applying a strength-based assessment rather than a needs-based model promotes pride and enthusiasm and a sense of collegiality among the community as it identifies untapped resources and makes new partners. *SWift® Resources* is a unique database/tool that was developed for this purpose under the MCHB *Building Community Health Across Arizona initiative (2002)*. The SWIf model was developed so that communities could identify not only services such as traditional care providers such as hospitals, clinics, governmental agencies, and schools; but other, often overlooked, critical resources, such as respite providers, local talent (choirs, singers, weavers, story tellers), services (drivers for car pools with vans, Girl and Boy Scout troop leaders, cooks who can prepare meals for special diets or special occasions). It catalogues skills, talents, resources and services that are of value to the local community. This depth of information assists the community in recognizing its strengths as well as its gaps in service. However, unlike other systems, it is a "bottom-up" system in which consumers and providers input the skills, talents and services that are unique to individual communities. Hence, families and local providers determine what services exist in their communities. These services are searchable by type of resource, service, skill by zip code, county, or in the DOC project, by Agency. The search yields service description, eligibility, cost if any, hours of operation, contact and personnel specific information as well as location. Additionally, the website generates a map with driving directions for the user. www.swifamilies.com. This model has two distinct advantages over traditional resource directories for the DOC project: 1) Since parent leaders and the Agency Team are responsible for

populating the database, they create networks and discover new partners, 2) Teams discover gaps in service within their communities and can look within the community network for ways to fill these gaps. The SWift website is currently being linked to the Arizona 2-1-1 system in two ways so that CYSCHN and their families can have easy access. 2-1-1 is developing a crosswalk so that the thousands of SWift resources statewide can be incorporated into the master system and the SWift homepage is being linked as a partner to the 2-1-1 homepage.

Because many families on the Nation do not have home access to the internet and many may not take advantage of the Chapter House computers, SWift developed a resource that will generate maps for local communities. These maps, like road maps, indicate landmarks, locations, and directions as well service descriptions, eligibility, cost, personnel, and contact information. Initially, maps will be made for Chapter Houses, IHS facilities, Navajo Nation Social Service staff, schools, NN Head Starts, Part C early intervention providers, and Title V service coordinators. Maps will be updated annually.

SWift® Resources Process

- Each Team identifies/recruits one member to serve as the *SWift Resource* Coordinator. This individual will have access to an internet accessible computer or can dedicate the time (approximately 2-3 hrs per week) to go to his or her Chapter House to input resources.
- *SWift Resource* Coordinators will meet in Window Rock with Jenny Rodgers, Administrative Coordinator, and Lee Hunter (SWift developer) to be coached on resource identification, documentation, and data input. Each *SWift Resource* Coordinator will be issued a *SWift Resource* login ID and Password necessary for data input.
- Monthly, *SWift Resource* Coordinators will join a conference call with approximately 15 coordinators statewide to share progress, discuss problems and solutions to data collection.
- Each month, *SWift Resource* Coordinators will submit time sheets to the Administrative Assistant for payment.
- Rodgers and Hunter will conduct *SWift Resource* Coaching with the Steering Committee to identify individuals who will provide resources to add to *SWift Resources*. The Administrative Assistant will assist in data input.
- Monthly, *SWift Resource* Coordinators will provide Agency Teams with updated reports.
- Quarterly, Rodgers will provide update reports to the DOC Steering Committee.
- *SWift Resource* Coordinator will conduct training on how to use the *SWift Resources* website at each chapter house within their Agencies.
- Rodgers will conduct *SWift Resource* Training with IHS and NN Social Service Staff.
- Thomas will link *SWift Resources* to Family Voices National Website and the Native American Tribal Health Board

Activity 1.5. Evaluation Benchmarks:

1. 100% of teams have identified a SWift Coordinator by 01 July 2006
2. 100% of SWift Coordinators are trained on SWift Resource data collection and entry by 10 August 2006

3. 80% of SWIfT Coordinators participate in monthly conference calls across 6 months from Oct 2006-Feb 2007
4. By 01 Nov 2006, www.swifamilies.com will be linked to DOC website, Family Voices, and Native American Tribal Health
5. By 01 Mar 2007, each Agency has identified their partners and resources in health, education, traditional ceremonies and healing, and social service
6. By 01 May 2007, 500 paper versions of the Agency Level and Nationwide Resource Maps for Chapter Houses, HIS clinics, and schools
7. Number of hits to the website will be calculated by zip code and service
8. Feedback comments on the website will be analyzed

Activity 1.6 *Teams at Work*-Community-based Participatory Research (CBPR)

