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INFANT MORTALITY PREVENTIONIN AMERICAN INDIAN COMMUNITIES: NORTHERN PLAINS HEALTHY START

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- Lower Brule Sioux Tribe
- Meskwaki Tribe in Iowa
- Oglala Sioux Tribe
- Omaha Tribe of Nebraska
- Ponca Tribe of Nebraska
- Rapid City Indian Health Board
- Rosebud Sioux Tribe
- Santee Sioux Tribe of Nebraska
- Sisseton Wahpeton Sioux Tribe
- Spirit Lake Sioux Tribe
- Standing Rock Sioux Tribe
- Three Affiliated Tribes
- Trenton Indian Service Area
- Turtle Mountain Band of Chippewa
- Winnebago Tribe of Nebraska
- Yankton Sioux Tribe

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The evaluation of the Northern Plains Healthy Start project was completed in conjunction with an ongoing national evaluation of the demonstration phase of the [Healthy Start Program in its fifteen original sites. The final report of the national evaluation of Healthy Start in the other 14 sites is anticipated in the spring of 2000.

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EXECUTIVE SUMMARY

In 1991 the federal Health Resources and Services Administration (HRSA) funded 15 demonstration projects around the country with a goal of reducing infant mortality. This initiative, known as Healthy Start, targeted areas with very high infant mortality rates. Applicants for demonstration funding agreed to develop a community-based approach to address infant mortality.

One of the selected demonstrations was in the Northern Plains, a very large geographic area spanning four states, where 19 Indian tribal communities came together under an umbrella organization, the Aberdeen Area Tribal Chairmen's Health Board. Their project, known as Northern Plains Healthy Start (NPHS), operated as a demonstration from September, 1991, to October, 1997. Subsequent to the demonstration NPHS has received continued funding, although at a lower level.

In 1993, HRSA awarded a contract to Mathematica Policy Research and its subcontractors--Harvard School of Public Health, Health Systems Research, and RIVA Market Research-to conduct a national cross-site evaluation of the Healthy Start demonstration. The national evaluation includes both process and outcome analyses of all 15 demonstrations, including a detailed evaluation of NPHS. Because the Northern Plains project exhibits features unique to rural Indian communities, such as a higher incidence of post-neonatal mortality, and because it is so large and complex, the evaluation team conducted a special study of NPHS. As with the broader national evaluation, the NPHS evaluation draws on multiple data sources, analyzing data from site visits, focus groups, the project's client data system, a post-partum survey, and vital statistics (birth and death certificates).

The NPHS project area covers four states and includes numerous tribal areas. The size of communities served by the project ranges greatly, from fewer than 1,000 residents in the smallest community to more than 20,000 in the largest. The vast geographic reach of the project means that most people have to travel great distances for health and social services. This geographic and cultural diversity creates unique challenges for the project.

There are numerous social and health problems in NPHS communities. The population has a high rate of poverty and unemployment and low levels of education. People frequently live in crowded, poor quality housing. Health problems are also very prevalent, including high rates of alcoholism. Infant mortality rates are about twice the national level and are attributable primarily to a high rate of post-neonatal mortality (after 28 days of life). These deaths have different causes (e.g., Sudden Infant Death Syndrome) than neonatal deaths within the first 28 days, which are often caused by prematurity and low birthweight.

While many health services for pregnant/post-pat-turn women and infants (the target population for NPHS) are financed by the Medicaid program, the Indian Health Service (IHS) is the primary provider of such services to Northern Plains Indians. Medicaid and IHS work together to provide health services in Indian communities, and there are few private health care providers. All of the 19 NPHS sites have IHS-funded ambulatory clinics (some are tribally operated) and almost half have

local IHS hospitals. For the remaining communities, women must travel a greater distance to deliver their babies.

The NPHS program was developed, in response to these community health issues and the community health care structure, to address the high rate of infant mortality among Northern Plains Indians. While each of the 19 project sites developed their own program, they have many common features. These include outreach/case management services provided by community lay workers, who help women obtain services such as prenatal care and social services. All project sites also provide transportation to services as well as one-on-one health education designed to promote a healthy life style. All sites offer health education classes on a variety of topics, and some have other support services.

The annual level of demonstration funding for NPHS at its peak of operation was approximately $5 million, which includes funding for all 19 sites, as well as for the central office staff. Each of the 19 sites has a core staff that includes a project coordinator/administrator, an outreach/case management worker, and at least one administrative staff person who usually is involved in collecting data as well as other administrative support. Larger projects serving more clients have a larger staff.

NPHS includes several other program components that were designed to foster collaboration with other tribal health and social services, as well as with non-Indian organizations that provide services to Indian women. This level of collaboration with outside organizations had not existed prior to NPHS. The project developed a multi-level state and local consortium, with members from various state and local organizations, to help with this collaboration. The project also coordinated with IHS programs, and tried to develop a program that complemented IHS services. The project did not emphasize the development of new clinical services, but instead tried to link women to existing services.

NPHS emphasized Indian culture, which guided the development of promotional and educational materials and led to the decision to employ local people in the program. The project also used elders as role models, incorporating them into the consortium membership and other program components.

The project served almost 3,000 clients in Fiscal Year 1996, the peak year of program operation. About half of these were maternal clients, and the remainder were either infants or others, such as fathers. There was substantial cross-site variation in the percentage of the eligible women who were served by NPHS. The program served a very disadvantaged group, demographically similar to the clients of the other 14 Healthy Start projects. For example, clients were younger and more likely to be unmarried than other women in the community. The clients had a high rate of social and health risks, although they were not significantly different from other pregnant Indian women in these risks (according to the survey, which was conducted in only 7 of the 19 sites).

Data show that almost all clients received case management services and a very high proportion (60 percent) received transportation services. Clients reported that transportation was one of the most valued NPHS services, and many individuals joined because the program offered such services.

Data from both the client data system and the survey also suggest that NPHS usually provided low intensity case management services, with more than a third of women having only one or two encounters with their case manager. However, project protocols called for a higher rate of case management encounters, and the number of encounters could have been underreported in these data sources.

In addition to the process analysis, the report provides an analysis of three key outcomes of the program: adolescent birth rates, the rate of adequate prenatal care, and infant mortality rates. NPHS program initiatives sought to reduce adolescent pregnancy through several efforts, including a targeted public information campaign and health education focusing on pregnancy prevention and child spacing. Other program initiatives sought to improve the rate of adequate prenatal care through case management and transportation, as well as collaborations with the IHS and other health care programs. The overall program goal was to reduce infant mortality by 50 percent during the demonstration. The program emphasized initiatives to reduce post-neonatal mortality, including use of infant home assessments to address risk factors for Sudden Infant Death Syndrome, the primary cause of post-neonatal death, and to minimize risk factors for accidents in the home.

The methodology for the outcome analysis compares NPHS rates for the three outcome measures over time to rates in two other Indian Health Service areas: the Alaska IHS area and the Billings IHS area, which includes tribal areas in Montana and Wyoming. The Alaska area has the second highest rate of infant mortality and the Billings area is adjacent to Northern Plains and has a similar geography, climate, and economy. Project staff considered these areas most comparable to the Northern Plains service area. A statistical model, similar to the one used in the outcome evaluation for the other 14 Healthy Start projects, is used to detect statistically significant results that can be attributed to the presence of NPHS in the project area.

The analysis shows that the presence of NPHS is significantly associated with reductions in the adolescent birth rate. The rate declined from 54.2 per 1000 females aged 12 to 17 to 44.3 per 1,000, (about 18 percent), from the 1984-88 baseline period to the 1995-96 period of full program operation. In the comparison areas the adolescent birth rate remained stable or declined only slightly. Still, the adolescent birth rate in the NPHS area remains higher than the rate in the Alaska IHS area (36.9 in 1995-96) and about the same as in Billings (45.6)--suggesting the need for additional improvement in this important measure.

The program's emphasis on cultural values probably made its case management and health education programs especially appealing to adolescents. The emphasis in the public education campaign on adolescent pregnancy also may have had a more general impact on community knowledge and attitudes, leading to a broader community influence on adolescent birth rates.

The program also seems to have led to improvements in the adequacy of prenatal care, as measured by the Kotelchuck index of adequacy. This composite index measures the timing of prenatal care and the number of visits. While the rate of adequate care improved in both the demonstration and comparison areas, improvements were greater in the demonstration period in the Northern Plains area. Focus groups, site visits, and survey results indicate that the provision of transportation services was a major component of the service package that increased, access to

adequate care. While these results are positive, many women still do not have adequate care, and rates in the Northern Plains remain lower than in the two comparison areas (45.9 percent with adequate care in Northern Plains in 199596, compared to 60 percent in Alaska and 50.1 percent in Billings). There is also need for additional improvement in this important measure.

Finally, the outcome evaluation examines overall infant mortality rates and post-neonatal infant mortality rates. Infant mortality declined from 18.9 per thousand live births in the 1984-88 baseline period to 12.6 per thousand in 1995-96, the period of full NPHS operation. This is a decline of 19 percent. Post-neonatal mortality declined even more rapidly from 11.3 to 6.4 per thousand, a decline of 43 percent. However, because similar levels of decline were observed in the comparison areas, the infant mortality reductions that occurred in the Northern Plains cannot be attributed statistically to the presence of Healthy Start. It is possible that the positive changes in adolescent birth rates and prenatal care use, or in other underlying causes of infant mortality that are not as easily measured, will lead to reductions in infant mortality over a longer period of time than could be measured in this evaluation.

Several conclusions emerge from these results. A major success of the Northern Plains Healthy Start demonstration was to show that tribes can come together in a collaborative venture to share resources and learn from each other. This was accomplished through a lengthy group process that took more time than was anticipated, but it resulted in an essentially common approach and substantial group participation in planning.

The Northern Plains Healthy Start program provided the opportunity for geographically dispersed communities to develop an administrative structure that was responsive to their unique needs. This required an investment in administrative structures that was greater than that in other Healthy Start programs. Those who desire to implement similar programs in geographically dispersed areas should recognize that higher administrative costs may be necessary for successful program implementation.

A major factor in the project's success was the strength of the leadership, both at the central project level and in many of the sites. However, this was offset by a high rate of turnover in this leadership, which resulted in substantial variation in the pace of implementation and in the quality of programs across the 19 sites throughout the project. The desire to distribute project activities and associated funding across the tribes may have contributed to this instability in project leadership.

The project introduced the concept of data gathering and evaluation to the operation of tribal programs. This was difficult but, ultimately, rewarding to those involved. Developing a functioning data system was a major accomplishment and allowed the staff and tribal governments to learn about using and sharing data to improve programs. While NPHS succeeded in collecting a common data set from all 19 locations, the data were not complete in all sites. Incomplete data was a problem for the other 14 Healthy Start projects as well. One factor leading to-difficulties for all projects was the complexity of the data set that was required by HRSA. Other factors that hampered the full development and use of the data system included the limited experience at the central office and in each site with developing and implementing such a system, as well as staff turnover.

The NPHS central office faced the challenge of developing a program with a set of common goals tied to infant mortality reduction, that at the same time allowed communities to think through their own local goals. Because the tribes faced many similar problems and issues, the process led to programs that had many common features, such as outreach/case management and transportation. However, the program model that was developed and implemented lacked some necessary components. For example, there was no strong smoking cessation component, and smoking is very prevalent among pregnant Indian women and has been shown to be related to Sudden Infant Death Syndrome.

The Northern Plains Healthy Start project provides a good model for how to develop culturally appropriate services in Indian communities, as well as other communities where cultural traditions differ from the dominant culture. There is strong evidence that the approach of making Indian culture a focus was a major project accomplishment.

The data shown in this report do not demonstrate a strong impact on infant mortality from the Northern Plains Healthy Start program, a result similar to preliminary findings from most of the other Healthy Start programs. This may be because of the low intensity of the NPHS intervention, as well as the uneven speed of implementation and quality of programs across time and across sites. However, it may also be that the time period observed was insufficient to observe such an impact. Site visits revealed that the program was not fully implemented until late in the demonstration period. It is possible that the impact of the project's efforts on infant mortality will be observed in later years.

I. INTRODUCTION

Healthy Start is a major federal program intended to reduce infant mortality by 50 percent in five years and to improve maternal and infant health in communities with high infant death rates. The program is a federally-funded community-based initiative in which local projects have designed and implemented interventions targeting women, their infants and families, and the communities in which they live. These interventions include outreach; case management for pregnant women and infants; one-stop shopping for services; social support services; broad-based public information campaigns; and enhanced medical services for women in their prenatal, delivery, and postpartum periods.

In fall 1991, 15 communities were selected as Healthy Start project areas. At the same time, they received first-year planning grants to design a comprehensive demonstration program for reducing infant mortality as well as a plan for its implementation. To be eligible, project areas had to have both a high infant mortality rate and the capacity to organize a community-based effort to strengthen the maternal and infant health care system. Specifically, a project area had to have between 50 and 200 infant deaths per year and an infant mortality rate of at least 15.7 deaths per 1,000 live births (50 percent above the national average) for the five-year period 1984-1988.

The original 15 Healthy Start demonstration projects areas are Baltimore; Birmingham; Boston; Chicago; Cleveland; Detroit; District of Columbia; Northwest Indiana; New Orleans; New York City; Northern Plains Indian communities in Iowa, Nebraska, North Dakota, and South Dakota; Oakland; the Pee Dee region of South Carolina; Philadelphia; and Pittsburgh. Twelve of the projects areas are urban communities. Northwest Indiana is a cluster of four small cities in Lake County, Indiana (Gary, Hammond, East Chicago, and Lake Station). Pee Dee includes six rural counties.

The Northern Plains Healthy Start project (NPHS)--the subject of this report--includes 19 American Indian tribal organizations in four states (see Figure I. 1). NPHS is unique among Healthy Start projects. All other projects except for Pee Dee are located in major urban centers, and all serve a majority of clients who are either African-American or Hispanic. Northern Plains serves geographically dispersed and very isolated rural areas. Also, it is the only project serving predominantly American Indian women and their families.

The Healthy Start program has developed strong, continuing congressional support since it was initially proposed. All 15 of the original projects, including NPHS, have received three years of funding beyond the original five-year demonstration period. In fiscal year 1996, seven new "special projects" received funding for two years to implement certain components of the Healthy Start program. In addition, Congress has appropriated funding to continue the program through fiscal year 1999, including funding some components of the original projects and over 50 new projects at much smaller levels than the original demonstration funding.

To assess the effects of Healthy Start on infant mortality and on the health of infants and mothers in the project areas, the Health Resources and Services Administration (HRSA) funded a cross-site national evaluation of the program. The national evaluation covers the planning year and the first five operational years for the 15 original Healthy Start projects. The evaluation includes a process analysis and an outcomes analysis (Devaney and McCormick 1993, Raykovich et al. 1996). The process analysis documents the context in which the projects operate, describing and comparing program planning and implementation, service delivery, and barriers to implementation (Howell et al. 1997, McCormick and Deal 1998, Devaney et al. 1999). The outcome analysis assesses whether Healthy Start achieved its goal of improving maternal and infant health and reducing infant mortality by 50 percent over 5 years.

FIGURE I. 1

NORTHERN PLAINS HEALTHY START PROJECT AREA

The components of the Northern Plains Healthy Start evaluation are similar to those of the overall national evaluation--including both process and outcome analyses--but these have been tailored to the size and tribal diversity of the project. The evaluation is designed to answer the following process analysis research questions:

- What is NPHS? What are the key features of the program? Was the implementation process successful? What factors facilitated success? What can be learned from the problems the project encountered?
- Who was served by the program, and what services did they receive?
- What did clients and providers like most about the program?

The outcome analysis studied the following questions:

- What was the impact of the program
  - On adolescent birth rates ?
  - On the use of prenatal care?
  - On infant mortality rates?

The information in the Northern Plains Healthy Start evaluation comes from multiple data sources, including:

- ***Document*** Review. A review of annual grant proposals and other materials provided by the sites.
- ***Site Visits.*** Site visits and telephone follow-up to nine of the project sites.
- ***Post-par&m*** Survey. A survey of Healthy Start clients and other post-partum women in seven sites.
- ***Focus Groups.*** Focus groups conducted with project staff in all sites and clients and providers in five sites.

- ***Client-Level Data.*** A Minimum Data Set (MDS), individual-level data, collected on clients in all sites.

- ***Birth and Death Certificates***. Vital statistics data obtained for the whole project area and two comparison areas (Alaska and Billings) from the Indian Health Service

Appendix B presents more detail on the Northern Plains Healthy Start evaluation.

This report summarizes the results of the evaluation of the Northern Plains Healthy Start program during its demonstration phase. Chapter II provides an overview of Northern Plains Indian communities, and the issues and concerns that led to developing the program. Chapter III provides an overview of the program as designed and implemented. Chapter IV presents data on client characteristics and service use from the MDS client data system and the postpartum survey. Chapter V presents trends in infant mortality and other birth outcomes for the Northern Plains and its two comparison areas. The final chapter presents conclusions and lessons learned from the Northern Plains Healthy Start experience.

II. THE NORTHERN PLAINS COMMUNITIES

This chapter describes the environment in which NPHS operates, including the cultural and economic context of the Northern Plains communities, the health care concerns of the American Indians who live there, and the other health care systems in the Northern Plains.

A. COMMUNITY CONTEXT

The NPHS project spans multiple states and includes numerous tribal areas. Specifically, the project area includes I9 Indian communities--on 17 reservations and in two other Indian service areas'--in North Dakota, South Dakota, Nebraska, and Iowa. Because two of these communities extend into Montana and Minnesota, several counties in these two states are also included in the project area.

The Northern Plains Indian communities are located in the region known as the "Aberdeen Area" after the Aberdeen, South Dakota Indian Health Service (IHS) regional office, which serves Northern Plains. The Aberdeen Area is one of 12 IHS service areas in the United. States. In 1997, there were approximately 113 thousand American Indian people living in the Aberdeen Area, of which about one-quarter were women of childbearing age (Table 11.1). The size of this population grew slowly throughout the 1990s from about 100 thousand in 1992.

Table II. 1 also shows how the population is distributed across the 19 NPHS sites. As shown, there is a wide range in population size, from 633 for the Ponca Tribe of Nebraska to 21,389 for the Oglala Sioux Tribe. Finally, the table shows the distribution of the population of women of childbearing age across the 19 sites, which also varies greatly in size from site to site. For

'Indian service area offices are responsible for administering IHS programs in a specific geographic area.

TABLE II. 1

AMERICAN INDIAN POPULATION OF NORTHERN PLAINS
HEALTHY START SITES, 1997

	American Indian Population	Female Population Aged 15-44	
	Number	Number	Percent
Cheyenne River Sioux Tribe	7,603	1,787	6.5
Crow Creek Sioux Tribe	3,534	896	3.3
Flandreau Santee Sioux Tribe	1,658	669	2.4
Lower Brule Sioux Tribe	1,925	491	1.8
Meskwaki Tribe in Iowa	703	192	0.7
Oglala Sioux Tribe	21,389	4,897	17.9
Omaha Tribe of Nebraska	3,479	752	2.7
Ponca Tribe of Iowa	633	165	0.6
Rapid City Indian Health Board	11,155	2,896	10.6
Rosebud Sioux Tribe	12,750	3,057	11.2
Santee Sioux Tribe of Nebraska	1,222	281	1.0
Sisseton Wahpeton Sioux Tribe	5,543	1,338	4.9
Sprit Lake Sioux Tribe	4,708	1,075	3.9
Standing Rock Sioux Tribe	9,177	2,205	8.1
Three Affiliated Tribes	5,614	1,314	4.8
Trenton Indian Service Area	1,464	373	1.4
Turtle Mountain Band of Chippewa	12,773	3,110	11.4
Winnebago Tribe of Nebraska	3,922	999	3.6
Yankton Sioux Tribe	3,815	876	3.2
Total	113,067	27,373	100.0

SOURCE: Indian Health Service User Population. The IHS user counts are greater than U.S. census counts of people reporting American Indian race in the service areas and less than the counts of IHS Indian registrants, which include some tribal members who have not had a health encounter in the past three years.

example, about 18 percent of women of childbearing age in the Northern Plains are members of the Oglala Sioux Tribe, while only about 1 percent are members of the Meskwaki, Ponca, and Santee Sioux Tribes.

The Northern Plains project area, made up predominantly of small rural communities, also includes the cities of Rapid City, South Dakota; Omaha Nebraska; and Sioux City, Iowa. The area also has an extremely diverse climate and terrain. The tribes there represent a diversity of cultures, with Lakota/Dakota as the predominant Indian language spoken.[2] The geographic areas that make up the NPHS service area are both large and separated by great distances, since the 19 sites cover a land mass of 107,377 square miles. As described in project materials:

> *Fields of wheat and corn shift to undisturbedprairie to the rugged beauty of the Badlands and the rustic majesty of the Black Hills... the contrasts are as endless as the beauties and challenges of the area.*

With this kind of geography come barriers to supplies and services. Most people have to travel far to go to school, to buy groceries, and to receive health services, especially hospital-based services. The reservations of the Lower Brule Sioux Tribe and the Meskwaki Tribe in Iowa, for example, are each 25 to 35 miles away from the nearest hospitals, which offer limited care, and 70 to 100 miles away from the hospitals that offer more comprehensive services such as cesarean deliveries and high-risk prenatal and neonatal intensive care. Not only does distance create an obstacle to the delivery of emergency and routine hospital care, but the roadways themselves are often underdeveloped, and driving conditions can be treacherous, especially in the winter.

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[2]Tribes in the area include 11 Sioux tribes as well as the Arikara, Chippewa, Hidatsa, Mandan, Meskwaki, Omaha, Ponca, and Winnebago tribes.

Despite their relative isolation from health care and other services, the Northern Plains Indians, as described in project materials, do not consider the geographic boundaries of "Indian country" to be limiting. Traveling 10 hours or more to visit relatives is not unusual if the family has the resources to do so, and word of mouth is still a primary means of communication. This connection in the face of huge distances reflects the closeness of the Northern Plains Indian communities and the strength of extended Indian families, an important source of social support in a difficult living environment. The NPHS communities are further enriched by their diverse traditions and languages, and by a strong sense of community pride. The NPHS projects grew out of the desire of these communities to build upon their strengths as a means of addressing the problem of infant mortality.

Like other Healthy Start projects across the country, the NPHS communities have an extremely high poverty rate. The 1990 census indicates that 3 1.6 percent of Indians residing in reservation states[3] overall, and 49.6 percent of Indians in the Aberdeen Area, live below the federal poverty level, as compared to 13.1 percent of the general U.S. population (see Table 11.2). The unemployment rate for Indians in the Aberdeen Area is also high for American Indians, 26.5 percent, as compared to 6.4 percent for the U.S. population (IHS 1997b). Compared with the rest of the country, educational levels are also lower among Indians in the Aberdeen Area, with especially great disparities in college completion rates. There is variation across tribal areas in the level of poverty and education, with the more urbanized areas having, for example, higher levels of education.

One focus group participant explained the evolution of poverty among American Indian cultures:

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[3]Reservation states are those in which the Indian Health Service has responsibility for providing health care to American Indians. Figures cited above are based upon the 1990 census in the 35 current reservation states.

We moved from a subsistence society. . . where we could almost live off the land and make our living off the land Everybody was kind of taken care of pretty good. Now we are into a poverty cycle because you have to have cash to function. You have lost all your land you had to sell your cattle. You were living on subsistence, and now you don't have any way to Iive anymore.

TABLE II.2

SELECTED DEMOGRAPHIC CHARACTERISTICS
NORTHERN PLAINS AND U.S. POPULATION
1990

	American Indians in the Northern Plains	U.S., All Races
Poverty and Unemployment		
Population Below Poverty Level	49.6%	13.1%
Males Unemployed (Age 16 and Older)	**26.5%**	**6.4%**
Education		
High School Education or Higher (Age 25 and Older)	64.4%	75.2%
Bachelor's Degree or Higher (Age 25 and Older)	7.8%	20.3%

SOURCE: 1990 U.S. Census Data, as reported in *Regional Differences in Indian Health 1997.*

Many other problems make life on the reservation difficult and affect the health of Indian children and their families. Inadequate housing and overcrowding are major problems. On the Lower Brule reservation, for example, "small dilapidated houses where many families live create crowded and unsanitary living environments." In the words of one focus group participant:

There 's like eight families living in one three-bedroom home. They are all related. The mother and then her three daughters, and-those three daughters have their boyfriends living with them and their kids. We don 't have anybody that really sleeps in the streets, but they don 't have homes of their own.

A breakdown in family structure, high crime rates, adolescent parenting, domestic violence including child abuse and neglect, and poor nutrition also plague the Northern Plains communities. A provider who participated in our focus groups discussed the epidemic of adolescent births:

We did a random sample, and we found 100 percent of the parents age 15 to 23 did not plan for their children. Some of them were really young, and they were all having their third or fourth child already, and they weren 't planned.

One of the most recent visible responses of American Indians to unemployment and other long-standing economic problems has been to establish casinos on their reservations. The casino established by the Winnebago Tribe of Nebraska, for example, has been credited with drastically reducing the unemployment rate in a short period of time, from approximately 75 percent in 1990 to 10 percent in 1994.[4] Jobs have been created not only in the casinos themselves but also through other tribal programs established with casino revenues. Portions of revenues also are distributed as cash payments to tribe members in the Meskwaki and Flandreau Tribes, thus increasing per capita income and a family's ability to buy homes and send their children to college. However, the benefits of casinos on Indian land have not come without costs. Anecdotal reports suggest that gambling, alcohol use, drug use, and tobacco use may have increased.

[4]Some of these gains have been reversed in recent years due to the growth of gambling establishments that are not under Indian auspices.

B. HEALTH CONCERNS OF THE NORTHERN PLAINS INDIANS

Mortality statistics from the IHS illustrate the disproportionately higher incidence of health problems among American Indians. For example, in comparing reasons for mortality for IHS service area Indians to the entire U.S. 1993 population,' the age-adjusted rate of alcoholism deaths for Indians was 579 percent higher in 1992-94, the tuberculosis rate was 475 percent higher, the diabetes mellitus rate was 231 percent higher, and the accident rate was 282 percent higher (IHS 1997b). Other prevalent health problems include hypertension, kidney disease, liver disease, and heart disease.

Alcoholism is the most critical problem for project communities, as emphasized in focus group discussions:

> *I'm 45 years old now, but when I graduated from high school, dropouts were rare. Then it seems like alcohol started coming in. The people I graduated. with from high school started drinking heavily. Now they start drinking at the age of 12, and it has been that way since the mid-70s.*

> *You have in the families that are still drinking, the children . . . have special needs. So you get a combination of not only physical problems but also the environmental problems. Their needs at home aren 't being met either. They are not getting the stimulation that they need.*

> *A pregnant mom is drinking. It's hard because then they don 't go to their prenatal appointments.*

There is also a high rate of homicide and suicide on Indian reservations. In 1992-94 the suicide rate was 70 percent greater, and the homicide rate was 4 1 percent greater, than 1993 U.S. rates (IHS 1996b). There is evidence that the isolation and despair on reservations affects these rates, especially

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'Mortality rates reported in this section have been adjusted by the Indian Health Service to account for miscoding of Indian race on death certificates.

for youth. For example, there were 6 suicides and 43 suicide attempts among adolescents on the Standing Rock reservation in one 6-month period in *1997 (Baltimore Sun* 1998).

Life expectancy for American Indians in the Aberdeen area is considerably shorter than for the U.S. population as a whole (Table 11.3). For some of the tribes participating in Northern Plains Healthy Start, the statistics are even more striking. For example, life expectancy on the Oglala Sioux reservation-56.5 years for men and 66 years for women--is lower than that of any nation in this hemisphere except for Haiti (Murray, Michaud, McKenna et al. 1998). This shorter life expectancy, combined with a relatively high birth rate, means that the Indian population is younger on average than other Americans. As shown in the table, 12.1 percent of the population is under age 5, compared with 7.7 percent nationwide, showing the increased need for maternal and child health services in this population.

TABLE II.3

POPULATION CHARACTERISTICS
NORTHERN PLAINS AND U.S. POPULATION
1992 - 1995

	American Indians in the Northern Plains, 1992-95	U.S. All Races, 1993
Life Expectancy at Birth (in years)	64.3"	75.5
Birth Rate (per thousand population)	32.2"	15.5
Percent of Population Under Age 5	12.1[b]	7.7

SOURCE: U.S. vital statistics, U.S. census data and IHS user data, as reported in *Regional Differences in Indian Health 1997.*

"Calendar years 1992- 1994
[b]IHS client population in FY 1995

In the context of this generally higher morbidity and mortality, infant mortality is also a serious problem in Northern Plains. In 1992-94, the Aberdeen IHS service area had the highest infant mortality rate of all IHS service areas nationwide at 15.6 deaths per 1,000 live births (IHS 1997b). As shown in Table 11.4, the infant mortality rate for Northern Plains Indians was nearly double that of the U.S. population in the time period. Also illustrated in the table, most of the disparity is due to post-neonatal mortality. Indian infants, including those in the Aberdeen IHS area, are more likely to die after the first month of life, as a result of sudden infant death syndrome, accidents, or other causes that generally occur in the post-neonatal period (Table 11.5). At the same time, Indian infants in the Aberdeen area are less likely than infants in the general U.S. population to die of problems in the neonatal period such as prematurity and low birthweight.

TABLE II.4

INFANT MORTALITY RATES
NORTHERN PLAINS AND U.S. POPULATION
1992 - 1994

	Northern Plains Indians, 1992 - 1994	U.S. All Races, 1993
Infant Mortality Rate	15.6	8.4
Neonatal Mortality Rate	7.1	5.3
Post-neonatal Mortality Rate	8.5	3.1

SOURCE: U.S. vital statistics, as reported in *Regional Differences in Indian Health, 1997.*

NOTE: Rates per 1,000 live births; Northern Plains rates are adjusted for miscoding of Indian race on death certificates.

TABLE II.5

PERCENT OF INFANT DEATHS BY CAUSE
NORTHERN PLAINS AND U.S. POPULATION
1992 • 1994

Northern Plains Indians, 1992-94		U.S. All Races, 1993	
	Percent of Deaths		Percent of Deaths
1. Sudden Infant Death Syndrome	*24.8*	1. Congenital Anomalies	*21.3*
2. Congenital Anomalies	*17.8*	*2.* Sudden Infant Death Syndrome	14.0
3. Pneumonia and Influenza	*6.2*	*3.* Disorders Related to Short Gestation and Low Birthweight	12.9
4. Accidents and Adverse Effects	*4.7*	*4.* Respiratory Distress Syndrome	*5.4*
5. Newborn Affected by Maternal Complications of Pregnancy	*3.9*	5. Newborn Affected by Maternal Complications of Pregnancy	*4.0*

SOURCE: U.S. vital statistics as reported in *Regional Differences in Indian Health 1997.*

Many of the interventions that the project developed built on the known risk factors for sudden infant death syndrome (SIDS), the most common cause of infant death in the NPHS service areas. These risk factors include adolescent pregnancy; a short interpregnancy interval; a lack of prenatal care; and exposure of an infant to smoking, both prenatally and post-natally (Willinger 1996).

C. HEALTH CARE SYSTEMS IN THE NORTHERN PLAINS

In the Northern Plains, the Indian Health Service and the Medicaid program both play major roles in the delivery of health care services for American Indians.

1. Indian Health Service (IHS)

a. Overview

The IHS is an agency within the U.S. Department of Health and Human Services that, through a government-to-government relationship between the federal government and Indian tribes, is responsible for providing comprehensive health services to American Indians and for raising their health status to the highest possible level (IHS 1996a). IHS is the payer of last resort for Indians. That is, IHS pays for medical care only after other sources of payment for which the patient is eligible--including Medicaid--have been exhausted.

Eligibility for IHS services is extended to persons of American Indian descent belonging to an Indian community served by IHS facilities and programs.[6] The IHS provides health care services free of charge to these eligible persons. Services are offered primarily through hospitals and clinics on the reservations. In the past, these facilities were operated directly by the IHS; however, as allowed for under the 1975 Indian Self-Determination Act (P.L. 93-638, as amended), responsibility for operating an increasing number of IHS-funded facilities is being assumed by tribes (Trujillo 1995; Noren, Kindig, & Sprenger, 1998).

[6]Services also will be made available, as medically indicated, to a non-Indian woman pregnant with an eligible Indian's child during the period of her pregnancy through approximately six weeks postparhlm.

b. Aberdeen Area IHS General Health Services

In the Aberdeen IHS service area, there are 28 ambulatory facilities--including 11 health centers,' 3 school health centers, and 14 health stations.[8] Tribes operate 7 of these ambulatory centers. Prenatal care services are generally delivered by these ambulatory care providers. Table II.6 shows that, while all 19 sites have ambulatory facilities, only 8 have IHS hospitals. All of the hospitals in the NPHS sites are operated directly by the IHS (IHS 1997b). Obstetrical (delivery) service is provided in only 5 sites; deliveries in the other 14 sites occur off the reservations, through referral to community hospitals, often at considerable distance from a mother's home.

In general, both IHS-administered and tribally-administered health programs contract with private physicians and community hospitals to deliver"contract health services," including diagnostic and treatment services that are not provided in IHS facilities (IHS 1994). Due to persistent problems in recruiting and retaining clinical staff (Noren et al. 1998), the IHS also may make short-term contractual arrangements with doctors, who are known as "locurn tenens" physicians. Interviewees indicated that IHS recruiting problems sometimes lead to retaining doctors who, in the best interest of patients, should be replaced but cannot be due to hiring difficulties.

'A health center is a facility, physically separated from a hospital, with a full range of ambulatory services--including, at a minimum, primary care'physicians, nursing staff, a pharmacy, a laboratory, and x-ray capabilities--which are available at least 40 hours per week.

[8]A health station is a facility, physically separated from a hospital or health center, where. primary care physician services are available on a regularly scheduled basis but for less than 40 hours a week.

TABLE II.6

LOCATION OF IHS FACILITIES IN SELECTED NORTHERN PLAINS HEALTHY START SITES
March 31, 1998

Reservation/Service Area	Hospital (Beds)	Obstetrical Service	Ambulatory Center(s)
Cheyenne River Sioux Tribe	✓ (27)	✓	✓
Crow Creek Sioux Tribe			✓
Flandreau Santee Sioux Tribe			✓[a]
Lower Brule Sioux Tribe			✓
Meskwaki Tribe in Iowa			✓[a]
Oglala Sioux Tribe	✓ (45)	✓	✓
Omaha Tribe in Nebraska			✓[a]
Ponca Tribe of Nebraska			✓[a]
Rapid City Indian Health Board[b]	✓ (32)		✓[a]
Rosebud Sioux Tribe	✓ (35)	✓	✓
Santee Sioux Tribe of Nebraska			✓[a]
Sisseton Wahpeton Sioux Tribe	✓ (18)		✓
Spirit Lake Sioux Tribe			✓
Standing Rock Sioux Tribe	✓ (16)		✓
Three Affiliated Tribes			✓
Trenton Indian Service Area			✓[a]
Turtle Mountain Band of Chippewa	✓ (29)	✓	✓
Winnebago Tribe of Nebraska	✓ (30)		✓
Yankton Sioux Tribe			✓

SOURCE: Indian Health Service Web Site and personal communication with Sandy Coulter of the IHS

[a] Tribally operated services

[b] The Rapid City Hospital is not on a reservation, serves multiple tribes, and is not associated with the Board. However, the Board does operate the separate All Nations Clinic.

c. Public Health Nursing

The IHS also runs other programs that have traditionally played a significant role in serving pregnant and postpartum women and young children. The Public Health Nursing (PI-IN) program is a generalized public health nursing service through which therapeutic counseling, education, case management, and advocacy services are provided to address the leading causes of morbidity and, mortality among Indian people. PI-IN services are open to all age groups and are provided in a variety of settings including homes, schools, clinics, and the broader community.

The PHN program has traditionally focused significant resources on serving mothers and children. Prenatal, postpartum, and well child care, including immunizations, rank among the top 10 reasons for home visits by PI-IN nurses, who promote the utilization of preventive health services, offer prenatal support, and provide services and counsel clients in ways to improve birth outcomes and child development. In the Aberdeen Area, PI-IN services are provided by 17 local PI-IN programs in 13 service areas. Eleven programs are operated by the IHS, and six programs (Cheyenne River, Spirit Lake, Omaha, Meskwaki, Trenton Indian and Winnebago) are operated by the tribes.

d. Community Health Representatives

The Community Health Representative (CHR) program is another IHS program serving persons living on the reservations and in Indian Health Areas. The CHR program is designed to improve access to services. The program is staffed by paraprofessionals, trained by the IHS but employed and supervised by the tribes. The specific services provided by Community Health Representatives in different communities vary but typically include health education, arranging and providing transportation, case management, patient monitoring (e.g., prescription monitoring, complying with

physician's directions for follow-up care), homemaker services, interpretation/translation, and case finding. These services are typically performed in clients' homes. In more remote areas; CHRs devote significant resources to transporting clients to medical appointments.