CBPR is the problem solving method that the DOC project proposes to use. It employs the scientific method to generate problem statements, form testable hypotheses, and choose interventions that yield empirical data by which to promote systems change at the local level. It is ideally suited for the DOC project as it has been used successfully in other similar projects in Arizona that have yielded significant changes such as the 1) *Parents as Partners in the Medical Home* (1997) project in which parents of CSHCN identified and tested indicators of family-centered medical homes, the physical environments of medical homes, and effective communication patterns during the medical encounter; 2) *Racing to the Future: Transition of AZ YSHN to Adulthood*, (2000) in which YSHN developed strategies to improve self-determination, families developed strategies to promote effective transition, and physicians developed networks and tools to promote transition to adult care; 3) *AZ Network of Medical Homes* (2001) in which teams of parents partnered with local physicians to transform existing pediatric practices into medical homes that provide family centered, comprehensive, culturally competent that is facilitated by local care coordinators; 4) *Building Community Health Across AZ* (2001) in which teams of parents in rural communities identified the needs for care coordination, organization and access to services, professional development for direct care personnel, and training for emergency and police personnel engaged in 'first response' activities; and 5) Arizona Centers of Excellence in Early Education (2003) in which a team of parents and educators have identified issues surrounding health literacy and developed a tool by which families track their communications with physicians and other health professionals to improve health outcomes for young children. In each of these projects, community teams led by parents identified their strengths, coalesced around significant issues, and used CBPR to resolve issues. The results of their efforts have had sustainable results. Today each of these communities continues to be committed to improving services for CYSCHN at the local level.

As described earlier, teams will meet monthly. The last meeting of each quarter, beginning in July of 2006, will be a large group meeting of all the Agency Teams. The location will be rotated among Agencies so that travel demands on families and other team members will be fair. Meetings will be held at local IHS facilities. The first meeting will be at Ft. Defiance Indian Medical Center. At the first quarterly meeting, Rodgers will facilitate of the group and introduce CBPR. Each team will be provided a CBPR Handbook at their initial meeting. The initial group meeting will be focused on the steps for conducting CBPR. It will start with Navajo introductions and invocation that will be rotated among the agencies followed by a discussion of barriers/issues for families and youth in each of the 5 Agency areas. This gives the youth an opportunity to network with the youth representatives from the other agencies. Jenny Rodgers and Tanis Bryan, SWI CBPR consultant, will model CBPR. (see Appendix 1 for CBPR Flow Chart).

In addition to funds available for parent leadership, *SWift Resource* mapping, and Navajo Child Health Survey collection, each Agency Team has an annual budget of \$5000 with which to implement their CBPR intervention. Rodgers, Project Director, will work with each team to develop a budget and payment schedule that is in compliance with Navajo Nation Office of Management and Budget. The Administrative Assistant will coordinate all receipts and payouts.

The following is a model of the meeting structure for CBPR. Items a-c occur at every meeting. Items d- occur over a series of meetings

- Call to order
- Introductions of current and new team members: clan affiliation, community partner, child/ youth special need
- Invocation- to be rotated among members
- Identification of an pressing issue around one of the following topics: Family/professional partnerships; comprehensive, family-centered, culturally competent Medical Home; Early screening and follow-up, Adequacy of insurance and the relationship between HIS and other sources of coverage; Ease of access to service systems; and Healthy Ready to Work Transition to adulthood. Definition of the issue(s) comes for either personal, or group experience. Initially, the question can be posed in a global fashion, e.g., barriers to service for CYSHCN or more specifically, e.g., barriers to a specific service/resource school, primary care, medical home, insurance, early screening/early intervention, transition etc. Each team member contributes his or her own personal experience to the discussion.
- Team select the most pressing issue to address. It is important to come to consensus on this issue so that all members contribute and participate. This is known as the problem statement.
- The team determines what is known and not known about the issue/barrier. After the *SWift* mapping and Navajo Children's Health Survey data are available, teams can ask questions of the data to inform their CBPR discussions and activities. Additionally, it is critical to know how other communities/groups have addressed this issue. The role of the project director and consultants is to locate and inform the teams of this information. This information is typically provided as 'Best Practice' or 'evidenced-based' strategies.
- The team examines and discusses 'what is known' and how this strategy might work or not work in their community. The team members are the experts on their community; hence they need to examine the potential interactions of known 'best practice strategies' with the demographics, language, economy, existing resources, logistics, beliefs, and traditions of the community.
- The team chooses a strategy or develops a unique strategy to implement. They construct a hypothesis that is responsive to their problem statement. Example:

Problem Statement: Our physician doesn't speak Navajo and does not understand our traditional beliefs. Hence, we are not comfortable following his treatment plan and do not return to the clinic.

Strategy: We develop family-delivered instruction to physicians on Navajo language, traditional beliefs, and family structure.

- The team will operationalize the strategy such that each step is observable and measurable. The project director and evaluator assist in this process. The outcome of this process is a CBPR Matrix that clearly defines timeframe, partners, locations, responsible parties, budget.
- The team, with the assistance of the project director and the evaluator, develops a way to track and evaluate their progress, i.e., collect data on their project. Data include quantitative measures such as: number of persons trained, pre and post testing scores, funds spent, ratings of satisfaction, and increase in number of visits to the clinic, and type and number of questions asked by physician, family, youth. Qualitative data are also obtained by using open-ended questionnaires of families, youth and physicians. The DOC project uses Microsoft Project to track all phases of each team's CBPR.
- Teams implement their CBPR projects. DOC project staff and consultants assist teams to monitor and modify strategies as needed.
- Teams internally report monthly on their progress and quarterly share their progress with other Agency teams at group meetings.
- Three times per year Agency teams report their progress to the Steering Committee.
- Annually (in May) the teams prepare a interim progress report for the Steering Committee, NN Social Services, Navajo Health Board, IHS and the respective Title V offices of Utah, AZ, and NM.

Activity 1.6 Evaluation Benchmarks

1. 100% of team participates in CBPR coaching by July 2006
2. Parent leaders demonstrate group facilitation by Sept 2006
3. Each Agency Team has identified an issue related to one of the 6 Performance Indicators
4. Each Agency has a minimum of 2 strategies (what is known) to examine
5. Each Agency's issue is aligned with their respective *SWift Resource* Data and Navajo Child Health Survey data by Jan 2007
6. Each Agency has chosen/developed an intervention and data collection mechanism by December 2006
7. Each agency has approved a budget for their project
8. By May 2007 an annual interim report reflects the initial steps and progress with respect to each project

Objective 2. *Giving Voice to Our Data*

A Navajo Nationwide Steering Committee will be developed with a broad representation of parents, youth, IHS physicians and related service providers, social service and health administrators, tribal council representatives, educators in early childhood, elementary and secondary education, Navajo Workforce Initiative representatives who assist adolescents in transition, representatives from Utah, AZ, and NM Title V offices who will open communications between the Nation and state Medicaid programs in order to examine issues around insurance for CYSCHN

Rationale. An integral component of CBPR is to change existing systems based on empirical findings generated by Team activities. The DOC project will use a Navajo Nationwide steering committee to disseminate and sustain the CBPR findings.

Activity 2.1 Steering Committee.

Constitute the Steering Committee of approximately 25 persons with individuals who are in positions to affect change within the health, education, and social services of the Navajo Nation. Two parents and one youth from each Agency Team will be nominated by each team to serve on the steering committee. Funds are allocated for travel and hourly stipends for families and youth. The Steering Committee will meet three times each year for 3-4 hours and will rotate locations across the Nation. As the committee is comprised of individuals with expertise in medicine, administration, social services, and other specialties, a major responsibility of the committee will be to assist community representatives to develop strategies and align them with the 6 MCH Performance Indicators. Jenny Rodgers, Project Director and Douglas Esposito, MD, MPH will co-chair the committee. Dr. Esposito is the Director of Pediatric Community Health at the Ft. Defiance Indian Medical Center. A list of individuals who have volunteered to serve on the steering committee is in Appendix A. The typical responsibilities of the committee are:

- Agency Team report on CBPR activities
- Discuss reports from the Navajo Child Health Survey
- Youth members report NYAC activities and projects
- Discuss Navajo progress toward meeting each of the 6 Performance Indicators (one per meeting across 2 years)
- Assist in the development and dissemination of annual interim report
- At the conclusion of the project, the Steering Committee will develop a series of recommendations to the HIS, NN Social Service Division, State Title V and Medicaid Offices, and education agencies including Head Start
- Assist with the preparation and presentation of scholarly reports and presentations

Activity 2.1. Evaluation Benchmarks

1. Two parents and one youth from each Agency Team join the steering committee
2. Co-chairs are parents of CSHCN as well as professionals
3. Agendas for each meeting include reviews of each Agency Team's CBPR
4. Each meeting includes discussion of research findings and their relationship to the 6 MCHB Performance Indicators
5. By June of each year, an interim progress report on Agency Team and steering committee activities developed by staff and approved by the Steering Committee and submitted to appropriate agencies and individuals

Objective 3. *Youth in Action*

A Navajo Youth Action Council (NYAC AZ) of YSHCN will be recruited. The team will inform Navajo tribal leadership of the unique needs and perspectives of Navajo YSHN, network with YSHN in other communities, and serve as models and consultants to other Native American communities wishing to promote YSHN transition to adulthood.