While CHR services are open to the entire population, clients receive priority when they are identified by the IHS as needing follow-up care and monitoring. The IHS identifies a variety of specific population groups that may be targeted for services, including persons with diabetes, cancer, communicable diseases, alcohol/substance abuse problems, elderly patients, and mothers and children. In most Northern Plains communities, CHRs primarily serve the elderly population and young mothers.

All of the 19 sites in the Aberdeen Area participate in the CHR program. The number of CHR staff positions across the Aberdeen Area ranges between 250 and 300, with an average of 17 staff persons per site. Staff, generally lay community workers, undergo a basic three-week training course before functioning as CHRs.

The PHN and CHR programs both share important characteristics with the Northern Plains Healthy Start program. This relationship will become clearer in the next chapter when NPHS services are described.

e. IHS Funding for Reservation and Urban Programs

Unlike Medicaid and Medicare, the IHS is not an entitlement program; therefore, its budget is determined by Congress through its annual appropriations process. As is sometimes the case for programs funded by discretionary spending, congressional appropriations for the IHS in recent years have increased at a slower rate than the growth in the IHS service population. When expenditures

are greater than anticipated, access to services, especially contract health services, may be restricted (Noren et al. 1998).

The IHS budget is directed primarily to Indians on reservations. Recognizing the growing tendency of Indians to move off reservations, the Indian Health Care Improvement Act of 1976 (P.L. 944378, as amended) authorized the funding of urban Indian health programs, partially supported by IHS funds. Currently, only 1 percent of the total IHS budget is directed to these urban health programs (Noren et al. 1998). While there are some urban Indian programs in the Northern Plains (for example clinics in Pierre, Sioux Falls and Aberdeen, South Dakota), all are outside the Healthy Start service area.

2. Medicaid

Since the mandatory and optional Medicaid expansions for pregnant women began in the 1980s, Medicaid has become a particularly important source of third-party coverage for Indian pregnant women and infants. Current law requires states to provide Medicaid coverage for infants and pregnant women with incomes up to 133 percent of the federal poverty level. The law also gives states the option of providing Medicaid coverage for infants and pregnant women with an income as high as 185 percent of the poverty level. Iowa is the only state of the four NPHS states to have expanded coverage to 185 percent of the poverty level (National Governors Association 1997). Given the generally low income of most Indians, a large number of pregnant Indian women, including NPHS clients, are eligible for Medicaid. However, there are a variety of barriers to enrollment. For example, many do not have transportation to the social services office where they must apply for coverage. And even when this barrier is removed, delays in application processing create a barrier to service use. As expressed by one outreach worker in a focus group:

I think one of the problems associated [with getting prenatal care] is Medicaid. When they don't qualify right away, some have to wait five or six months before they get their card, so they are not seen [right away]. A lot of our moms aren't being seen until they are five or six months pregnant because they have to wait to get that card.

3. Barriers to Indian Health Care

Despite the ability of Indians to receive free health care services from the Indian Health Service, and the fact that many are eligible for Medicaid, there are numerous factors that hinder Indians' receipt of health services. Cultural issues, for example, were identified as an important area of concern. Anecdotal reports shared by interviewees during the site visits indicated that Indian women often perceive non-Indian health care providers and institutions to be insensitive, a perception which may be driven by providers' lack of understanding about Indian culture and conditions in Indian communities. Quotes from the focus groups illustrate some clients' lack of satisfaction with how they are treated by service providers. In the words of two American Indian women:

When you go to the Indian Health Service, because of the short staff there is a lot of waiting, and then you encounter a lot of rudeness and abrupt behavior towards patients, or a lot of apathy from health care providers. A lot of that is a result of burnout in the health care providers.

People don't want to come to the Indian Health Service because of the history of poor health care. The Indian Health Service has a lot of non-Indian people. That promotes distrust.

As discussed earlier in the report, many people live great distances from services, and face difficulties in arranging transportation. Beyond transportation barriers, access to health sites is also limited generally by the poor service infrastructure in rural communities. In contrast to the trend in most areas of the country, where public clinics are increasingly privatizing the delivery of personal

care services, in Northern Plains Indian communities there continues to be a continuing heavy reliance on public IHS clinics.

D. COMMUNITY CONCERNS

As we have illustrated, the Northern Plains Healthy Start project faced unique geographic, political, administrative, and community issues that shaped its program development. Early in the program, a NPHS task force highlighted the following issues that it wanted to address in its program (Hudson 1993).

- **Access to Services**
  - Distance to care/lack of transportation
  - Fear of the system
  - Lack of continuity of care
- **Family Factors**
  - Teen pregnancy
  - Lack of male involvement in the family
  - Family violence
  - Breakup of the extended family
  - Neglect of children
- **Safety**
  - Car accidents
  - Home safety
- **Behavior Issues**
  - Substance abuse
  - Smoking
  - Nutrition
- **Reproductive Health**
  - Family planning
  - Lack of knowledge about sexuality
- **Need for an Emphasis on Spirituality and Indian Belief Systems**

Many of these concerns mirror the community-related issues discussed in this chapter. The next chapter describes the program as it developed over the six-year demonstration period in response to these community concerns.

III. THE NORTHERN PLAINS HEALTHY START PROGRAM

NPHS shares the following goal with other Healthy Start projects: to reduce infant mortality by 50 percent over the five-year grant period. NPHS also shares a philosophy with the other projects: that infant mortality must be addressed through a strong, community-based approach. This philosophy is reflected in the following precepts expressed in NPHS materials:

- Infant mortality reflects adverse medical, social, and environmental factors that affect the lives of infants, pregnant women, and their families.
- Direct community involvement in the planning and implementation of NPHS will encourage participation and promote program success in decreasing infant mortality.
- A high-quality system of local primary care in addition to transportation to secondary and tertiary care must be readily available and accessible to all infants and pregnant women.
- Personal, traditional, caring relationships support pregnant women and new mothers, and enhance the health outcomes of infants, children, and families.
- Community involvement supplements, in culturally meaningful ways, a woman's contact with providers of health, social, and educational services. . .
- Infant health is enhanced when services reach families in the home, in local environments, and through traditional ways.
- Infant health is related to community awareness that children are our link to the extended family's and the community's future.

Also, while NPHS shares broad program goals and concepts with the other 14 original demonstration projects, it has a unique focus on post-neonatal infant mortality.

In developing the NPHS project, each of the 19 sites conducted its own planning process to assess its needs, identify priorities, and develop strategies to address infant mortality. While the tribes went about these tasks independently, there was a great deal of consistency in the issues and

strategies they identified. As a result, the Northern Plains program model is very similar from site to site, despite the fact that there are 19 separate NPHS projects.

A. PROJECT ADMINISTRATION

1. Grant Oversight

The grantee for NPHS project is the Aberdeen Area Tribal Chairman's Health Board (AATCHB) in Aberdeen, South Dakota. Each of the 17 tribal governments and two Indian Service Areas (the Trenton Indian Service Area ad the Rapid City Indian Health Board), is a member of AATCHB. This organization was developed as an entity that could bring sovereign Indian nations in the Aberdeen Areas together to address matters pertaining to Indian health, in a manner that respects the individual governing authority of its members. In this role, AATCHB communicates with and advises the Aberdeen Indian Health Service and other agencies and organizations on health matters affecting the tribes and administers a variety of programs to promote Indian health, including Northern Plains Healthy Start.

As the grantee, AATCHB has considerable responsibility for oversight, daily administration, and ensuring the proper execution of the project. In order to recognize and respect the autonomy of each organization, the relationship between each tribe or service area and AATCHB, as well as the parameters of each site's program are defined in separate memoranda of understanding (MOU). Each MOU includes a budget and a work plan outlining the responsibilities of the AATCHB and the site.

AATCHB has a core NPHS staff responsible for:

- Developing program performance standards
- Establishing policy and ensuring compliance
- Monitoring and evaluating performance
- Providing administrative supervision
- Operating the project's data reporting system
- Providing staff development and training
- Monitoring NPHS activities
- Identifying and advocating for additional financial resources

Each tribe or service area is responsible for:

- Developing and implementing a site-specific plan that will meet NPHS project goals
- Developing an organizational chart for the Healthy Start Program
- Recruiting and selecting program staff
- Establishing policies and procedures for staff supervision and evaluation
- Complying with NPHS policies
- Coordinating NPHS services so they are not duplicated
- Supporting and assisting the local Healthy Start consortium

AATCHB reported that negotiating the initial MOUs (which are renewed annually) with all of the sites was a time-consuming process, taking nearly a year. In addition, the AATCHB worked through a development process with each site to accommodate each tribal government structure and health care delivery system, reflecting the importance of local tribal autonomy.

AATCI-IB faced the significant challenge of overseeing 19 separate but linked projects spread over a vast geographic area. The grantee's management responsibilities were further complicated by the need to satisfy federal requirements while respecting the independence of the tribes and meeting their needs for support and guidance. Striking a balance in this regard was hindered by considerable instability in the project director position at AATCHB in the early years of the project. This turnover led to frequent changes in project focus and at times poor communication and technical assistance to the 19 sites. At the time of our second round of site visits in January 1996, the linkage with the central office was reported to us is having been significantly strengthened.

Because of the early problems, the project was designated by HRSA as being on "exceptional status" in 1993. However, since the fourth project director had the support and respect of the central office staff and local project coordinators from a previous post with the AATCHB, her leadership led to the project's exceptional status being lifted in 1994.

2. Organization of Healthy Start Projects Within Tribal Governments

Each Indian tribe has a unique government structure. Generally, the main governing body of each tribe is an elected tribal council and daily administration is directed by a tribal chairman who typically serves a brief term (two to four years). The tribes are subject to federal, but not state, laws within reservation boundaries. The Healthy Start projects are usually integrated into each tribes' existing health program structure, although there are a few exceptions. The projects are typically supervised by the tribal health director.

The projects are significantly influenced by the tribal councils--especially by the frequent rotation in council membership. These changes have caused staff turnover and related morale

problems in some NPHS sites, as well as in the central office. Unlike U.S. federal, state, and local government positions, tribal government positions are not governed by civil service protections.

3. Staffing

With the implementation of Healthy Start, approximately 100 positions were created across the 19 NPHS sites (see Table III.l), a considerable contribution to the local economy. According to project budgets for Fiscal Year 1996, 12 of the 19 sites support between 3 and 5 staff positions, another 6 sites support between 6 and 8 staff positions, and the Oglala Sioux project supports 11 positions.

The Healthy Start staff positions generally fall into three main categories: managerial, service delivery, and data/administrative support.

- ***Managerial Positions.*** Each site employs a staff person, generally holding the title of community coordinator, who is responsible for the overall administration of the project. Duties of the community coordinator include overseeing program operations, supervising staff, developing all reports and applications, administering the program budget, and monitoring the accomplishment of project goals and objectives. In addition to these daily project management responsibilities, the community coordinators play an important role in raising community awareness about their Healthy Start programs and initiatives; developing and sustaining collaborative relationships with federal, state, and local resource agencies; and conducting program sustainability activities.

- ***Service Delivery Positions.*** The majority of staff positions supported by the NPHS projects relate to the delivery of services to clients. Called case managers, outreach workers, caseworkers, and a range of other titles, the duties of these staff persons include recruiting pregnant women, their male partners, and infants into Healthy Start and providing these clients with case management, home visiting, transportation, health education, and referral services. These staff are also often responsible for broader community education activities.

TABLE III.1

NORTHERN PLAINS HEALTHY START BUDGETED STAFF POSITIONS
FISCAL YEAR 1996

Site	Managerial Staff	Service Delivery Staff	Data and Administrative Stilff	Total
Cheyenne River Sioux Tribe	1	5	1	7
Crow Creek Sioux Tribe	1	2.5	1	4.5
Flandreau Santee Sioux Tribe	1	1	1	3
Lower Brule Sioux Tribe	1	2	1	4
Meskwaki Tribe in Iowa	1	2	1	4
Oglala Sioux Tribe	1	7	3	11
Omaha Tribe of Nebraska	1	2	2	5
Ponca Tribe of Nebraska	1	4	1	6
Rapid City Indian Health Board	1	5	2	8
Rosebud Sioux Tribe	1	4	2	7
Santee Sioux Tribe of Nebraska	1	2	--	3
Sisseton Wahpeton Sioux Tribe	1	2.5	1	4.5
Spirit Lake Sioux Tribe	1	4	1	6
Standing Rock Sioux Tribe	1	2	1	4
Three Affiliated Tribes	1	2	2	5
Trenton Indian Service Area	1	2	1	4
Turtle Mountain Band of Chippewa	1	4	1	6
Winnebago Tribe of Nebraska	0.5	3.2	.2	3.9
Yankton Sioux Tribe	1	3	1	5
Site Total, Site-Specific Staff	18.5	59.2	23.2	100.9
Central Office Staff	2	0	4	6
Total Northern Plains	20.5	59.2	27.2	106.9

SOURCE: Northern Plains Healthy Start FY 1996 grant application.

- ***Data/Administrative Support Positions.*** In all but one case, the Healthy Start projects employ staff whose primary responsibilities consist of entering case management participant files into the automated database and conducting general office activities.[1] In many projects, the case managers and outreach workers also share responsibility for entering case management data.

The original structure of the project assured that each project, no matter how small its service population, would generally have at least one staff person in each category. The result is that smaller service areas have proportionately more staff than larger ones.

Despite these three clear job categories, most projects have a small staff, so their functions overlap. Each staff person typically performs a range of client service and administrative functions. Projects with relatively large staffs have more of an opportunity to delineate functions clearly; for example, the Rapid City Healthy Start project has established teams that clearly distinguish between outreach workers (who provide transportation services) and case managers.

The general category of service delivery staff also includes several types of staff other than outreach workers and case managers. For example, the Ponca Tribe of Nebraska and the Winnebago Sioux Tribe, among others, use full-time van drivers. The Yankton project includes a part-time teen advocate responsible for working directly with teen parents and peers, and for providing outreach services to teenagers. Despite the prevalence of substance abuse in the project communities, only one Oglala Healthy Start project has a staff member with specific expertise in substance abuse. However, other sites refer women to other programs when they are available in the community.)

During the peak period of program operation there were six staff who worked in the NPHS central office in Aberdeen: the project director, a computer systems analyst, a maternal and child health specialist, and administrative staff.

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[1] In one small project, the community coordinator is responsible for the entry of all statistical data and computer operations.

On the site visits we discussed the composition of the staff according to their training. Some projects use professionals such as nurses or social workers for case management. However, most outreach workers/case managers are lay workers, many with experience in other programs that serve mothers and children. As revealed during the site visit interviews, the emphasis on hiring lay workers is believed to be a critical aspect of the program. Compared with highly educated workers, they relate well to clients and foster client trust, since they live in the same communities. Referrals to Healthy Start from IHS generally consist of a name but no address or phone number, so being familiar with and having the trust of the community is an important asset in project staff. This reliance on community workers was noted as a strength of the program by one of the women in the focus groups.

> *The good thing about it is they use the community people. They use the community resources that are there. These arepeople that not necessarily college educated, which is good because these are the people that live the Lakota ways.*

Having an adequate training program is important, given this heavy reliance on lay workers. The NPHS central office trained local project staff in service delivery strategies and protocols, and in understanding maternal and child health issues. The tribes also sometimes sponsor training in other areas such as cultural awareness, computers, or stress management, for example, although it was not always clear to site visitors how regular or adequate these training programs were at the time of our visits.

4. Budget

Table III.2 shows trends in the NPHS operating budget across the period of the demonstration project. Fiscal Year 1992, the planning year, was the smallest budget, at just under $1 million. The

budget grew from 1993 to 1996, and then stabilized at about $5 million per year in Fiscal Years 1996 and 1997, the periods of full program operation.

As shown in Figure III. 1, in Fiscal Year 1996 NPHS planned to use 44.4 percent of its funds for administration (including 20 percent for the Central Office), 37.7 percent for service delivery,

TABLE III.2

ANNUAL BUDGET OF NORTHERN PLAINS HEALTHY START
FISCAL YEARS 1992 - 1997

Project Year	Budget ($)
FY92	979,563
FY93	2,873,500
FY94	3,192,096
FY95	4,414,699
FY96	5,283,160
FY97	5,181,579
Total	$21,924,597

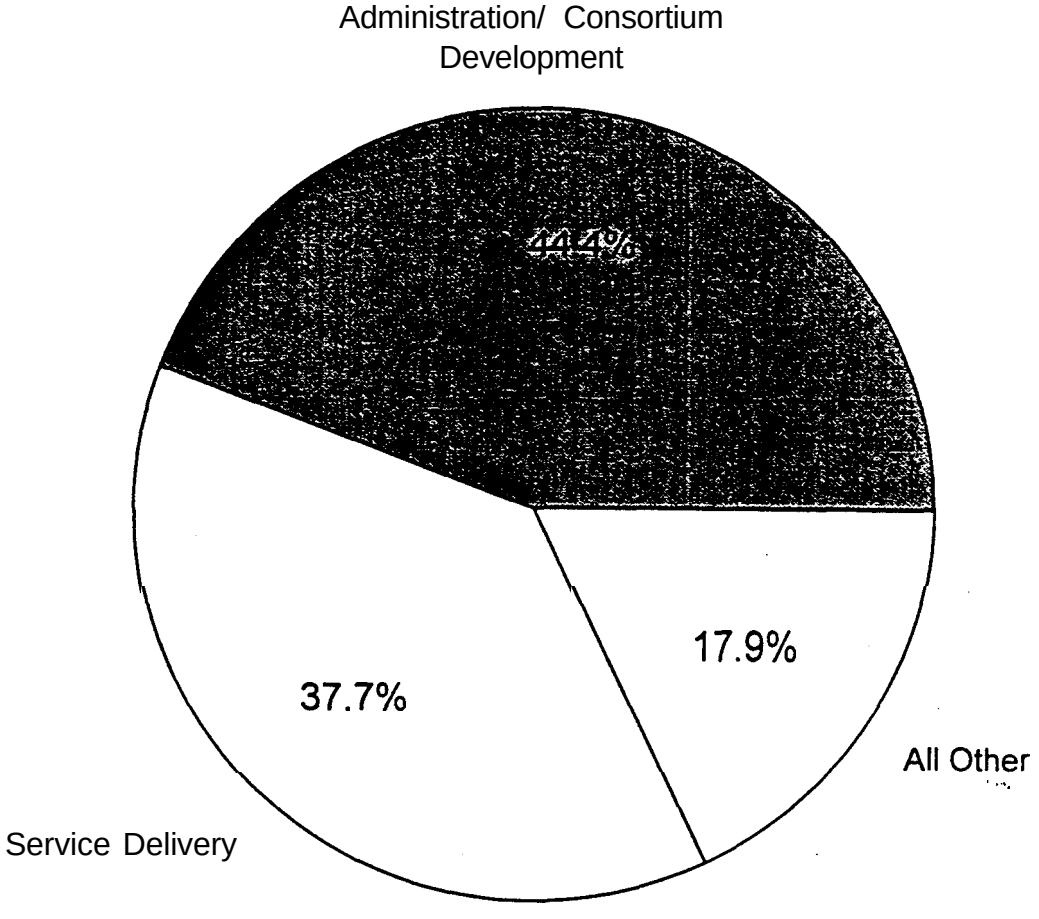
SOURCE: Northern Plains Healthy Start grant applications.

and the remaining 17.9 percent for public information and developing the project's management information system.[2] The relatively large proportion of the budget for administration was due to the project's geographic reach and the need to have both a central administrative structure plus

[2]The distribution of expenditures by expenditure category for the 14 other Healthy Start projects is provided in Howell et al. 1997.