Rationale. In *Olmstead v L.C.*(1999) the Supreme Court ruled that individuals with disabilities must "have the opportunity to live close to their families and friends, to live independently, to engage in productive employment and participate in community life." As individuals move from childhood to adulthood, these

guarantees become more important and sometimes more difficult to ensure. The National Indian Health Board (NIHB) has taken a leadership role in assisting tribes to develop comprehensive systems of care for health, employment, transportation, assistive technology, caregivers and other human service needs of American Indian and Alaskan Native young adults between the ages of 16 and 30. .Development of a NYAC is responsive to Olmstead and complimentary to the future work of the NIHB.

Activity 3.1 The typical activities of the NYAC are

- Each Agency Team will nominate at least one member to join the NYAC. Members will be between the ages of 16-26 and have a special health care need.
- Each member will be issued a logon ID and password to the *Team Talk YAC AZ* group. This portal and 'virtual community' includes a secure chat room, email system, virtual library, and calendar. Youth leaders in the YAC-AZ will coach the NYAC to use the system.
- NYAC will be asked to logon twice weekly and to make at least one posting to the site.
- David Carey and Nora Stiles, SWI Youth Coordinators, will coach NYAC using the FAST TRACK Curriculum which includes:
 1. Self-determination goal setting
 2. Choosing a career and setting an educational plan
 3. Applying for a job
 4. Managing money, SSI, insurance, banking
 5. Managing your health, making a doctors appointment, following medical directions, healthy living lifestyles, making healthy choices
 6. Leisure and recreation activities in the community
- NYAC will travel to Flagstaff to meet face-to-face with the YAC-AZ in October of each year. Teams will identify an issue on which they want to work for the following year. Possible topics will include youth-centered medical home care, leadership skills, diabetes management, finding employment. Youth will present their issues to the Steering Committee at each meeting.
- NYAC will nominate a member to the National Youth Action Council

Activity 3. Evaluation Benchmarks

1. 5 or more members join the initial NYAC by December 2006
2. Each member demonstrates ability to use Team Talk
3. Each member serves as interviewer on Navajo Child Health Survey
4. At least 1 youth will actively participate in Agency team
5. Each member will make at least one weekly posting to the Team Talk
6. NYAC members will attend all three annual steering committee meetings and provide a report on activities
7. At least 80% of NYAC members will meet in Flagstaff, AZ to identify issues and identify group solutions to problems

Objective 4. *Build it from the Ground Up*

The objective is to increase the number of culturally competent social workers available to the Navajo Nation through a partnership with the New Mexico Title V Office for Children with Special Health Care Needs

Rationale: Of the biggest barriers to establishing integrated services on the Navajo nation is the dearth of qualified social workers and related service providers. Moreover, the existing providers often are ill prepared to support individuals in culturally competent ways. "Importing" professionals has worked to some degree for the Indian Health Services. However, the majority of professionals are recruited to the Nation with credentials already conferred. They spend a short period of time in the community and move on to more lucrative urban assignments. The MCHB in collaboration with the University of New Mexico MPH program identified specific needs to advanced training for professionals working in the region. This includes public health training and continuing education training, with special emphasis on community-based practice.

The New Mexico Title V Office for CSHCN has agreed to partner with the DOC project to implement an internship program for social work students recruited out of universities adjacent to the Navajo Nation. New Mexico leadership believe that if social work students receive first hand experience with families in rural communities on the Nation that interns 1) will be more culturally competent, 2) learn more appropriate skills and knowledge rather than having to adopt new paradigms later in practice; 3) develop close personal and professional associations that may enhance retention of these valuable staff beyond the internship, and 4) Navajo families' perception of social workers will change from quasi law enforcement to helping and supportive; and 6) the interns will provide direct support to youth in the process of transition in the Shiprock Agency. New Mexico Title V will contribute \$50,000 to the DOC to conduct this portion of the project.

Activity 4.1 New Mexico Office for CSHCN (Title V) Mentorship Project

The New Mexico Office for CSHCN (Title V) will negotiate participation of University Schools of Social Work in Arizona (Northern Arizona University), New Mexico (Highlands College) and Utah (Utah State University) to establish the mentorship project at Shiprock on the Navajo Nation. Shiprock, in Northern New Mexico, is the second largest population center on the Navajo Nation.

Activity 4.1 Evaluation Benchmarks

1. A minimum of one program will participate and provide no less than 6 student interns

Activity 4.2 New Mexico Office for CSHCN: Curriculum

The New Mexico Office for CSHCN (Title V) has developed curriculum materials for training and internship for graduate level social workers. The curriculum will be paired with the SWI *Fast Track Curriculum* for YSHCN. The Fast Track Curriculum is already being used with the NYAC Navajo Nationwide. Agency Teams in collaboration with NN Social Services will review these materials for cultural competency and make revisions accordingly.