FIGURE III. 1

NORTHERN PLAINS HEALTHY START BUDGET
FISCAL YEAR 1996



SOURCE: Northern Plains Healthy Start FY 1996 grant application; Howell et al. 1997.

NOTE: All other includes management information systems and public information activities.

individual administrative structures at each site. The central office role included many activities that were needed to successfully manage such a geographically dispersed project. These included quarterly meetings of site managers, training, and technical assistance to sites. In addition, the NPHS central office developed and coordinated the project's consortium, which was a large effort including multiple levels of state and local consortia. NPHS did not enter into contracts with other outside organizations or providers, and it did not fund any clinical providers, as was common in the 14 other Healthy Start projects.

The project distributed its funds to the 19 sites using a complex algorithm that accounted for a site's population, geographic size, birth rate, and infant mortality rate. The 1996 budget allocations for each NPHS site varied primarily according to the size of proposed site staff, which was, in turn, generally closely related to the service area population size (see Tables II. 1 and 111.2). For example, the Oglala Sioux site, with a relatively large service area and population, received nearly 3.5 times the funding of the smallest site. On average, each site received a grant of $223,671 in Fiscal Year 1996. The sites varied in the way they allocated their funding. Some planned to use a larger proportion for administration, and others planned to spend more of their funds on service delivery.

B. PROGRAM SERVICES

The main components of the NPHS service model include outreach/case management, health education, transportation, a variety of other support services, and an incentive program. Table III.3 shows which of these various services are offered in each of the 19 sites.

TABLE III.3

SERVICES PROVIDED BY NORTHERN PLAINS HEALTHY START

Site	Outreach/ Case Management	Health Education	Trans- portation	Mental Health Services/Substance Abuse Counseling	Child Care	Support Groups	Clinical Services	Incentive Program
Cheyenne River Sioux Tribe	✓	✓	✓	✓	✓			✓
Crow Creek Sioux Tribe	✓	✓	✓					✓
Spirit Lake Sioux Tribe	✓	✓	✓		✓			✓
Flandreau Santee Sioux Tribe	✓	✓	✓			✓		✓
Lower Brule Sioux Tribe	✓	✓	✓	✓	✓	✓		✓
Oglala Sioux Tribe	✓	✓	✓	✓				✓
Omaha Tribe of Nebraska	✓	✓	✓					✓
Ponca Tribe of Nebraska	✓	✓	✓			✓		✓
Rapid City Indian Health Board	✓	✓	✓		✓	✓		✓
Rosebud Sioux Tribe	✓	✓	✓				✓	✓
Meskwaki Tribe in Iowa	✓	✓	✓					✓
Santee Sioux Tribe of Nebraska	✓	✓	✓	✓				✓
Sisseton Wahpeton Sioux Tribe	✓	✓	✓					✓
Standing Rock Sioux Tribe	✓	✓	✓			✓		✓
Three Affiliated Tribes	✓	✓	✓					✓
Trenton Indian Service Area	✓	✓	✓		✓			✓
Turtle Mountain Band of Chippewa	✓	✓	✓					✓
Winnebago Tribe of Nebraska	✓	✓	✓	✓	✓	✓		✓
Yankton Sioux Tribe	✓	✓	✓	✓		✓		✓
Total Sites with Service	19	19	19	6	6	7	1	19

1. Outreach/Case Management[3]

A key function of the NPHS projects is to identify pregnant women, their partners, and their infants, and to facilitate their use of appropriate health care and related services. This includes their enrollment in public programs for which they are eligible.

One important way to identify new NPHS clients is through referrals from other agencies. The IHS is a particularly important source of new referrals because IHS clinics typically provide lists of pregnant women to their local Healthy Start projects. Tribal judges also refer substance abusing pregnant women for services. Several projects (e.g., Rosebud) also have found it effective to recruit new clients directly by stationing Healthy Start staff in IHS clinics. Word-of-mouth is also a very common means of referral to the NPHS projects, and recruiting young women into Healthy Start through their mothers and grandmothers was cited by project staff as a successful strategy. Community public information campaigns also help to reach new clients.

"Targeted case management," as it has been termed by the project, is used to assess the client's needs and assure the delivery of services to promote a healthy birth and infant development. Targeted case management evolved over the first several years of the project. It **is** described in project materials as follows:

> *The NPHS targeted case management approach is . . . . a process of planning and coordinating care and services to meet an individual's needs and maximize access to necessary medical care, to assess and address psychosocial, physical, spiritual, and environmental factors, and to provide educational services . . . . to address the risk factors associated with infant mortality and to promote healthy babies, healthy families, and healthy communities.*

---

[3]Since there is generally little distinction between outreach and case management activities in the NPHS projects, the discussion of these services has been combined.

NPHS case management is a holistic home and community-based approach that includes activities such as assessing the client's medical and psychosocial risks, developing an individualized service plan, providing education and transportation services, procuring emergency supplies, providing assistance in enrolling the client in entitlement programs, referring her to needed services, advocating for her needs, and encouraging her to participate in Healthy Start classes and events.

Home visiting, project officials believe, responds to the particular needs of Indian clients living in Indian communities. First, it provides the most comfortable environment for the client in which to receive educational and related services. It also responds to the fact that many clients do not have access to transportation and are more likely to receive services if they are brought to the client's home.

In addition to facilitating the delivery of services to the client, the home-based approach provides an opportunity to deliver services in a way that addresses risk factors associated with post-neonatal causes of infant mortality, which account for the majority of Indian infant deaths. When in the home, case managers assess the safety of the home environment, specifically the availability of smoke and carbon monoxide detectors; covers on electrical outlets; adequacy of heating, clothing, and insulation; and signs of domestic violence, and address these issues in the service delivery plan. Furthermore, the home visits by the case manager provide a critical opportunity to engage extended family members--male partners are targeted in particular--in educational activities. Given that extended Indian families typically live together, the project recognized the need to educate these family members about factors that can affect the health of the infant (for example, second-hand smoke).

In the early phases of the project, evaluators observed little uniformity in the intensity of case management across sites; however, the central office later developed a standard protocol, laying out

In the early phases of the project, evaluators observed little uniformity in the intensity of case management across sites; however, the central office later developed a standard protocol, laying out a minimum number of visits for different types of clients. Targeted case management calls for a minimum of 10 visits for pregnant women, 2 visits for postpartum women, 8 visits for infants, and 2 visits for family members/fathers. This approach is outlined in a complete set of documentation forms, which are used to collect information for the minimum data set in all 19 NPHS sites.

Case management and related transportation and health education services are similar in nature to those provided by the IHS-sponsored PI-IN and CHR programs described earlier in Section II.C. As described, both of these programs provide home visits to pregnant women, mothers, and infants. The CHR program plays a particularly important role in transporting clients to medical appointments. The degree of coordination between NPHS and these related programs has varied in the different communities. On one end of the spectrum, evaluators in some cases observed little coordination and heard reports of clients receiving the same services by multiple programs; in other sites the programs coordinate well. For example, in Winnebago, the NPHS and PI-IN programs divide maternal and infant clients with the PHN program seeing women and infants on the reservation, and NPHS providing services to clients living off the reservation. More commonly, the implementation of NPHS has led to shifts in the focus of the PI-IN and CHR programs. For example, the PHN program has increased its clinical focus, while NPHS places more emphasis on psychosocial issues.

The effect of NPHS on the CHR program has been twofold. First, NPHS has helped to train CHRs in maternal and child health issues, improving capacity to address the needs. of pregnant/postpartum women and infants. Also, the CHR program has shifted its emphasis to elderly clients. Thus, the three programs have tended to specialize, in order to allow for an efficient use of

resources. Through its links to these existing programs, NPHS has reportedly brought a new leve of expertise concerning MCH issues that was generally not there previously.

2. Health Education

Health education, a core component of the NPHS model, is provided during case managemer home visits and in group classes. The classes cover a range of topics including early and regula prenatal care, pregnancy, family planning, sexually transmitted diseases, child development, infan care, parenting, and home and car seat safety. Given high rates of substance use in the Northern Plains, both individual and class-based health education stress fetal alcohol syndrome/fetal alcoho effects (FAS/FAE), smoking cessation, and substance abuse prevention. Recently, several sites hav added classes on nutrition and on the father's role during pregnancy and after the birth. Project staf also provide health education in the schools. Site visits revealed that the content and qual:) health education materials and programs was quite variable from site to site.

NPHS also provides community education. A key feature of this effort is the NPHS public information/media campaign, which includes three main components:

- ***A project video*** for women of childbearing age and young parents that emphasizes the importance of early and regular prenatal care while tying in tribal beliefs about the importance of preparing for the infant's arrival; the video also discusses infant care, again incorporating tribal perspectives. Each site has five copies of the tape.
- ***Two brochures on prenatal care,*** developed with support from Vanguard, HRSA's public education technical assistance contractor.
- ***A quarterly newsletter,*** *The Dream Catcher,* which highlights activities of NPHS and the health concerns of Indian women and children.

NPHS community awareness efforts also include radio, television, and newspaper advertisemc interviews on local television networks; and promotional materials such as diaper bags.

The project also conducts special public education events. The unique "Diary of a Teen Mother" was a photo exhibit produced to educate and inform young people about the realities of being a pregnant teen/teen parent. The exhibit featured clients from each of the local NPHS projects. Photos of the young women and their children were accompanied by handwritten descriptions of the personal challenges and sacrifices involved in being a teenage mother. The exhibit traveled to the 19 NPHS sites upon request; it visited each of the 19 sites at least once and some more than once.

3. Transportation

The NPHS communities are geographically dispersed, and most residents have to travel great distances for supplies and services. Given the high poverty rate in Northern Plains, many residents do not have their own transportation, and because of the lack of public transportation on reservations, residents often cannot get to health and social service facilities. Providing transportation is therefore one of the primary functions of NPHS. As described by one project staff person during a focus group discussion:

> *Transportation is extremely valuable because a very high percentage of our parents do not have reliable transportation available. There is no public transportation on the reservation, which means you must own a car to get around. A lot of our people don't own cars. It takes money to own a car. And welfare won't support you to buy a car. They say, we'll reimburse you for mileage to take your child up for a medical appointment, but if you don't have a car how are you going to get there?*

Transporting mothers, infants, and pregnant women to medical and social service appointments takes a major portion of Healthy Start staff time. Rather than hiring staff specifically to provide transportation services, many projects incorporate transportation into the responsibilities of case managers. The Spirit Lake project reported that its case managers spend approximately 75 percent of their time providing transportation. Case managers provide support and counseling during these

trips. Some sites have special transportation workers who drive women to services (e.g., the Winnebago site). To supplement the Healthy Start funds available for transportation, some sites (all North Dakota sites and Lower Brule) have obtained Medicaid reimbursement to transport clients who are Medicaid recipients.

NPHS also has eliminated some transportation barriers by bringing services closer to residents. For example, the Rosebud Sioux Tribe has established monthly "one-stop shopping" well-child clinics in communities on the Rosebud Reservation. Held in conjunction with WIC and the IHS public health nursing program, these clinics have an American Indian pediatrician hired by Healthy Start who provides well-child examinations. The clinics also offer immunizations and WIC vouchers. A project staffperson participating in a focus group discussion commented on the value of these clinics:

> *If we didn't go out to the communities to do that, a lot of those children wouldn't have a well-baby checkup at all.*

4. Other Support Services

Some NPHS projects offer additional support services designed to reduce infant mortality in their communities. These services include mental health counseling and referrals; child care (during health education classes); support groups; and linkage with job training, housing, education and other programs.

In keeping with the project-wide goal of involving male partners in the Healthy Start program, a few projects have launched special initiatives to encourage male participation. For example, the Winnebago Tribe's project operates a condom distribution program, and the Standing Rock project employs a male project coordinator who facilitates a male support group. Held weekly, this group

gives men a chance to discuss issues in a "safe" environment. The benefits of such programs were described by an American Indian man who participated in one of the focus groups:

> *My son and my dad, and the grandpa went to the thing that they had for fathers. It was really good to hear an Indian man that looks Indian and is an Indian. Although he wasn't from this reservation, the way he talked it was just like-the way to go. Around here the woman's deal is to take care of the kids. It was innovative to try to get the fathers involved. The way it is now, a lot of the mothers are out there working and it is the dad who is at home with the child. So they've got to know these skills and techniques.*

Childhood safety is also emphasized by some sites. These include the following efforts to keep children safe while riding in cars:

- The Rosebud project operates the Child Safety Seat Loaner Program, which rents child safety seats for a nominal fee. The program was originally funded by a grant, which has since expired, from the South Dakota Office of Highway Safety. Education and instruction on the use of child safety seats are provided by project staff to all mothers of newborn infants being discharged from the IHS hospital.

- The Turtle Mountain Band of Chippewa works with its local traffic safety program to provide Healthy Start participants with information about the importance of home and vehicle safety and access to car seats.

- Healthy Start distributed a large number of car seats that were donated to the Indian Health Service by a manufacturer.

Additional NPHS project activities include hosting and participating in community fairs, hosting annual holiday parties at which Christmas presents are distributed to families (Oglala Healthy Start), offering hospital tours to pregnant women, and assisting in hospital discharge planning after delivery (Crow Creek and Santee Healthy Start).

5. Incentive Programs

Incentive programs are another dominant feature of the NPHS project. Under these programs, Healthy Start clients earn supplies for themselves and their babies by performing certain activities--attending education classes, keeping prenatal and well-baby appointments, and practicing healthy behaviors. In some cases, points also are provided for additional activities. For example, several sites award points for completing the forms for the automated data system, for WIC recertification, and for pursuing higher education and "self-betterment." *The Health Diary--a* portable record of health care and other important events for mother and infant developed by HRSA--is used in some sites as the standard for education, prenatal and well-child visits, and home visits. Clients take the *Health Diary* on visits to be signed by health providers as verification of the visits (Center for Health Policy Studies, 1995).

The NPHS staff believe that incentive programs are instrumental to their project's success in attracting and retaining clients. In the words of two providers in the focus groups:

> *The incentive program is a very crucial part of the program as many participants are poor and need this to obtain items for their infants...Many individuals come to the program because of the incentive program.*

> *The incentive program has contributed to maintaining consistency of involvement by the participants.*

C. PROMOTING LINKAGES IN THE COMMUNITY

Better collaboration and coordination among community organizations is likely to be one of the lasting legacies of the NPHS project. All 15 Healthy Start demonstration projects were required to develop a consortium of community representatives that "reflects a partnership of consumers, providers of services, and community organizations and groups, both public and private" (U.S.

DHHS, 1991). NPHS responded to this requirement by designing a consortium appropriate to the unique structure of the project.

Very different from the other project consortia, the NPHS consortium had three levels, each of which operated fairly independently under the overall coordination of the central office staff

- ***Area-Wide Consortium*** The NPHS area-wide consortium included representatives from the four-states in the project area. The primary purpose of this consortium was to facilitate coordination between federal/state programs and tribal programs with the intent of improving the delivery of services to Indian populations and to allow for cross-state and cross-site communication. Given the difficulty of convening meetings when members are spread over four states, the area-wide consortium generally met on an annual basis.

- ***State-Level Consortia.*** Each state that is home to a tribal project (North Dakota, South Dakota, Iowa., and Nebraska) had a consortium. These state-level consortia provided the impetus for sustaining Healthy Start activities through improved coordination with state funding agencies. The state consortia also served as forums for studying how changes in federal and state policy such as Medicaid managed care and welfare reform affect the Indian population. These consortia did not typically meet more than once or twice a year; however, the North Dakota consortium was more active.

- ***Local-Level Consortia.*** Each of the 19 NPHS sites had its own consortium. Elders, tribal officials, spiritual leaders, and service providers were among the community members represented in these diverse organizations. In the early years of the project, these consortia participated actively in the planning and implementation phases. They continue to facilitate coordination of services provided by different agencies and to build bridges between Indian and non-Indian organizations. The frequency of meetings, quarterly on average, has decreased over time. Because the NPHS projects operate in small communities where health and social service providers interact on a routine basis, the need to frequently convene formal meetings is less pressing than it is in large urban areas.

These three levels of consortia are key to accomplishing the program goals of (1) advocating for the Indian community and (2) coordinating and sustaining Healthy Start services within the larger community- and state-level service delivery systems. Efforts of the local consortia have improved coordination among service providers, and the state-level and area-wide consortia have helped to

develop and strengthen relationships between tribal and state officials. For example, the North Dakota state consortium deserves credit for facilitating Medicaid reimbursement for case management services in several projects. The consortia are also a key part of NPHS efforts to bolster linkages with non-tribal health programs.

NPHS promotes linkages across the health care and social service systems in several other ways, as illustrated by the following examples:

- Healthy Start project staff commonly serve as members of community advisory boards and related committees and programs.
- In some sites (e.g, Winnebago), NPHS projects complement tribal maternal and child health/public health nursing programs by providing home visiting and education services to infants and pregnant and postpartum Indian women who live outside the reservations (tribal maternal and child health staff can only conduct visits to persons who live on the reservations).
- Both the Meskwaki Tribe in Iowa and the Santee Sioux projects play an important role in delivering Women's, Infants, and Children's (WIC) nutritional services to Healthy Start clients. The Santee Sioux project office is a WIC distribution center, and the Meskwaki Tribe in Iowa delivers WIC vouchers to Healthy Start clients who have not picked them up from the WIC office.
- The Rosebud Healthy Start project has collaborated with the local IHS and WIC offices to establish community-based well-child clinics in underserved areas across the Rosebud reservation. Under this arrangement, Healthy Start pays a pediatrician to give medical exams, the IHS nurses provide immunizations, and the WIC agency certifies clients for MC benefits.

D. ACTIVITIES TO PROMOTE CULTURAL AWARENESS AND INVOLVEMENT

NPHS aims to enrich the lives of its clients by emphasizing cultural traditions that foster behaviors that make mothers, babies, and families healthier. NPHS project materials stress the belief that many of the health and social problems facing Indian people can be ameliorated through a

renewed emphasis on traditional Indian family values. This philosophy has been embraced by the local projects, as illustrated in the following passage from Rapid City Healthy Start project abstract:

> *'That our Babies Will Live" is the mission statement of the Rapid City Healthy Start program. It is taken from the traditional Lakota Sun dance prayer 'That Our People Shall Live." . . .The staff recognizes that the family is the basic foundation of the Rapid City Indian community. If the family is not strong and healthy, the infants born into that family will be at risk. We further recognize that the vast majority of Indian people live within an extendedfamily context. It is from this circle that they give and receive their support.*

The emphasis on American Indian tradition, culture, and values has guided the NPHS approach. Promotional and educational materials feature traditional Indian patterns and designs, photographs of extended Indian families, discussion of traditional values, and quotes from Indian leaders. The NPHS brochure discusses the critical role of aunts, uncles, and grandparents in raising children, and the role of communities in ensuring that the needs of moms and babies are met. The brochure emphasizes its message with pictures of babies with their parents, grandparents, other relatives, and friends, and with a quote from a traditional Lakota prayer, "Mitakuye Oyasin. We are all related."

In addition to these materials, NPHS developed culturally sensitive ways to strive for a reduction in infant mortality. The project's involvement of elders generally and grandmothers specifically, fit with the culture of the Northern Plains tribes, in which elders are revered and grandmothers serve as family matriarchs. For example, elders have been actively involved in local consortia, and several projects have involved elderly women in efforts to support and advise young mothers. Other examples of the project's culturally-appropriate strategies include the following:

- *Annual Wacipi* Each year, the Flandreau Santee Sioux Tribe sponsors an honoring ceremony for babies born within the last year. This ceremony is known as a Wacipi, or pow wow. The Wacipi is held in the spring to coincide with traditional values honoring the spring as a time of rejuvenation for the earth and new life. The ceremony' is marked

by traditional dancing, drumming, singing, and prayers for the new babies and parents, and is attended by many members of the community.

- ***Winyan Waste.*** The Cheyenne River Healthy Start program has developed this guide for women participating in the Healthy *Start* program. *Winyan Waste,* which translated literally means 'Good Woman," may be more liberally interpreted as "a women who would have all the knowledge needed...to make good decisions concerning herself, her children, and her family." Through its lessons on the importance of prenatal care, good nutrition and fitness, infant care, and substance awareness, this guide aims to assist women in learning "the things that mothers, sisters, aunts, and grandmothers would have taught on a daily basis in traditional culture."

American Indian Healthy Start clients and community members alike clearly appreciate the emphasis on culturally relevant approaches to delivering services. In the words of focus group participants:

I 'm considered a spiritual leader here on the reservation. I've participated in functions of the Healthy Start. They brought traditional counseling. One time they had a feast and they brought all these parents in that had lost children. They brought them together and consoled the parents, They see cultural values and apply them. That 's why a lot of people are more comfortable with this program.

The Code of Culture has the seven rites that we handed to the people. For many years we haven 't practiced them. Healthy Start was one of the key players that brought them back They sponsor things like the sacred birth of the child and the coming-out ceremonies.

My Healthy Start worker told me how it used to be in the old days when women were pregnant. In the old days when you conceived that 's when you started taking care of your baby,

I think that is why so many people that get help from Healthy Start now didn 't have help before. These other agencies didn 't know how to help American Indians.

IV. NORTHERN PLAINS HEALTHY START CLIENTS AND THEIR SERVICES

This chapter provides quantitative data from various sources to describe the clients served by the 19 NPHS sites and the services provided to them by the program. The data, based on both a postpartum survey and the cross-site Minimum Data Set (MDS), illustrate differences across the 19 sites and between NPHS and the 14 other Healthy Start projects.' See Appendix B for a detailed description of these data sets.

A. NORTHERN PLAINS HEALTHY START CLIENTS

1. Clients Served

According to the MDS, in FY 1996 NPHS served 1,355 maternal clients and 985 infant clients (see Table IV.1). In addition, NPHS served 362 "other" clients for a total of 2,702 clients. "Other" clients are those that could not be classified as either maternal or infant clients from the data available in the MDS. These clients may be fathers, adolescents who are not parenting, older children, or maternal/infant clients who could not be identified as such.

In comparison, the 14 other Healthy Start projects served, on average, 1,839 maternal clients and 1,5 17 infant clients in the same year (data on "other" clients were not available from the other 14 projects). So, despite the geographic reach of its service area, the NPHS project fell well within the range of 785 to 7,287 total maternal and infant clients served in the other 14 projects in the same

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'Conclusions drawn from either of these data sources must take into consideration certain important limitations. For example, the reference year for the MDS service data, 1996, is the only year of full project implementation for which data are readily available. In addition, not all clients were included in the MDS, due to phase-in problems with the data system. The NPHS Year 2 (1995) Telephone Update Report indicates that service data in the MDS were not complete for all clients at that time. The postpartum survey data includes clients from only seven of the Northern Plains sites and has a small sample size. As a result, differences between participants and non-participants are difficult to detect, and patterns are not fully representative of all 19 sites.

TABLE IV. 1

NUMBER OF NORTHERN PLAINS- HEALTHY START CLIENTS BY SITE
FISCAL YEAR 1996

	Type of Client				Percent of Total Clients	Total Births (1990)	Ratio of Maternal Clients to Births
	Maternal Clients	Infant Clients	Other Clients'	Total Clients			
Cheyenne River Sioux Tribe	134	125	52	311	11.5	174	.77
Crow Creek Sioux Tribe	108	79	22	209	7.7	81	1.33
Flandreau Santee Sioux Tribe	24	13	5	42	1.6	12	2.00
Lower Brule Sioux Tribe	21	4	2	27	1.0	92	.23
Meskwaki Tribe in Iowa	22	16	7	45	1.7	23	.96
Oglala Sioux Tribe	192	104	47	343	12.7	490	.39
Omaha Tribe of Nebraska	15	8	1	24	.9	112	.13
Ponca Tribe of Nebraska	59	38	20	117	4.3	103	.57
Rapid City Indian Health Board	128	9	10	147	5.4	254	.50
Rosebud Sioux Tribe	40	57	12	109	4.0	310	.13
Santee Sioux Tribe of Nebraska	8	19	2	29	1.1	10	.80
Sisseton Wahpeton Sioux Tribe	119	147	45	311	11.5	166	.72
Spirit Lake Sioux Tribe	89	67	44	200	7.4	114	.78
Standing Rock Sioux Tribe	105	46	15	166	6.1	168	.63
Three Affiliated Tribes	47	30	10	87	3.2	165	.28
Trenton Indian Service Area	38	37	5	80	3.0	29	1.31
Turtle Mountain Band of Chippewa	39	61	20	120	4.4	257	.15
Winnebago Tribe of Nebraska	74	62	21	157	5.8	192	.39
Yank-ton Sioux Tribe	93	63	22	178	6.6	90	1.03
Total Northern Plains	1,355	985	362	2,702	100.0	2,842	.48

SOURCE: Northern Plains Healthy Start Minimum Data Set (counts of clients). Northern Plains Year 2 Comprehensive Plan (counts of births).

*These are clients who were recognized as FY96 participants, but could not be identified as mothers or infants.

[b]The number of births by site is not available for more recent years. However, the total number of births in the Northern Plains has been fairly stable during the 1990s, in the range of 2,500 to 2,900 births per year.

year. In addition, the ratio of maternal clients to total births in NPHS is similar to the other 14 projects.

Table IV. 1 also shows how the number of clients served in FY 1996 was distributed across the 19 NPHS sites. Because the NPHS serves a widespread project area that includes tribes of various sizes, the total number of clients varies considerably by site. For example, the Santee Sioux Tribe, located on a small reservation with approximately 300 women of childbearing age (see Table II. 1), served only 29 clients in 1996. Located in a larger and more densely populated community of approximately 5,000 women of childbearing age, the Oglala Sioux Tribe site served 343 clients. The Oglala Sioux, Cheyenne River, and Sisseton Wahpeton sites all had relatively large caseloads, together serving approximately 35 percent of all NPHS clients in 1996, according to data in the MDS.

Table IV. 1 also shows the number of births in 1990 reported by the project in its Comprehensive Plan for each of the 19 sites (such data are not readily available for more recent years), and the ratio of maternal clients to the number of births. There is considerable site-to-site variation in the ratio of maternal clients to total births, reflecting different levels of penetration across sites. While sites with a larger number of births usually served more clients, this was not always true, and the ratio of maternal clients to births ranged from .13 to 2.00. A similar variation was observed across the 14 other Healthy Start project areas.[2]

[2]For more information on the implementation of Healthy Start in the other 14' projects see *The Implementation of Healthy Start Lessons for the Future* (Howell, et al. 1997). The report provides quantitative and qualitative information on each project including administration, services, other interventions, and sustainability. Page 46 of the report provides detailed client service data for each project in FY 1996.

2. NPHS Client Characteristics

Table IV.2 shows the demographic characteristics of NPHS clients according to the postpartum survey and the MDS. It also shows comparable data from birth certificates for all Indian women delivering in Northern Plains, as well as for Healthy Start clients in the 14 other Healthy Start projects. NPHS clients included in the survey, those reported in the MDS clients in the other 14 projects, and those identified from 1995 birth certificate data have a generally similar demographic profile, with some exceptions.

According to both the MDS and the postpartum survey, more than a quarter of NPHS maternal clients were under 20 years old, 72 percent were not married, and about half had not completed high school. The two sources of client data did not agree on the age and education of clients, with more younger and less educated clients included in the survey than in the MDS. More than half of NPHS clients had an annual household income less than $5,000. According to the survey, NPHS clients and non-participants were generally similar, but clients were significantly more likely to be under 20 and to be unmarried.

The majority of NPHS clients had incomes that were well below the federal poverty level (see Figure IV. 1). Approximately 40 percent of NPHS clients were reported in the MDS as having a monthly income of less than $200, and approximately 75 percent were reported as having a monthly income of less than $800. A small proportion of NPHS clients appeared to be in a better position financially: approximately 5 percent of clients had a yearly income of $20,000 or more. A substantial proportion of clients were living in crowded quarters, and a small fraction of this group were living in very crowded quarters (household sizes of 9 or more).

TABLE IV.2

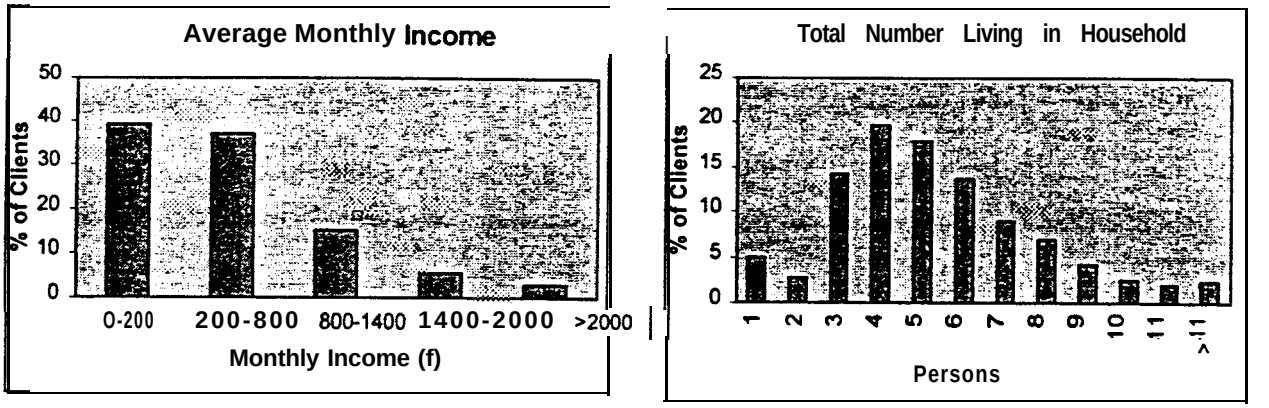
DEMOGRAPHIC CHARACTERISTICS OF HEALTHY START CLIENTS AND OTHER WOMEN DELIVERING INFANTS IN NORTHERN PLAINS 1995- 1996

Characteristics	Postpartum Survey 1995: Northern Plains Clients	Postpartum Survey 1995: Northern Plains Nonparticipants	Postpartum Survey 1995: 14 Other Projects Clients	Northern Plains MDS Clients, Fiscal Year 1996	Northern Plains, All Deliveries to Indian Women, Calendar Year 1995
	PERCENT OF WOMEN				
Maternal Age					
< 20	36.4 63.6	80.7 19.3	33.0 67.0	25.1 74.9	24.8 75.2
Maternal Education					
< High School	58.6	43.9	45.6	49.4	40.3
≥ High School	41.4	56.1	54.4	50.6	59.7
Marital Status					
Never Married	72.2	42.3	67.8	72.5	69.7
Married/Other	27.8	57.7	32.2	27.5	30.3
Household Income					
≤ $5,000	56.3	50.9	44.6	58.1	Not Available
$5,000+	43.7	49.1	38.4	41.9	
Number of Women	99	57	1,347	1.355	2,552

SOURCES: Healthy Start Postpartum Survey; Northern Plains Healthy Start Minimum Dataset; birth certificates.

FIGURE IV. 1

AVERAGE MONTHLY INCOME AND HOUSEHOLD SIZE
NORTHERN PLAINS HEALTHY START CLIENTS
FISCAL YEAR 1996



SOURCE: Northern Plains Healthy Start Minimum Data Set

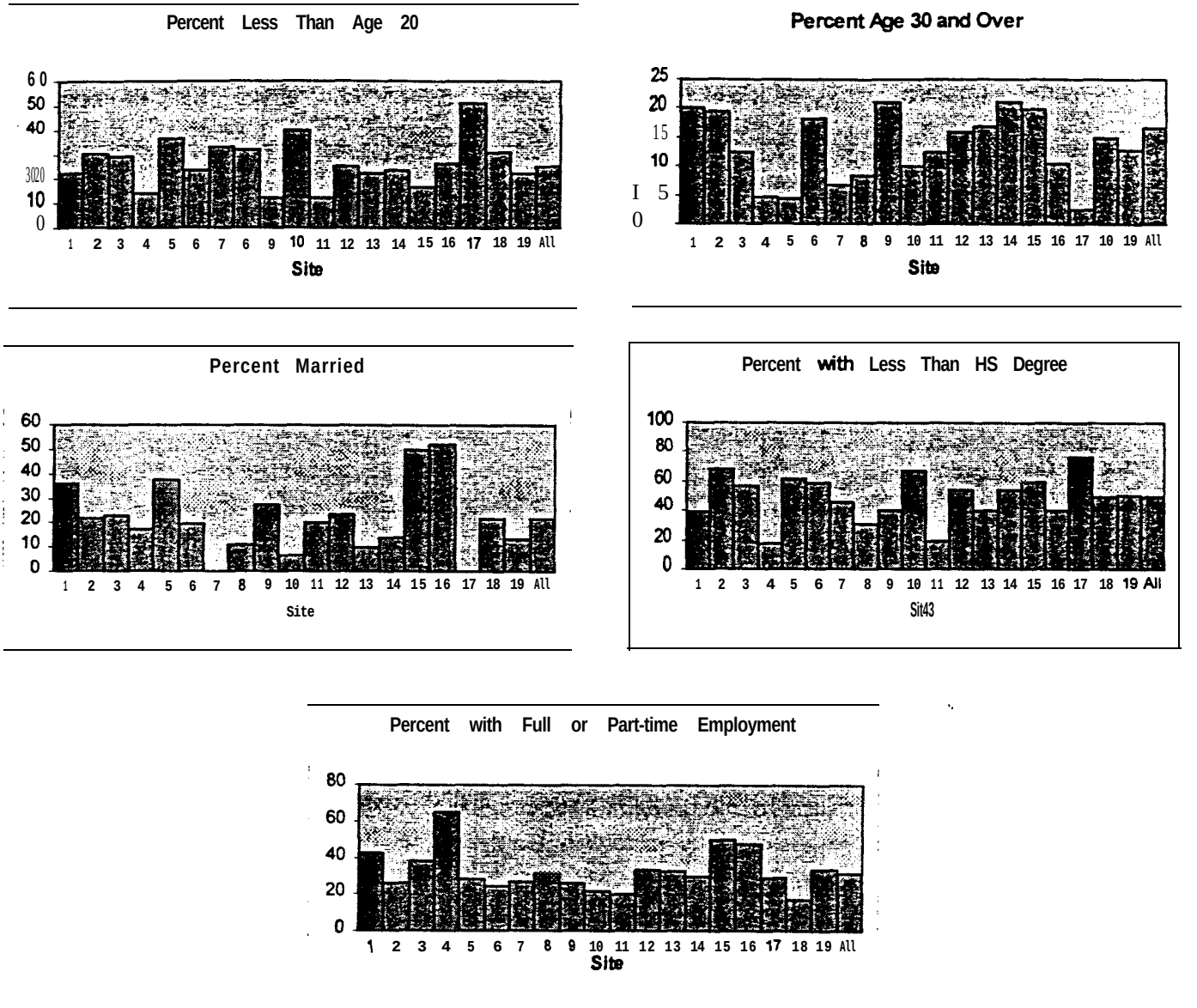
There was site-to-site variation in the characteristics of NPHS clients (Figure IV.2). The percentage of NPHS clients who were under age 20 ranged from a low of 12.5 in Rapid City to a high of 5 1.3 in Turtle Mountain. Similarly, the percentage of clients who had not completed high school varied widely, from 17.7 percent in Lower Brule to 76.5 percent in Turtle Mountain.

Data from the postpartum survey show that NPHS clients were at high obstetrical and social risk in several ways (see Table IV.3). These risk factors include the following:

- Approximately 30 percent of NPHS clients were told by their health care provider that their pregnancies were high risk.
- Only 36.5 percent of participants became pregnant at the time they wanted.
- A large proportion of clients (55.3 percent) reported smoking during or near the time of their pregnancy.
- A smaller but substantial proportion (17.2 percent) of NPHS clients reported drinking alcohol or using drugs during or near the time of their pregnancy.