Activity 4.2 Evaluation Benchmarks

1. By August 2007 NM curriculum and Fast Track will have been reviewed and aligned for use in Internship training

Activity 4.3 Recruit, identify and train mentors

Rodgers, Project Director, and parent leaders in Shiprock Agency will identify practicing social workers in the Shiprock Agency who will agree to mentor student interns. Mentor qualifications include 5 or more years of clinical practice, ability to speak Navajo and articulate the traditions and beliefs of Navajo people, and an MSW degree

Activity 4.3 Evaluation Benchmarks

1. # Mentors recruited
2. 100% complete files on each mentor

Activity 4.4 Mentor-Student Intern Match

1-2 students for each mentor will be identified. Shiprock Public Schools, Navajo Nation Workforce Initiative Act, NN Vocational Rehabilitation, and Family Voices NM will identify approximately 30 adolescents to participate in the project. These youth will be between 16-30 years and have some condition that qualifies them as YSHN

Activity 4.4 Evaluation Benchmarks

1. 12 + individuals will be recruited by July 2007

Activity 4.5 Pilot through Summer and Fall Sessions

Interns will meet with their cohorts of YSHN on a weekly basis, for 5 weeks, to engage in Fast Track. Each meeting will last approximately 4 hours, during which YSHN will develop self-determination skills, develop resumes, set goals, and learn about independent health care management

Activity 4.5 Evaluation Benchmarks

1. Youth complete a series of self-determination, aptitude and health surveys, and pre- and posttests on specific content
2. Number of YSHN who complete the program
3. Number of YSHN who complete a resume
4. Number of YSHN who enroll/continue in school program aimed at employment
5. Number of YSHN who are employed at the end of the training
6. Satisfaction of YSHN
7. Skill level of Interns
8. Satisfaction of Interns
9. Materials, and delivery of instruction are reviewed and revised for use in the winter session

Activity 4.6 Evaluate and Refine Intern Training

Project procedures and materials are refined and disseminated to initiate projects in other regions of the Navajo Nation. The findings of the pilot study are presented to Agency Teams, Steering Committee and NYAC. Efforts are made to support replication at other agencies.

Activity 4.6 Evaluation Benchmarks

1. How many Agency Teams are interested in adopting the project for their YSHN
2. Reaction of the NYAC to the project

Work Plan

Table x. Objectives, Activities, Responsible Parties, and Timeline

JR= Jenny Rodgers, Project Dir, AA= Administrative Asst; LH= Lee Hunter; TT = Trish Thomas; KB = Karen Burstein; TB= Tanis Bryan; LC= Lynn Christiansen; PL= Parent Leaders at Agency Team; NYAC= Navajo Youth Action Council; CM= Community Members, SWIC= SWift Coordinators

#	Objective	Activity	Staff	Beginning	End
1	Constitute Agency Teams				
1.1		Recruit members	JR, AA, CM	May, 2006	July, 2006
1.2		Advertise, build website	On SAT	May, 2006	August, 2006
1.3		Coach & Convene meetings at 5 Agencies	JR, LH, PL	July, 2006	August, 2006
		Meet quarterly as a large group (5 Agency Teams)	JR, AA, LH, TT, PL, CM	July, Sept, Dec, March	
1.4		Collect Navajo Child Health Survey	KB, JR, AA, PL, CM	July, 2006	November, 2006
2					
1.5		Map Community Resources identify gaps	JR, AA, LH, SWIC	July, 2006	ongoing
1.6		Conduct CBPR with Agency Teams	JR, TB, TT, PL	September, 2006	ongoing
2.0	Coordinate & Disseminate Data				
2.1		Constitute Steering Committee	JR, CM, AA	May, 2006	July, 2006
		Meet 3 times per year	JR, CM, AA	June, Sept, January	
		Analyze NCHS data and compare to other regions	KB, JR, AA, CM	November, 2006	February, 2007
		Review Agency Team CBPR data	JR, PL, KB, TB	3 x per year	March, 2009
		Assist in preparation of interim annual reports	JR, AA, CM	June, 2007, 2008,	May, 2009
		Assist in preparation of final reports and disseminate findings	JR, AA, CM, PL, NYAC, KB,	February, 2009	May, 2009
3	Build a Navajo Youth Action Council				
3.1		Members recruited to join Navajo Youth Action Council	JR, PL, CM	December, 2006	Quarterly
3.2		Join virtual community Navajo Team Talk	LH, JR, AA, NYAC	December, 2006	January, 2006
3.3		Youth post to website	NYAC, LH	weekly	ongoing