FIGURE IV.2

CHARACTERISTICS OF NORTHERN PLAINS
HEALTHY START CLIENTS BY SITE
FISCAL YEAR 1996



SOURCE: Northern Plains Healthy Start Minimum Data Set

1. Cheyenne River Sioux Tribe
2. Crow Creek Sioux Tribe
3. Flandreau Santee Sioux Tribe
4. Lower Brule Sioux Tribe
5. Meskwaki Tribe in Iowa
6. Oglala Sioux Tribe
7. Omaha Tribe of Nebraska
8. Ponca Tribe of Iowa
9. Rapid City Indian Health Board
10. Rosebud Sioux Tribe
11. Santee Sioux Tribe
12. Sisseton Wahpeton Sioux Tribe
13. Spirit Lake Sioux Tribe
14. Standing Rock Sioux Tribe
15. Three Affiliated Tribes
16. Trenton Indian Service Area
17. Turtle Mountain Band of Chippewa
18. Winnebago Tribe of Nebraska
19. Yankton Sioux Tribe

TABLE IV.3

OBSTETRIC, BEHAVIORAL, AND ENVIRONMENTAL RISK CHARACTERISTICS
HEALTHY START CLIENTS AND NONPARTICIPANTS, 1995

Client Characteristics	Northern Plains Clients	Northern Plains Nonparticipants	Clients for 14 Other Heal thy Start Projects
OBSTETRIC RISK CHARACTERISTICS (%)			
High Obstetrical Risk	28.3	33.3	35.6,
Intended Pregnancy	36.5	44.4	22.3
BEHAVIORAL RISK CHARACTERISTICS (%)			
Alcohol/Drug Use in Pregnancy	17.2	14.9	9.7
Smoking in Pregnancy	55.3	46.8	22.7
ENVIRONMENTAL RISK CHARACTERISTICS (%)			
Any Stress During Pregnancy"	96.0	91.2	93.5
Loss of Loved One During Pregnancy	47.5	47.4	42.5
Abuse During Pregnancy	24.2	21.0	21.8
Number of Women	99	57	1,347

SOURCE: Healthy Start Postpartum Survey.

"Any stress is defined as women who reported that they experienced any of the following stressors: stress from partners, stress about money, illness or death of a loved one during pregnancy, being treated badly or abused during pregnancy, did not feel safe at night, or lived in a neighborhood with drug pushers.

The data also suggest that other postpartum women ("nonparticipants") living in the project area face similar risks to those of NPHS clients. The majority of NPHS clients and nonparticipants living in the project area reported having experienced environmental stress, with more than 90 percent of women reporting some major stress during pregnancy; more than 47 percent reported the loss of a loved one and more than 20 percent reported being abused.

Additionally, the profile of such risk factors for women in the Northern Plains is very similar to that of Healthy Start clients in the other 14 Healthy Start projects where the survey was conducted. The exceptions were reported alcohol/drug use and smoking which were both substantially higher in the Northern Plains.

B. SERVICES RECEIVED BY NPHS CLIENTS

1. Case Management

Case management is a cornerstone of NPHS services. Site visits revealed that most Healthy Start services--including transportation, home visits, and health education--are also closely linked to outreach/case management activities.

In the survey, women were asked if, during their pregnancy or after their baby was born, there was one person who made sure they had needed services or who visited them at home to see how they were doing. Women who responded "yes" to this question were identified as receiving case management. Women were also asked whether this person was from Healthy Start. As illustrated in Table IV.4, NPHS clients were significantly more likely than nonparticipants to have received any case management services in FY 1996. In addition, a larger percentage of NPHS clients received case management services than did clients of the 14 other projects. Almost all NPHS clients who received case management reported that Healthy Start was the source of those services. The

intensity of services for clients was also greater; NPHS clients were more likely than nonparticipants to have received three or more home visits. Also, more than 80 percent of NPHS respondents reported that their case management services were extremely helpful (data not shown).

TABLE IV.4

RECEIPT OF CASE MANAGEMENT SERVICES
HEALTHY START CLIENTS AND NONPARTICIPANTS
1995

	Northern Plains Clients		Clients from I4 Other Healthy Start Projects	
Services	Clients	Nonparticipants	Clients	Nonparticipants
Case Management (Any)				
Yes	80.8	43.9	58.4	28.0
No	21.2	56.1	41.6	72.0
Case Management (Healthy Start)				
Yes	71.7	--	58.7	--
No	28.3	--	41.3	--
≥ Three Home Visits				
Yes	65.8	24.0	44.7	37.9
No	34.2	76.0	55.3	62.1
Number of Women	99	57	1,347	1,329

SOURCE: Healthy Start Postpartum Survey.

Figure IV.3 illustrates the proportion of NPHS maternal and infant clients who received one, two, and three or more case management contacts by NPHS staff in FY 1996 as reported in the MDS. Recall that the MDS data are for all Northern Plain clients while the postpartum survey was conducted for a small sample in seven sites, although contacts in the MDS may be underreported. The average number of yearly contacts per maternal client was 3.7, a number that is comparable to

that reported in the other 14 Healthy Start projects' MDS data sets. For the full sample, as reported in the MDS, 42.1 percent of NPHS maternal clients received one contact, 13.8 percent received two contacts, and 44.1 percent received three or more contacts. In contrast, a smaller proportion of infant clients received intensive services (3 or more contacts). The majority of infant clients received two contacts.

As part of the case management process, infant clients received home environmental assessments and risk assessments, as described in Chapter III. These were oriented toward identifying and addressing risks related to postneonatal mortality due to SIDS, accidents, and other preventable causes. Table IV.5 shows MDS data on the percent of infant clients who had either a home environmental or risk assessment. Overall, 58.6 percent received environmental assessments and 68.9 percent received risk assessments. These percentages varied considerably by site. Again, the data are from the client minimum data set, and there may be underreporting of assessments in the data system.

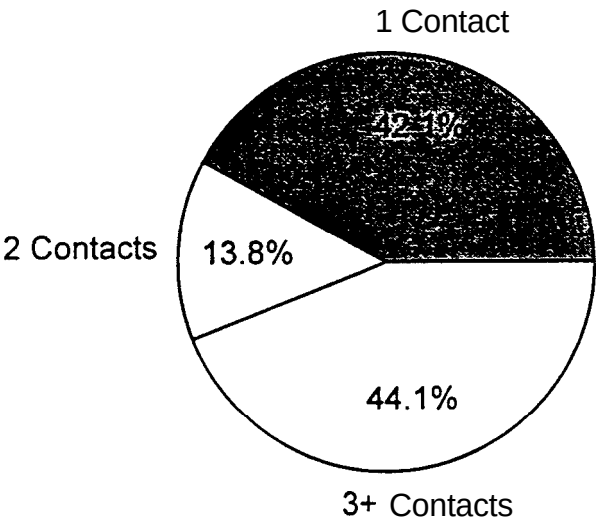
Service intensity patterns varied by site within the NPHS project. While the average number of contacts per client was 3.7 overall in fiscal year 1996, the average number by site ranged from one to eight contacts per client. Eight of the nineteen NPHS sites averaged more than three contacts per client.

Standard protocols called for more visits than were documented in either the postpartum survey or the MDS, although it is certainly very possible that the number of contacts was underreported in the MDS. However, the data suggest that service intensity was lower than that contained in case management protocols.

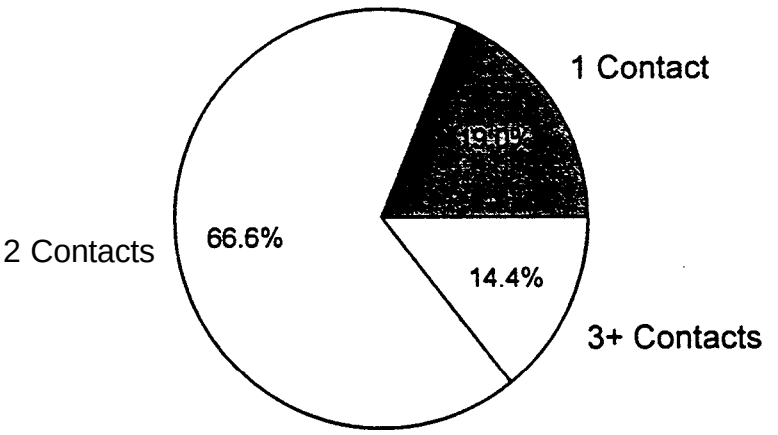
FIGURE IV.3

MATERNAL AND INFANT CLIENT CONTACTS
NORTHERN PLAINS HEALTHY START
FISCAL YEAR 1996

Maternal Clients



Infant Clients



Source: Northern Plains Healthy Start Minimum Data Set

TABLE IV.5

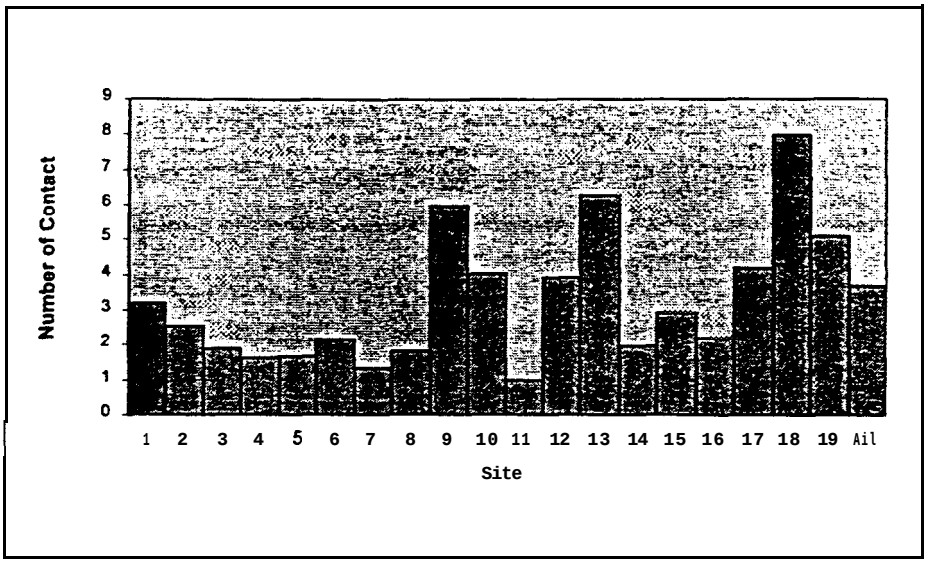
RECEIPT OF HOME ENVIRONMENTAL ASSESSMENT AND RISK ASSESSMENT
NORTHERN PLAINS HEALTHY START
FISCAL YEAR 1996

	Percent of Infants Receiving Home Environmental Assessment	Percent of Infants Receiving Risk Assessment
Cheyenne River Sioux Tribe	90.4	92.0
Crow Creek Sioux Tribe	43.0	50.6
Flandreau Santee Sioux Tribe	15.4	92.3
Lower Brule Sioux Tribe	75.0	75.0
Meskwaki Tribe in Iowa	31.3	37.5
Oglala Sioux Tribe	52.9	55.8
Omaha Tribe of Nebraska	12.5	50.0
Ponca Tribe of Iowa	15.8	42.1
Rapid City Indian Health Board	33.3	55.6
Rosebud Sioux Tribe	43.9	66.7
Santee Sioux Tribe of Nebraska	73.7	89.5
Sisseton Wahpeton Sioux Tribe	100.0	100.0
Sprit Lake Sioux Tribe	71.6	77.6
Standing Rock Sioux Tribe	10.9	50.0
Three Affiliated Tribes	6.7	26.7
Trenton Indian Service Area	54.1	59.5
Turtle Mountain Band of Chippewa	24.6	19.7
Winnebago Tribe of Nebraska	54.8	90.3
Yankton Sioux Tribe	71.4	71.4
Total	58.6	68.9

SOURCE: Northern Plains Healthy Start Minimum Data Set

FIGURE IV.4

AVERAGE NUMBER OF MATERNAL CLIENT CONTACTS BY SITE
NORTHERN PLAINS HEALTHY START
FISCAL YEAR 1996



SOURCE: Northern Plains Healthy Start Minimum Data Set

NOTE: See Figure IV.2, page 55 for key.

2. Health Education

Health education was a critical component of the NPHS **service** package. As shown in Table IV.6, almost all NPHS clients received one-on-one counseling on at least one issue related to their health or to the health of their child. The topics that were most commonly discussed were reported to be the birth process, infant development, breastfeeding, nutrition, smoking, and parenting. As in the other projects, a smaller but substantial proportion of clients participated in classes on the same topics, with 48.5 percent participating in at least one class. A higher proportion of Northern Plains

clients who responded to the survey received health education than did clients in the 14 other projects.[3]

TABLE IV.6

RECEIPT OF HEALTH EDUCATION SERVICES
HEALTHY START CLIENTS
1995

Services	Northern Plains Clients	Healthy Start Clients from 14 Other Healthy Start Projects
	PERCENT OF WOMEN	
One-on-One Education		
Yes	90.9	82.6
No	9.1	17.4
Education in Classes		
Yes	48.5	40.7
No	51.5	59.3
Number of Women	99	1,344

SOURCE: Healthy Start Postpartum Survey

3. Transportation

In Chapter III, we discussed how transportation was a common service offered by NPHS, given the wide distance between clients' homes and services. Data from the survey show that the use of transportation services distinguished NPHS clients from others in their communities and from clients of other Healthy Start programs around the country (Table IV.7). More than 60 percent of NPHS

[3]For more detailed information on health education in Healthy Start, see Harrington, Foot, Closter, and O'Connor (1998).

clients reported receiving transportation assistance, compared with only 8 percent of nonparticipants, and 20.5 percent in the other 14 Healthy Start projects.

TABLE IV.7

RECEIPT OF TRANSPORTATION SERVICES
HEALTHY START CLIENTS AND NONPARTICIPANTS
1995

Services	Northern Plains Clients		Other 14 Healthy Start Project	
	Clients	Nonparticipants	Clients	Nonparticipants
	PERCENT OF WOMEN			
Received Transportation	60.0	8.0	20.5	5.5
Joined Healthy Start Because of Transportation	27.3	--	9.5	
Number of Women	99	57	1,347	1,329

SOURCE: Healthy Start Postpartum Survey.

Transportation also played an important role in Northern Plains in bringing women into the project. NPHS clients were asked in the postpartum survey what they had heard about Healthy Start that made them want to find out more about the project. As shown in Table IV.7, 27.3 percent reported that transportation was the reason they were interested in Healthy Start, in comparison to 9.5 percent of clients in the 14 other projects.

V. PROGRAM OUTCOMES

A. OVERVIEW OF THE OUTCOME EVALUATION

As discussed earlier in the report, the design of the national evaluation of Healthy Start includes both a process analysis of program implementation and an analysis of program outcomes. Chapters II through IV of this report have highlighted the results of the process analysis, since much of what can be learned from this demonstration relates to the lessons learned from the development of the program and its implementation. In particular, its unique structure as an affiliation of many geographically dispersed Indian organizations provides a potential model for other health programs in Indian communities and in isolated rural areas in general. Such issues can best be studied with qualitative methods.

In addition, it is also important to investigate whether there is evidence that the program achieved its goals during the time period of the demonstration. The research questions that can be addressed with the outcome analysis, given the available data sets, are the following:

- What was the impact of the program on adolescent pregnancy rates?
- What was the impact of the program on the use of prenatal care services?
- What was the impact of the program on infant mortality, in particular post-neonatal mortality?'

Two types of data are available to address these outcome questions: (1) the post-parturn survey, which asked a series of questions about prenatal care use; and (2) birth and death certificates for the

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'The outcome analysis for the other 14 Healthy Start projects examines several other birth outcomes that are not relevant to the outcome analysis for Northern Plains Healthy Start (rates of low birthweight, prematurity, and neonatal mortality). The rates for those birth outcomes were not high in the Northern Plains in the baseline period, so the analysis presented here does not focus on them.

Northern Plains and comparison areas in the years proceeding and immediately following the demonstration, which can be used to measure adolescent pregnancy rates, prenatal care use, and infant mortality.

To draw conclusions about whether NPHS affected outcomes, the national evaluation design specifies two types of comparisons:

- A comparison between clients of the program and other women who did not participate. This allows for a specific focus on women served by the program, comparing them to similar women who were not served.

- A comparison between all Indian women in the demonstration area with Indian women in two matched comparison areas. This type of comparison recognizes that not all eligible individuals know about or choose to participate in the program, but that they may be affected by the presence of the demonstration in the community.

Making such comparisons is critical to determining whether any changes observed are due to the demonstration or to other factors (such as secular trends in infant mortality).

Both types of comparisons are used in the analysis of outcomes presented in this chapter. The former comparison (clients to nonparticipants) is used for the analysis of prenatal care use from the post-partum survey, and the latter comparison (all Indian women in Northern Plains to all Indian women in two comparison areas) is used in the analysis of the three outcome measures using vital statistics data.

Neither of these comparison groups is optimal for an outcomes analysis, since there is no random assignment of women to demonstration services. For this reason, particularly in the case of this Northern Plains outcomes analysis for which we have limited sample sizes'and limited ability to control statistically for differences in groups, the results of the outcomes analysis should be interpreted with caution.

The matched comparison area design assumes that observed differences in outcomes between project areas and comparison areas can be attributed to Healthy Start. For this assumption to be true, it is critically important that the selected comparison areas be as similar as possible to the Healthy Start project areas prior to implementation of Healthy Start. Ideally, selected comparison areas resemble the project areas in all ways except the availability of the Healthy Start program. In particular, because the overall objective of Healthy Start is to reduce infant mortality, project areas and their comparison areas should have similar baseline infant mortality rates.

In addition, the face validity of the match is as important as preprogram similarities in key outcomes. In particular, comparison areas should match the project areas as closely as possible along demographic and cultural characteristics, as well as in the degree of urbanization.

For the above reasons, it was important to restrict comparison areas to other Indian Health Service Areas. After discussion with staff of Northern Plains Healthy Start, two comparison areas were chosen: the Alaska IHS area--which had the second highest baseline infant mortality rate among native women in the U.S. following Aberdeen--and the Billings IHS area--which is adjacent to the Aberdeen IHS area and has similar geography, climate and economy.

Outcome measures for demonstration and comparison areas are compared across four time periods:

- 1984-88: the period used by federal officials in developing the demonstration program, to identify areas with high infant mortality around the country
- 1989-91: the immediate pre-Healthy Start demonstration period, before any program activities were funded other than planning
- *1992-94*: the period of early program implementation during which site visits revealed that the program was not yet fully operational
- 1995-96: the period of full program implementation.

A regression model is used to calculate whether the availability of Healthy Start in the demonstration area has a statistically significant relationship to the observed outcomes. The model controls for time trends as well as the presence or absence of Healthy Start in the area.

B. ADOLESCENT PREGNANCY

NPHS identified family factors, including adolescent parenting, as one of the important contributors to infant mortality that it chose to target in its program. Through intensive case management with adolescents, as well as community-wide education efforts like the "Diary of a Teen Mother" traveling photo exhibit, the project sought to prevent early parenting in its communities.

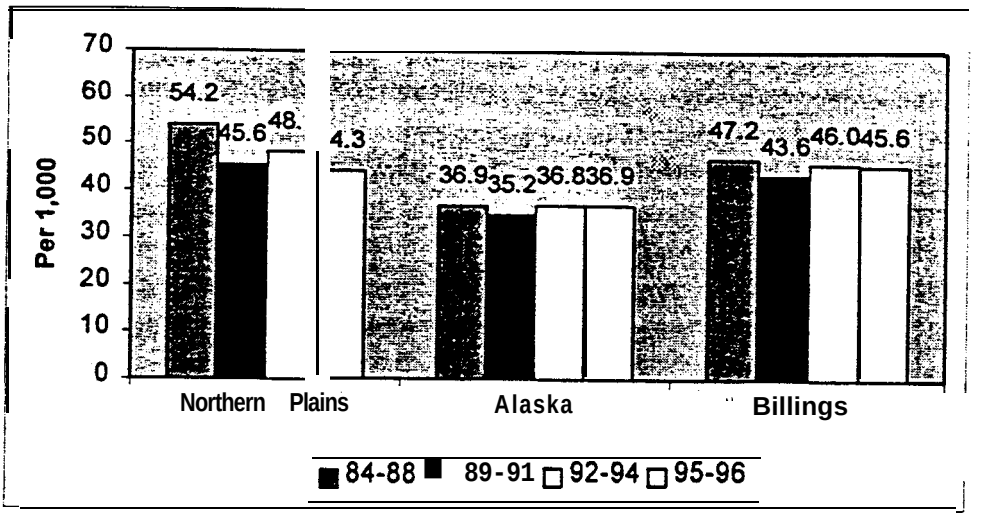
The adolescent birth rate is measured, in both the baseline period and in the demonstration period, as follows:

- Numerator: the number of births to women aged 12-17 from birth certificates
- Denominator: the number of women aged 12-l 7 from Indian Health Service user data.

Figure V. 1 below shows trends in adolescent birth rates for Indian women in the Northern Plains and in the two comparison areas, the Alaska IHS Area and the Billings IHS Area. The graph shows that adolescent birth rates declined in the Northern Plains by 22 percent, from 54.2 per thousand adolescents 12-17 in 1984-88 to 44.3 per thousand in 1995-96. In contrast, adolescent birth rates remained essentially constant in the same time period in the Alaska IHS area and declined only slightly from 47.2 to 45.6 in the Billings area. The presence of the Healthy Start program was

FIGURE V. 1

ADOLESCENT BIRTH RATES
(PER 1,000 FEMALES AGED 12-17)
1984 - 1996



SOURCE: Birth certificates (numerator) and IHS user data (denominator)*

significantly related to lower adolescent birth rates (.O 1 level, one-tailed test), suggesting that NPHS did have a significant impact on this important program outcome.

While it is difficult to tie the process analysis findings directly to these outcome findings, the process results suggest that:

- Culturally appropriate outreach/case management services tailored to the needs of adolescents led to a greater awareness of the adverse consequences of early parenting in young women.
- The targeting of adolescent pregnancy in the project's public information campaign also increased awareness among extended family members and the community at large.

[2]A user has obtained services from an IHS health facility at least once in the past three years.

These program interventions may have led to reductions in adolescent births in the Northern Plains, as is suggested by the outcome findings.

C. PRENATAL CARE USE

Another risk factor for infant mortality identified by NPHS was poor access to prenatal care. The postpartum survey provides great detail on the timing, frequency and content of prenatal care. Using data from the postpartum survey, Table V.1 shows that NPHS clients were similar to nonparticipants in measures of prenatal health care use. However, while differences were not statistically significant due to small sample sizes, the pattern of prenatal care was generally somewhat better for clients than for nonparticipants in the program. It is important to note that almost no NPHS clients received care in private doctors offices while 11 percent of nonparticipants did, suggesting that NPHS clients were more often served in IHS clinics than nonparticipants.

A large majority of both NPHS clients and nonparticipants received timely prenatal care, with about 75 percent of both groups starting prenatal care in the first trimester of pregnancy, rates that are similar to the other 14 Healthy Start project areas. However, fewer women had adequate prenatal care according to the Kotelchuck Index, which takes into account both the timing of care and the number of visits (Kotelchuck 1994). Apparently women in the Northern Plains start care relatively early, but do not return for prenatal visits as often as clients in other Healthy Start project areas, perhaps reflecting the distance to care and the transportation issues that were identified.

Both NPHS clients and nonparticipants have greater continuity of prenatal care than in other project areas (67.7 percent and 57.4 percent respectively); however, continuity between prenatal care and delivery providers was poorer (46.5 percent and 61.4 percent respectively). This may be a consequence of the structure of the health care system, a discussed in Chapter II, in which women

TABLE V. 1

PRENATAL HEALTH CARE USE
HEALTHY START CLIENTS AND NONPARTICIPANTS
1995

	Northern Plains		Other 14 Projects	
	Clients	Nonparticipants	Clients	Nonparticipants
	PERCENT DISTRIBUTION			
Site of Prenatal Care				
Private Office	2.0	11.1	16.4	31.2
Other	98.0	88.9	83.6	69.8
Start of Prenatal Care				
First Trimester	76.8	73.7	79.9	82.4
Later	23.2	26.3	20.4	17.6
Adequacy of Prenatal Care (Kotelchuck Index)				
Adequate or Better	61.1	57.1	77.2	81.3
Less Than Adequate	39.9	43.9	22.8	18.7
Continuity of Prenatal Care				
Same Doctor Seen Throughout Pregnancy	67.7	57.4	47.2	50.9
Other	32.3	42.6	52.8	49. 1
Continuity of Delivery Care				
Saw Delivery Provider Prior to Delivery	46.5	61.4	47.2	50.9
Other	53.5	38.6	52.8	49.1
Satisfaction with Prenatal Care				
Very Satisfied	93.9	90.7	84.9	81.1
< Very Satisfied	6.1	9.3	15.1	18.9
Perceived Quality of Prenatal Care				
Excellent	26.2	24.6	45.7	41.3
< Excellent	73.7	75.4	54.3	58.7
Number of Women	99	57	1,347	1,355

SOURCE: Healthy Start Postpartum Survey.

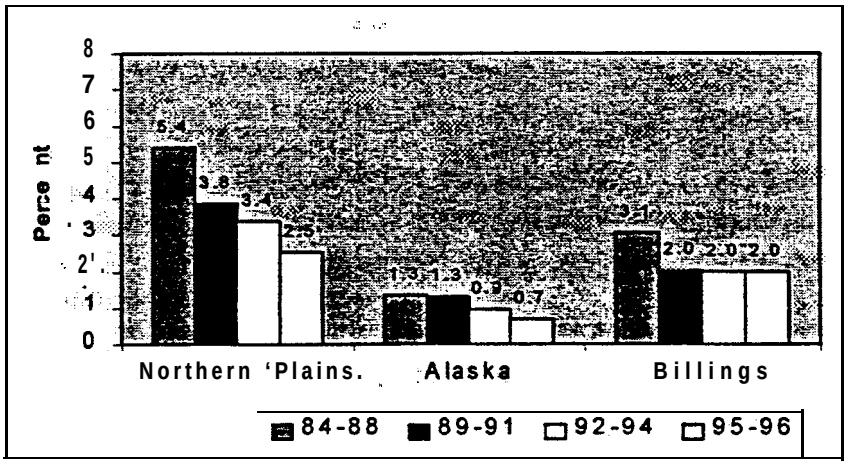
living on some reservations receive care at the IHS prenatal care clinic, but deliver elsewhere.

More than 90 percent of both clients and nonparticipants reported being satisfied with their prenatal care. However, despite these indications of satisfaction with prenatal care, it is curious that only 26 percent of NPHS clients and 25 percent of nonparticipants perceived their care as excellent. These rates are lower than in other Healthy Start areas. Perhaps the expectations of Indian women for high quality care are relatively low.

In addition to these survey results based on a small sample of women from seven NPHS sites, vital statistics data also provide more information on prenatal care for all Indian women in the Northern Plains and in the two comparison areas. Figure V.2 below shows trends in the percentage of births to Indian women who received no prenatal care in the Northern Plains and in the comparison areas.

FIGURE V.2

PERCENT OF BIRTHS WITH NO PRENATAL CARE
1984-1996

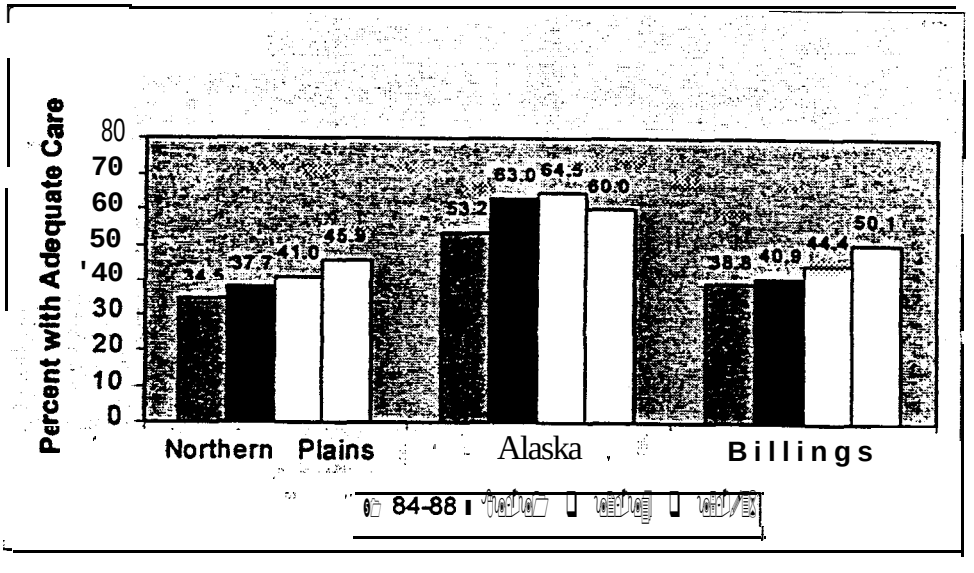


SOURCE: Birth certificates

In the Northern Plains, the percent of births with no prenatal care dropped from 5.4 percent in 1984-88 to 2.5 percent in 1995-96. However, the presence of Healthy Start is not significantly related to the percent of pregnant women with no prenatal care, according to statistical tests. This could be because this measure of prenatal care is crude. The index of adequacy of prenatal care, as discussed above, is a more refmed measure which includes both the timing of prenatal care (whether or not it was in the first trimester) and whether the woman received the full number of visits recommended by the American College of Obstetrics and Gynecology. Figure V.3 below shows trends in the rate of adequacy of prenatal care in the Northern Plains and comparison areas. As shown in the figure, rates of adequacy of care for Indian women are lower in the Northern Plains than in Alaska, and about the same as in the Billings area.

FIGURE V.3

PERCENT OF BIRTHS WITH ADEQUATE PRENATAL CARE
(KOTELCHUCK INDEX) 1984- 1996



SOURCE: Birth certificates

Rates of adequate care have climbed in the Northern Plains during the time period before and during Healthy Start, from 34.5 percent in the 1984-88 period to 45.9 percent in the period of full program operation. According to statistical tests, the presence of Northern Plains Healthy Start was significantly related to the improvement in the adequacy of prenatal care, suggesting a positive program impact.

These results from the birth certificates can be combined with those from the post-partum survey to provide an overall picture of the programs' possible impact on prenatal care use. Taken as a group, the results from both data sources suggest that the program's case management and transportation services were successful at helping women meet their prenatal appointments. The data from the survey, administered in 1995 in 7 sites, show that the major reason for inadequate care in the Northern Plains is that fewer visits are received than are recommended. The rate of early (first trimester) care is higher than the rate of adequacy of care. The survey also suggests that NPHS clients had somewhat higher rates of adequacy of care than nonparticipants. The NPHS services seem to have augmented the IHS prenatal care service system in a way that made services more accessible to pregnant women. From the focus groups, site visits, and survey results it seems likely that the provision of transportation services was the major component of the service package that increased access to adequate care. While these results are positive, the fact that many women still do not have adequate prenatal care, and that rates in the Northern Plains remain lower than in the two comparison areas, means that there is room for more progress in improving the use of prenatal care in the project area.

D. INFANT MORTALITY

The overall program goal for Healthy Start, both in the Northern Plains and in the other 14 demonstration project areas, was to reduce infant mortality by 50 percent during the demonstration period. This was always viewed as a very optimistic goal, given the relatively short time period of the demonstration and the difficulty of addressing this complex problem. Further, in the Northern Plains the major way to reduce infant mortality was always viewed to be through a reduction in the post-neonatal mortality rate, since neonatal mortality rates were already relatively low.

Figures V.4 and V.5 below show trends in infant mortality and post-neonatal mortality in the Northern Plains and the two comparison areas. Infant mortality rates (the number of infant deaths per 1,000 live births) and post-neonatal mortality rates (the number of infant deaths after 28 days per 1,000 live births) declined in both demonstration and comparison areas.

FIGURE V.4

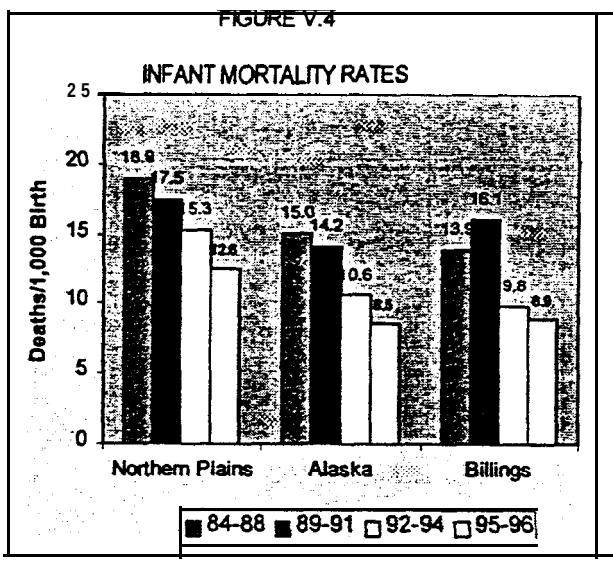
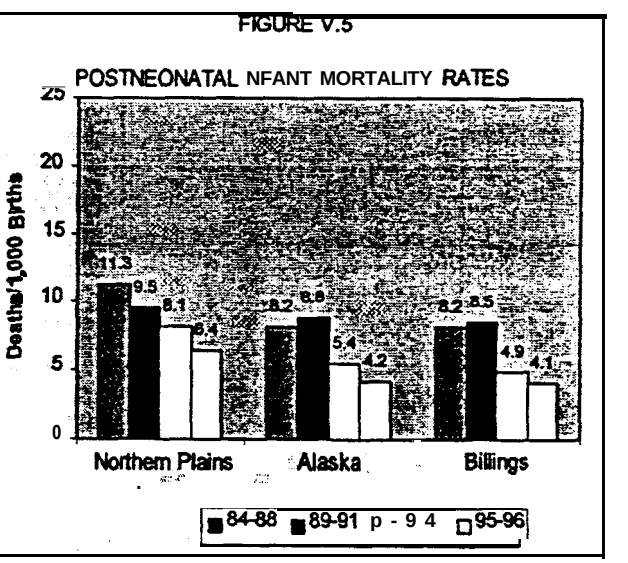


FIGURE V.5



SOURCE: Birth and death certificates

In the Northern Plains, infant mortality rates for Indians dropped from 18.9 deaths per 1,000 in 1984-88 to 12.6 per 1,000 in 1995-96, a 33.3 percent decline. Post-neonatal mortality rates also declined from 11.3 to 6.4 per 1,000 over the same period, an even greater rate of decline of 46 percent. However, declines in the comparison areas also occurred for both overall infant mortality and for post-neonatal mortality. The rates of decline in demonstration and comparison areas were very similar during the period. Consequently, it is not possible to conclude from this analysis that the drop in infant mortality and post-neonatal mortality is attributable to the NPHS project. It is possible that efforts in the comparison IHS areas (for example, infant death review programs, SIDS prevention programs such as the Back to Sleep Campaign, or other factors) led to the comparable downward infant mortality trends in those areas. It is also very possible that positive interim outcomes in the NPHS area, such as reduced adolescent births or improved prenatal care, may lead to reductions in infant mortality over a larger period than can be measured in the national evaluation of Healthy Start.

VI. CONCLUSIONS

The evaluation of the Northern Plains Healthy Start program has shown that, through sustained effort and substantial federal funding, a program to reduce infant mortality can be implemented in rural Indian communities. Several factors contributed to or hampered the success of the NPHS efforts to reduce infant mortality.

A. COLLABORATION AND COORDINATION OF SERVICES

A major success of the Northern Plains Healthy Start demonstration was to show that tribes can collaborate to share resources and learn from each other. This was accomplished through a lengthy process that resulted in an essentially common approach and high levels of participation in planning.

Many of the tribal groups that participated--diverse in geography, culture, language, history, political structure, and administrative approaches--had not worked together closely in the past. Collaboration required patience and a substantial investment of project resources, a lesson that was learned in the other 14 Healthy Start projects (Howell et al. 1997). This need was greater in the Northern Plains because of the culturally diverse and geographically dispersed area. For example, the added administrative cost of frequent meetings was necessary to develop a common approach to such things as case management protocols and data development. This regular communication contributed greatly to successful implementation but also increased administrative costs.

The collaboration across a diverse group of tribes resulted in a political process that, while generally very beneficial, also had negative consequences. For example, a desire to distribute project activities and associated funding across the tribes may have contributed to instability in project leadership and prevented distribution of funds based on the size of the target population. A basic

program infrastructure was developed in each of the 19 sites, even in those with a very small number of pregnant women and children.

The project also fostered a collaboration with outside organizations that had not existed prior to NPHS. The consortium structure encouraged the development of cross-sector links, especially with the state agencies like Medicaid, that also served NPHS clients. The NPHS program provided a strong base from which Indian communities could develop such collaboration, since the program provided services that could enhance the other service programs in their communities. Developing the consortia was initially difficult because of the distance between the various collaborators and some lack of trust. However, real progress was made in overcoming those barriers. This collaboration took time, effort, and resources. It is uncertain whether the collaboration will continue without federal funding.

A final important collaboration was between Indian Health Service programs, the primary health care provider in the Northern Plains Indian communities, and Healthy Start. NPHS sites generally made a conscious effort to develop distinct identities from IHS service programs, and were not usually collocated with IHS services. However, NPHS services were integrally related to IHS services. For example, IHS referred many women to Healthy Start. Also, NPHS services complemented and augmented the transportation and home visiting programs sponsored by IHS. The data show that the adequacy of prenatal care services received by Indian women in the Northern Plains improved during the demonstration period, and that most NPHS clients received prenatal care from the IHS. Consequently, the collaboration between NPHS and the IHS seems to have been generally successful.