3.4		Participate in <i>Fast Track</i>	SWI staff, NYAC	February, 2007	April, 2007
3.5		Meet with YAC-AZ and develop group goals	JR, NYAC, AA	May, 2006	May, 2006
3.6		Nominate national membership	NYAC, AA	annually	ongoing
4	Build capacity for culturally competent professional social workers				
4.1		Recruit university training programs with minimum of 6 graduate students	LC	January, 2007	April, 2007
4.2		Agency Teams and NYAC align SW curriculum and Fast Track curriculum and review both for cultural competence	LC, New Mexico staff, SWI staff, JR	January, 2007	April, 2007
4.3		Recruit mentor social workers in Shiprock Agency	JR, LC, NN Social Services Dept, AA	March, 2007	May, 2007
4.4		Recruit youth for project	JR, NYAC	March, 2007	May, 2007
4.5		Pilot project and review & revise materials	JR, CM, PL, NYAC, AA	July, 2007	October, 2007
4.6		Expand project to other Agencies	PL, Steering committee, JR, LC	November, 2007	ongoing

Resolution of Challenges.

Many challenges face the Navajo Nation as we attempt to provide services to the Dine'. The great strength of the Nation is our land, yet it's immense size and population diaspora continue to frustrate Navajo Administration, BIA, and IHS. The Navajo nation faces infrastructure problems in the areas of housing, roads, telecommunications, and utilities. Unemployment continues to be a barrier to all members of Navajo communities, especially people with special needs. Unfortunately, many of these issues are beyond the scope of this project. We can do little to alter the economic status of 42.9% of our people. However, we can assist our YSHN to be better prepared for adulthood. We can do little to change the infrastructure or provide improved housing and modern technology to many disparate citizens, but we can provide accurate estimates of those resources available in our communities. We can not pave our roads but we can connect our participants through the internet available at our Chapter Houses. There are many inroads we can make to reduce health disparities and improve access to service for CYSCHN and their families. We can grow leaders in our communities, empower parents to collaborate with professionals, partner with our neighboring states, and prepare our physicians and other medical providers to deliver services to our children in ways that are respectful of our traditions, beliefs, and language.

Evaluation and Technical Support Capacity.

The DOC project employs process, formative and summative methods to evaluate the course and outcomes of the project.

Data evaluating process and outcomes of community collaborations is needed, as noted by the U.S. Agency for Healthcare Research and Quality. "Articles lacked information about the implementation of Community Based Participatory Research, from both community participation and research perspectives. Owing in part to page limitations in journals publishing rigorous experimental research, researchers tend not to describe fully their research methodology, adherence to CBPR principles, and the degree to which the collaboration may have benefited or threatened the research quality⁵³." Most of the studies reviewed for the publication were non-experimental in design; only a limited number included any sort of intervention.

The proposed Resource Center approach *will* align community development and research expertise so that by the end of the project, research data on both process and outcomes at the community and integrated service systems levels will be able to evaluate the attributes of the complete CBPR approach.

Process evaluation assesses the manner in which the collaboration functions. It will include indicators as described by Figueroa, Kincaid, Rani and Lewis in *Communication for Social Change: An Integrated Model for Measuring the Process and Its Outcomes*⁵⁴:

- Leadership: extent of leadership; equity and diversity; flexibility; competence in encouraging and securing participation; vision and innovation; trustworthiness and popularity
- Degree and equity of participation: access to, extent and level of participation
- Information equity: awareness and correct knowledge of the issue; free flow of information
- Collective self-efficacy: perceived ability to take action as a group; perceived capability of other community members; perceived ability to solve problems as a group
- Sense of ownership: importance of the issue to participants; sense of responsibility; contribution to the group; benefit from the group; sense of ownership of either credit or blame in the group outcome; personal identification with the group
- Social cohesion: sense of belonging; feelings of morale; goal consensus; trust; reciprocity and network cohesion
- Social norms: group beliefs and rules about behaviors regarding participation, leadership and the specific group action.

Formative- From the beginning of the project the director and administrative asst. will maintain accurate records of participants, volunteers, and consultants. These data will include minutes of meetings, phone conferences, teleconferences, and agendas. Upon award of grant, Rodgers and evaluator Burstein will develop a system for tracking activities toward outcomes using Program Evaluation and Review Technique (PERT) charts in Microsoft Project. The PERT chart will be updated monthly and archived on TEAM TALK so that Agency Team parent leaders, steering committee members and consultants can monitor areas of interest and provide comment on activities. Rodgers will have a monthly phone conference with her core consultants, T. Thomas, L. Hunter, T. Bryan, and K. Burstein, during which she will provide directives, update on progress, and problem solve. Prior to each steering committee meeting Rodgers and Esposito will inform the committee of progress on each objective/activity through Team Talk, so that they are prepared for discussions at the scheduled meetings. These data will inform the annual interim report to the steering committee and the final report which will be posted on the DOC website and archived on Team Talk. At the Agency level, Rodgers and Burstein will assist each team to construct a PERT chart for their individual CBPR goals and activities. Each team will monitor their own progress using meetings and Team Talk, and report to the other teams at quarterly all team meetings. In this way teams share successes and build upon each others' ideas, identify areas of need within their CBPR and avoid duplication of efforts. A strong emphasis will be placed in monitoring the Agency Team activities to determine if capacity building is occurring. Data will be collected on the number of families initially engaged, new families recruited to the team, opportunities for leadership activities across the members, new community/Agency partners engaged

in the team, number of resources collected and loaded to SWIfT resources. The data source will be meeting minutes and CBPR data. Similar data will be collected from the NYAC. However, much of their data will be collected from their Team Talk archive. Youth leaders will be charged with collecting and reporting their data and presenting it to the steering committee. Furthermore, DOC will monitor the number of hits and usage patterns of Team Talk to determine its efficacy.

Summative data will consist of and 1) CBPR data from each Agency Team CBPR. Outcome evaluation will assess the degree of change from one point of time to another, relative to the team's established participatory action research goals and objectives pertaining to the 6 core MCHB components. Indicators will be specific to each CBPR goal but might include:

- Increases in populations affected by the measure, e.g., CSHCN, adolescents with disabilities, parents engaged in Head Start policy councils, physicians at IHS c medical centers etc. by the CBPR activities
- Number of procedures within service system that are influenced by the community teams
- Improved service delivery due to integrated team's CBPR activities
- Improved identification of existing community resources/number of resources mapped
- Improved access to community resources due to project (convergent NCHS data)
- Number of replications of the CBPR activities by other organizations and communities

2) Navajo Child Health Survey (NCHS) (modified SLAITS), which will be administered in fall of 2006 and again in winter of 2008-09.. These data will inform the project of Navajo changes in the 6 Performance Indicators. and progress toward Agency level CBPR. NCHS yields numeric data that will be analyzed using descriptive and inferential statistics that include relative frequencies by Agency, Nationwide for comparisons to other populations, e.g., neighboring states and significance testing for changes across time. DOC will follow the scoring methods described in *Design and Operation of the National Survey of Children with Special Health Care Needs*⁵¹. As data are being collected twice, we will analyze gain scores in each of the Performance Indicators using Analysis of Variance, *t*-test, and Pearson Correlations, and multiple regressions to determine the amount of variance due to specific demographic characteristics.

Specific benchmarks for each Objective and Activity have been listed and explained in the Methodology. This was done to assist readers to align Activities with assessment and data sources.

Organizational Information.

The Navajo Nation has the capacity to administer a project of the size and scope to the proposed DOC. Currently, the Nation administers a multi-year, multi million dollar competitive grant award from the U.S. Dept. of Education. The administrative offices provide fiscal administration, health, education, transportation, communication and governance. Offices are equipped with internet access, phones, and the necessary equipment to meet the needs of the project. Additionally, the individual Chapter Houses are all equipped with internet access and working systems. ONSat, the Navajo technical division provides maintenance on these systems. HIS has the capacity and space for Agency Teams in which to meet and conduct their business. The Chapter Houses are accessible for residents as well as family Team members. Navajo Nation ascribes to the policy of Navajo First for employment. Hence, it is guaranteed that diverse populations will be employed by the project. As youth with special needs are specifically identified in the scope to the project it is further guaranteed that individuals with disabilities will be employed by the project. Parents employed by the DOC project will be paid a rate commensurate with coordinator, entry social worker, and teaching positions within Navajo employment structures. All public buildings on Navajo Nation are Smoke Free.

Southwest Institute is a non-profit organization whose mission is to contribute to the emergent knowledge-base on health and human services and disseminate the results in ways that are responsive to the beliefs, values, and needs of families and children and the professionals who serve them. Our objective

is to improve the health, education and social services for families and children by conducting research, demonstration, implementation projects and as well as to providing education and consultative support and technical assistance to local and national organizations engaged in health, education and welfare activities. SWI has emerged as a premier partner in the design, implementation, and evaluation of projects of national significance in Arizona and the southwest.

Navajo Nation approved job descriptions for Senior Project Manager and Administrative Asst. are located in Appendix B. Resumes and bio-sketches for the key are located in Appendix C. The following are overviews of the Key Personnel on the DOC project:

Jenny Rodgers, MPH is a member of the Navajo Nation and a parent of a child with special needs. In addition to a Master's in Public Health, she has a 30-year history serving Dine' (the Navajo people). Her current position is that of Senior Program and Policy Specialist with the Navajo Division of social Services. In this capacity, she conducts strategic planning reviews and interprets policies that impact Navajo social services, and monitors federal and state contracts. She is currently analyzing the relationship between state Medicaid programs and directs projects in the area of behavioral health. Her vast knowledge of the Navajo people, their language and their needs suits her well to direct the DOC project. Additionally, her participation and collaboration with numerous private and public organizations such as the Governor's Behavioral Health Planning Council and Children's Subcommittee, National HIS Institutional Review Board and the National Indian Youth Council Board provides access to the broad network of families and professionals necessary to make DOC a success. Rodgers will be responsible for the day-to-day operations of the DOC project, oversee the NCHS data collection, convene and support the 5 Agency Teams, co-coach (with Tanis Bryan) the Teams on CBPR, monitor/support as parent leaders to collect CBPR data, convene and co-chair the steering committee, coordinate the work of the project consultants, approve all expenditures, provide up-information to Navajo administration, and prepare interim and final reports. She will work with Lynn Christiansen, NM Title V Office to recruit and conduct the internships with social work students as well as facilitate the NYAC. Ms Rodgers commits full time to the DOC project, The Navajo Nation supports one half of her time and the project supports the other half.

Ms. Rodgers will be assisted by an Administrative Assistant, who will be hired from a pool of individuals with competencies in organization, computer literacy, health literacy, Navajo business and financial systems, and Navajo language. This individual will be responsible for coordinating the project activities, assist members to set up Team Talk accounts, assist SWIFT coordinators to input data, serve as ONSat contact with respect to website, input NCHS data, maintain electronic Team Talk Calendar and notify all members of meetings and events, and process requests for payments by families and consultants. Additionally, she will coordinate the preparation of the interim and final reports.

Consultants

Patricia Thomas, Training and Technical Advisor, Family Voices- Ms. Thomas is a nationally recognized authority in family professional partnerships as well as cultural competence and American Indian populations. Her expertise is rooted in her experience as a parent of a young adult with special needs. She is part of the WAKAMIAH Group, a grass roots organization that works to educate Indian families on the importance of culturally competent care, in respect to their receipt of health and educational services. Her main focus will be to assist the teams to develop American Indian parent leadership within the teams. Ms. Thomas will provide consultation to the Agency Teams as they identify issues, form hypotheses, and construct culturally competent solutions. She commits 2 days per month to the project.

Lee Hunter, MEd, has worked for 32 years with children and adults with disabilities and their families, and has been instrumental in building parent led community based community teams across rural AZ. For the past three years she has been the manager of the federally funded SWI project ***Building Community Health Across Arizona***, in which family teams examine and test strategies for improving access to health

care for families and children with special needs. During the previous nine years, she provided oversight to the Community Development Unit within the Arizona Department of Health Services, Office for Children with Special Health Care Needs, providing technical assistance to community groups across Arizona. Her vision and ability to facilitate community change through her relationships with Parent Leaders has resulted in an enhanced role for parent leadership in Arizona. Ms. Hunter will assist Rodgers to convene and coach the Agency Teams as they recruit parents, develop partnerships, and become leaders in their respective Agencies. Hunter commits 2 days per month to the project.

Tanis Bryan, PhD was the primary investigator in one of the first six Learning Disability Research Centers, and is currently engaged in Community Based Participatory Research (PCBPR) with families and youth with special health care needs. She is the director of a Transition project funded by MCHB, to assist adolescents and young adults with other health impairments make the transition to adulthood. The combination of her work in the field of learning disabilities and OHI/TBI/OI/DD provide one day per month to the project.

Karen Burstein has been the principal investigator on numerous federally funded research projects on health care and as the external evaluator on two federally funded projects in early childhood. Burstein has numerous scholarly publications and technical reports to her credit. Prior to her work at SWI, she was a research professor at Arizona State University for 12 years, where she developed and taught numerous courses in research and evaluation methods and special education. Additionally, Burstein has provided consultation to health and education organizations throughout the country. Burstein is the parent of a child with extensive special health care needs. Burstein's experience fits well with the requirements for project evaluation. She will modify the NSCSCHN instrument as the NCHS, oversee the random selection process for interviews, train interviewees, build the data matrices, analyze the NCHS data, and assist with the assessment of the CBPR projects and assist the steering committee to interpret the data sets. She also will assist Rodgers in tracking formative data and project outcomes. Burstein commits 10 hours per month to the project.

APPENDICES

Appendix A:

- CBPR Model
- Logic Model

Appendix B: Job Descriptions for Key Personnel

- Project Director
- Administrative Asst

Appendix C: Biographical Sketches of Key Personnel

- Jenny Rodgers
- Lee Hunter
- Trish Thomas
- Tanis Bryan
- Karen Burstein

Appendix D: Letters of Agreement and/or Description(s) of Proposed /Existing Contracts

- Multiple

Appendix E:

- Organizational Chart

Appendix F: Other Relevant Documents

- List of Steering Committee
- SWft Resource Home Page
- References