B. PROGRAM ADMINISTRATION

The Northern Plains Healthy Start program provided the opportunity for Indian communities to develop an administrative structure and program that was responsive to their own unique needs. This is a very different approach from most federally-funded programs in Indian communities, which generally provide a more prescribed approach.

There were many administrative difficulties in bringing so many individual project sites at such great distance under one administrative umbrella. To give each site the independence to develop its own program and foster high quality programs and accountability, the project used a common basic staff structure. Staff included at least a project coordinator, an outreach/case management worker, and administrative staff to prepare data and reports, ensuring that sites could operate independently and be linked administratively and through data sharing. Without these basic components in all 19 sites, it is unlikely that NPHS would have become fully operational in all locations. Still, NPHS required a greater investment of funds in such administrative structures than was generally true in other Healthy Start programs. Those who want to implement a similar program across geographically dispersed areas should recognize that these higher administrative costs are necessary for successful program implementation.

A major factor in the project's success was the strength in the leadership, at the central project level and in many of the sites. However, high turnover resulted in substantial variation in the pace of implementation and in the quality of programs across the 19 sites and across time.

Data gathering and evaluation proved difficult but beneficial to the operation of tribal programs. A functioning data system allowed the staff and tribal governments to use and share data to improve programs. However, the project's data system was only a qualified success. While NPHS succeeded in collecting a common data set for all 19 locations, the data were incomplete, particularly in

important areas such as transportation services. Also, distance made it difficult to bring staff together for training or to provide them with on-site technical assistance. Developing the data system also took time away from the direct delivery of services.

These difficulties were also experienced by the other 14 Healthy Start projects. One factor leading to difficulties for all projects was the complexity of the data set required by HRSA. Limited staff experience at thecentral office and in each of the sites developing and implementing such a system also hampered development and use of the system.

NPHS developed a unique identity as a separate program from other tribal and IHS initiatives and programs on the reservations that serve mothers and infants. There are both positive and negative consequences to establishing NPHS as a distinct program. For example, this approach allowed for a continued stream of financing for maternal and child health programs that was protected from tribal budgetary decisions. One the other hand, a distinct and separate identity may have limited the potential synergy with other programs.

C. THE NORTHERN PLAINS HEALTHY START SERVICE MODEL

To reduce infant mortality, the NPHS central office attempted to develop a program with a set of common goals tied to infant mortality reduction, but at the same time it allowed individual communities to design their own local goals. Because many of the issues and problems were common, the programs had many common features. In contrast to the other 14 Healthy Start projects, the NPHS program focused on risk factors associated with post-neonatal mortality. However, the program--which relied on outreach/case management provided by lay community workers--had many features in common with those developed elsewhere. This suggests that problems of poverty and associated risks, which the NPHS target population shared with the target

populations of other Healthy Start projects, were as important as factors unique to rural Indian communities (if not more so). However, the rural/frontier setting of NPHS required them to focus heavily on transportation services, integrated with outreach and case management. This emphasis appears to have been an important contributor to improved use of prenatal care services among NPHS clients.

The program model lacked some components, such as a smoking cessation strategy. In fact, the project reportedly had difficulty reducing rates of smoking even among the project staff, who served as role models for the project clients. Smoking is very prevalent in Northern Plains, and changing this behavior will take a broader public education effort than was possible through NPHS.

Analysis of information from the MDS client data system, which records individual encounters between outreach/case management workers and clients, indicates that a relatively low intensity NPHS intervention was implemented. This pattern was confirmed through analysis of post-partum survey data, although women reported more contacts in interviews than were recorded in the client data system, suggesting underreporting in the latter source. Still, regardless of the data source, more than a third of clients reported having only one or two contacts with their case manager during pregnancy; The MDS reported even fewer visits for infants, more than a third of whom did not receive home environmental and risk assessments. Project protocols called for more encounters to produce the desired impact on infant mortality.

Finally, the NPHS service model did not generally incorporate changes to clinical services, but instead it emphasized improved linkages to existing services. It is possible that a strategy that focused on strengthening clinical services would have been more effective in reducing infant mortality, but this would have required a closer link to Indian Health Services providers and possibly sharing funds with those providers. Even with such a strategy, which was adopted by most of the

other I4 Healthy Start projects, project funds were insuffkient to make large changes in clinical services.

D. INCORPORATING CULTURAL VALUES INTO PROGRAMS

The Northern Plains Healthy Start project provides a good model for developing culturally appropriate services in Indian communities and other communities with cultural traditions that differ from the dominant culture. The project began with a strong focus on this issue because one indirect cause of infant mortality was viewed to be the breakdown in Indian traditions and beliefs, which then leads to unhealthy lifestyles.

The focus on incorporating Indian culture affected all aspects of the project's activities. First, the staff were drawn from the communities served by the project, assuring a familiarity with Indian beliefs. Employment of local residents also improved the economy of their communities, a secondary but important objective. All project brochures and other materials were developed by local artists and used Indian symbols and language and reflected other aspects of Indian culture, such as festivals and other tribal events. Discussions of the project's goals and activities were always placed in the context of traditions that foster strong families and healthy lifestyles. For example, discussions about family planning referred to historical child-spacing practices of tribes in the Northern Plains.

Evidence that making Indian culture a focus of the project was a major factor in the project's success comes from anecdotal reports from site visits and focus groups and the outcomes analysis, which showed a significant reduction in adolescent birth rates associated with Northern Plains Healthy Start. Since adolescents have a particular need for strong personal identity as a protection

from poor self-esteem and unhealthy lifestyles, the project may have made its services especially appealing and accessible to that particular group.

E. INFANT MORTALITY REDUCTION

The data shown in this report do not demonstrate a strong impact on infant mortality from the Northern Plains Healthy Start program. This result is similar to preliminary findings from most of the other Healthy Start programs, although those data are still being analyzed at the time of this report. The reasons for the lack of an impact on infant mortality, with the favorable results for both adolescent birth rates and for improved adequacy of prenatal care, are uncertain. The low intensity of the NPHS intervention, the lack of a clinical intervention, or the uneven speed of implementation and quality of programs across time and across sites may provide the major explanation for this finding. Also, programs such as NPHS may be of limited impact in the face of other persistent problems such as poverty, unemployment, and related social problems. Finally, while these factors may explain why NPHS did not have an apparent impact on infant mortality, it is also possible that the time period observed was insufficient to observe such an impact. Site visits 'revealed that the program was not fully implemented until late in the demonstration period. Consequently, data included in this report are for only two years of full program implementation. It is possible that the impact on infant mortality of the project's continued efforts will be observed in later years.

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APPENDIX A

NORTHERN PLAINS HEALTHY START EVALUATION TECHNICAL ADVISORY GROUP

NORTHERN PLAINS HEALTHY START EVALUATION
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APPENDIX B

NORTHERN PLAINS HEALTHY START EVALUATION DATA SOURCES

To obtain the most comprehensive information possible, we collected data through the following activities: review of project documents, site visits and telephone follow-up, a postpartum survey, focus groups, the Healthy Start Minimum Data Set (MDS), and vital statistics data. Because of the relatively small population size at each Northern Plains site and the great distance between sites, it was not possible to collect every type of data at every site. Table B. 1 lists the 19 Northern Plains sites and the data collection methods used in each.

1. Document Review

The reviewed documents include the annual grant proposal submitted to HRSA by NPHS and the proposals submitted by each NPHS site. Each Healthy Start project submits an annual grant proposal, which contains a wealth of information on the community issues surrounding infant mortality, numbers and demographic characteristics of project area populations, and the activities through which the project plans to address infant mortality. In the case of Northern Plains, the central project office prepares its proposal from the individual site proposals it solicits and negotiates with the 19 project sites. Each individual proposal is included in the project's overall annual submission to HRSA.

We reviewed these documents to record the following: population characteristics, community problems and issues surrounding infant mortality, activities planned by each site, site budgets, and the type of staff who implemented the projects.

2. Site Visits and Telephone Follow-Up

Periodic site visits to and telephone follow-up with the projects were the main ways used to collect data for the qualitative analysis of program implementation. All projects were visited in

TABLE B. I

TYPE OF EVALUATION DATA COLLECTION
BY NORTHERN PLAINS SITE

Site	Document Review	Site Visits	Postpartum Survey	Focus Groups	MDS Data	Infant Mortality Data
Cheyenne River Sioux Tribe	✓	✓		✓	✓	✓
Crow Creek Sioux Tribe	✓		✓	✓	✓	✓
Flandreau Santee Sioux Tribe	✓	✓		✓	✓	✓
Lower Brule Sioux Tribe	✓		✓	✓[a]	✓	✓
Meskwaki Tribe in Iowa	✓	✓		✓	✓	✓
Oglala Sioux Tribe	✓			✓[a]	✓	✓
Omaha Tribe of Nebraska	✓		✓	✓	✓	✓
Ponca Tribe of Nebraska	✓			✓[a]	✓	✓
Rapid City Indian Health Board	✓	✓		✓	✓	✓
Rosebud Sioux Tribe	✓			✓[a]	✓	✓
Santee Sioux Tribe of Nebraska	✓		✓	✓	✓	✓
Sisseton Wahpeton Sioux Tribe	✓	✓		✓	✓	✓
Spirit Lake Sioux Tribe	✓	✓		✓	✓	✓
Standing Rock Sioux Tribe	✓	✓		✓	✓	✓
Three Affiliated Tribes	✓		✓	✓[a]	✓	✓
Trenton Indian Service Area	✓	✓		✓	✓	✓
Turtle Mountain Band of Chippewa	✓		✓	✓	✓	✓
Winnebago Tribe of Nebraska	✓	✓		✓	✓	✓
Yankton Sioux Tribe	✓		✓	✓	✓	✓
Total Number of Sites	19	9	7	19 (5 intensive)	19	19

[a]Designates "intensive" sites where on-site focus groups were conducted with demonstration clients and providers Staff from other sites participated in focus groups at a central location.

MDS: Minimum Data Set

January-April 1994. These visits were followed by telephone interviews in April 1995, a second round of site visits in January-February 1996, and a final round of telephone calls in May-June 1997. Structured protocols ensured that the information gathered was comparable across projects.' Key program areas explored included:

- ***Project Structure.*** For example, we examined staff roles, training, retention, and reporting relationships.
- Community ***Context***. These factors include political systems, major community health problems, sources of medical care, and the Medicaid program.
- ***Consortium.*** We examined the structure of the consortium and the role of local (sub-area) consortia.
- ***Public Information and Education.*** We discussed the types of activities, including the media used and the classes offered.
- ***Outreach and Case Management.*** We reviewed the case management process for a typical client, eligibility, and the experience and training of individuals providing services, as well as attending one or more home visits.
- ***Service Delivery.*** We obtained a complete list of the service providers available in the community.

We developed a plan to visit as many Northern Plains sites as possible and to include a diverse range of sites in those we could visit. In the first round, we visited four sites in April, 1994--the Flandreau Santee Sioux Tribe, the Omaha Tribe of Nebraska, the Sisseton Wahpeton Sioux Tribe, and the Spirit Lake Sioux Tribe--following up with telephone contact in the summer of the next year. In the second round, in January 1996 we visited three more sites--the Meskwaki Tribe in Iowa, the Rapid City Indian Health Board, and the Trenton Indian Service Area. Although we had planned to visit the Standing Rock Sioux Tribe at the same time, we canceled the original visit because of

'See Howell, et al. (1994) for more detail on the visits.

inclement weather. As part of other project activities, we made brief visits to the Cheyenne River Sioux Tribe in August 1995 and to the Standing Rock Sioux Tribe in August 1998.

We also made an effort to visit as many different kinds of sites as possible. Included were reservation and urban sites, and sites in all four of the Northern Plains states. Finally, we interviewed central project staff to obtain an overview of all projects. Consequently, the programs we observed and our impressions of their implementation experience are substantially representative of the NPHS project.

3. Postpartum Survey

Women were interviewed for the postpartum survey when they came to clinics run by the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) program. The WIC clinics were convenient places to reach women soon after their pregnancy and to ask them questions about their pregnancy and the Healthy Start program. Both Healthy Start clients and non-participants were interviewed, providing an opportunity to compare the characteristics and experiences of these two groups.

The survey, designed to encompass the range of prenatal and postpartum experiences of a sample of women, covered six general topics: (1) prenatal care; (2) labor, delivery, and postpartum care; (3) use of Healthy Start-funded services; (4) outreach, case management, and home visits; (5) family planning; (6) demographic characteristics; and (7) other life factors. Table B.2 gives greater detail on the questionnaire content.*

*McCormick and Deal (1998) present findings from a comprehensive analysis of the survey data, showing the effect of Healthy Start participation on a wide range of outcomes in the 14 other Healthy Start projects.

TABLE 8.2

HEALTHY START POSTPARTUM SURVEY QUESTIONNAIRE
TOPICS AND MEASURES

Topics	Measures	
Prenatal Care	Month of awareness of pregnancy Month of pregnancy test Month of start of prenatal care Waiting time to first appointment If delayed, the reasons for the delay Source and changes of source of prenatal care Type of provider/site of provider Satisfaction with source Clinical information (e.g., height, blood pressure)	Satisfaction with prenatal care Perceived quality Continuity of provider Number and average duration of visits Health education counseling provided Complications of pregnancy Concordance of language Barriers to prenatal care Health habits before and during pregnancy (smoking, alcohol use. drug use)
Labor and Delivery	Satisfaction with delivery Duration of postpartum stay Duration of neonatal stay Maternal and neonatal complications	Birthweight/gestational age of child Health education counseling Assistance in coordinating postpartum and well-child care
Postpartum Care	Receipt of postpartum checkup Compliance with appointment or reasons why not	Waiting time in office Postpartum counseling
Well-Child Care	Age at first visit Office wait Barriers to well-child care Immunization completion	Rating of infant health Satisfaction with well-child care Mode of feeding Confidence in parenting
Financial Support	Insurance coverage WIC	AFDC Household income
Outreach and Case Management	Number and type of individuals providing help Number of contacts Types of assistance provided	Number of home visits Perceived helpfulness
Family Planning	Use before and after pregnancy Preferred mode Method of payment	Rationale for selecting specific mode Reasons for not using family planning lntendedness of pregnancy
Sociodemographics	Residential stability/homelessness Household composition Employment status Marital status Educational attainment Race/ethnicity	Neighborhood safety Stressful events/daily hassles Social support Religiosity Household income

Developing a sample of WIC clinics for Northern Plains was somewhat more difficult than developing the clinic sample for the other projects. In the other 14 Healthy Start project areas, it was possible to develop a complete inventory of WIC clinics. This inventory was used to develop a two-staged sampling plan, first sampling the clinics and then randomly sampling postpartum women in the clinics. Through this scientific sampling process, it was possible to develop accurate estimates for the full Healthy Start population, using sample weights, in those 14 sites.

In Northern Plains, however, we did not develop a full inventory of WIC clinics or the number of American Indian women served at each because evaluation resources were limited and data on women were not readily available by clinic. In addition, given the many clinics spread throughout the Northern Plains states, project resources also limited the number of clinics at which the survey could be fielded. Thus, it was necessary to conduct the survey in WIC clinics in a selected number of tribal areas. Included in this sample were the WIC clinics for the Crow Creek Sioux Tribe, Lower Brule Sioux Tribe, Omaha Tribe of Nebraska, Santee Sioux Tribe, Three Affiliated Tribes, Turtle Mountain Band of Chippewa, and Yankton Sioux Tribe. The population of these tribes includes about 30 percent of the American Indians in the Northern Plains Healthy Start service area. As in the site visits, we attempted to achieve geographic and cultural diversity in the survey sample. In addition.

The screening portion of the Northern Plains postpartum interview did not exclude women who were non-Indian. The dataset therefore includes eight non-Indian women, four clients and four non-participants.

4. Focus Groups

Focus group, using semi-structured discussion in small groups, provide qualitative data that cannot be obtained from structured surveys. Focus groups were conducted with demonstration participants, providers, and program staff. HRSA reallocated some of the resources originally planned for focus groups in the other Healthy Start projects to conduct a more extensive set of focus groups in Northern Plains. Eighteen focus groups were convened in the summer of 1995. The focus group team, led by Luke Henderson of RIVA Market Research, visited the Lower Brule Sioux Tribe, Oglala Sioux Tribe, Ponca Tribe of Nebraska, Rosebud Sioux Tribe, and Three Affiliated Tribes to conduct on-site focus groups. Participants in these on-site focus groups included providers and Healthy Start clients. The team also conducted off-site focus groups at the quarterly meeting of site coordinators in Aberdeen, and staff from all 19 sites participated in the off-site focus groups. The on-site focus groups gave us an opportunity to increase the on-site presence of the national evaluation to every site (see Table B.1).[3]

5. MDS Data

The Healthy Start Minimum Data Set (MDS) is a standard client-level data set required of each Healthy Start demonstration program. It contains a variety of data for each pregnant woman, postpartum woman, and infant served by Healthy Start. While program guidance stated that the data had to be delivered quarterly to the national evaluator, implementing the data system was more difficult than initially anticipated, and usable data were obtained only for fiscal year 1996 (October 1995-September 1996). This was the year in which Healthy Start was considered to be fully implemented, and consequently good year to examine the program.

[3]Extracts from the focus groups are included in Chapters II and III of this report. For a more extensive write-up and for the focus group protocol, see Devaney et al. (1996).

In Northern Plains, MDS data collection was especially complex because the 19 geographically dispersed sites had to implement a uniform computer system. Despite this diffkulty, the project did succeed in collecting and combining the data from all 19 sites into a uniform system. We could not analyze data for all variables in the MDS because some data were substantially incomplete--in Northern Plains and in the other 14 Healthy Start projects as well (Howell et al. 1997). We did collect substantially complete uniform data on the following variables for the Northern Plains project:

- Project site
- Maternal age
- Marital status
- Education
- Employment
- Number of Healthy Start encounters

The Northern Plains MDS data has two major advantages over the MDS data from the other 14 projects. First, while program guidance required data to be submitted only on infants and pregnant/postpartum women, the NPHS data set includes records for some other individuals. For example, some data were available for male partners, nonpregnant/parenting adolescents, and older children. Also, individual encounter data was usually not available from other projects, but it was available for the Northern Plains.

6. Vital Statistics Data

Data from birth certificates and infant death certificates came from the Indian Health Service (IHS), which periodically obtains files from the National Center for Health Statistics (NCHS). NCHS obtains vital event records from all states in order to create a national research database and to generate routine statistics on vital events. These certificates have geographic identifiers for IHS service areas and race codes for American Indian infants.

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