Wakanyeja Pawicayapi, Inc. and the Case for Direct Billing

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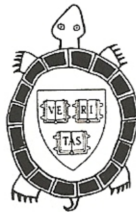

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May 20, 2002

Ethleen Iron Cloud-Two Dogs, Director
P.O. Box 325
Porcupine, SD 57772

Dear Ethleen:

Congratulations on coming thus far with Wakanyeja Pawicayapi, Inc. (The Children First, Inc.). It is a desperately needed service on the Pine Ridge reservation and I applaud you on your efforts to bring this to the attention of the state and federal governments.

Attached is a report containing information that I hope will be helpful with initiating a demonstration project to bill the Center for Medicaid/Medicare (CMS) directly for mental health services to Medicaid-eligible children.

1. Chapter 1 demonstrates the need for youth mental health services on the Pine Ridge Reservation.

2. Chapter 2 shows why the current service model must incorporate more community-based and culturally sensitive approaches.

3. Chapter 3 makes the case for direct billing with CMS. It discusses the inadequacy of the current system of funding and the importance of restoring the federal trust responsibility to tribes. The latter part of the chapter talks provides information on the three possible mechanisms we have encountered.

4. The Appendix consists of articles that I believe may be of relevance to Wakanyeja Pawicayapi, Inc.

I hope that this report will be of assistance to Wakanyeja Pawicayapi, Inc. as you attempt to secure long-term funding. Thank you and the staff for the incomparable experience I had in working on this paper.

Best Wishes,

Julie Ahn

Executive Summary

Wakanyeja Pawicayapi, Inc. (The Children First, Inc.) is initiating a demonstration project to direct bill the Center for Medicaid/Medicare (CMS) for mental health services to Medicaid-eligible children. The immediate goal of this effort is to develop and implement a three-year demonstration project for a direct billing process between Wakanyeja Pawicayapi, Inc. (WPI) chartered under the Oglala Sioux Tribe (OST) and CMS for home/community-based integrated mental health services to children with serious emotional disturbances and their families on the Pine Ridge Indian Reservation. The objective of WPI is to demonstrate that direct billing for intensive case management/care coordination using a wraparound and Lakota traditional healing model can be cost-effective and will demonstrate an effective government to government relationship between the tribe and the federal government. Once this has been shown, it is hoped that long-term funding for WPI will be secured.

Wakanyeja Pawicayapi addresses youth with serious emotional problems through a wrap-around service delivery model. The program is spiritually based on traditional virtues and values of the Lakota people. The wraparound feature provides much better collaboration between mental health agencies, schools, healers, and other services. Funding for WPI, from the Substance Abuse Mental Health Services Administration (SAMSHA) will expire in 2005. Due to the growing number of tragedies resulting from insufficient mental health services for children and adolescents at Pine Ridge and the difficulty that the State of South Dakota and IHS are having in meeting this need, it is the desire of OST and WPI to obtain a direct government to government relationship. This effort is in the early stages, involving monthly conference calls amongst the stakeholders – WPI, OST, CMS, Indian Health Service (IHS), and the State of South Dakota (State).

It is important to realize that while the growing number of tragic incidents among children and adolescents at Pine Ridge is partly due to insufficient funds at IHS and State level, an increase in funding alone to raise the number of service providers will not address the entire problem. Even when mental health services are available, they are underutilized or used reluctantly by American Indian families. Research has shown a need for tribally run services that incorporates culturally sensitive methods. In the long term, decreasing the prevalence of children with severe mental health illnesses will help break the cycle of mental distress in future generations on Pine Ridge.

Introduction

This paper is intended to be a resource for the Director of Wakanyeja Pawicayapi, Inc., Ethleen Iron Cloud-Two Dogs, in her efforts to initiate a demonstration project to direct bill the Center for Medicaid/Medicare (CMS) for mental health services to Medicaid eligible children. It can also be used as a reference for all other participants (including CMS, Indian Health Service, State of South Dakota) that are/will be involved in this endeavor.

Chapters 1 and 2 talk about the mental health needs of adolescents on the Pine Ridge reservation. They call for:

- More service providers;
- a community approach; and
- a more culturally sensitive model.

The Wakanyeja Pawicayapi, Inc. model fulfills these requirements by using a community based and culturally sensitive program.

Chapter 3 demonstrates how the current system of funding inadequately meets the mental health needs of the Pine Ridge Reservation and why a direct billing system is required to restore the federal trust responsibility of the United States. The latter half of the chapter provides information about three possible mechanisms through which direct billing with CMS can occur.

The Appendix is a compilation of related articles that may also be used as a reference.

Chapter 1: The Need for Services

Although American Indian communities share similar challenges and strengths, they are not a homogenous group. Every tribe has a unique culture, language, set of traditions, and spiritual practices. Most notably, some reservations are wealthier than others. Thus, poorer tribes have a greater need for services addressing poverty.

Poverty is directly related to mental health. Pine Ridge is located in Shannon County, the poorest county in the country. The median income is $2600 and 69% of the residents live below the poverty line. Because poverty is associated with higher rates of mental illness, Pine Ridge has a great need for mental health services. How to deliver these services to this reservation in the best way possible is the issue we need to address.

Moreover, individuals within tribes and tribes in general vary in the degree to which they have assimilated, become bicultural, or maintained traditional culture, language, and spiritual practices. These factors affect how tribal children express their mental distress, how parents or other caretakers seek care, and what forms of mental health systems are most acceptable to various tribal populations. In this context, the most important role for child and adolescent psychiatry today may be to offer consultation and technical support across the broad arena of health and human services that strengthen the safety net for Indian children's mental well-being. What is most clear is that no uniform mental health delivery system can be developed or implemented universally for reservation populations, which means that there is a great need for informed, community-specific assistance.

The Youth Population

The American Indian population is remarkably young. The median age is 20.4 years as compared to the median age of 30.3 years the general U.S. population.[1] Over 38,000 with 20,000 under 22.

The few studies that have examined population based data for the prevalence of mental disorders for Indian children conclude that the American Indian youth experience significantly higher rates of mental health problems than other United States youth groups. Most analysis has focused on the more severe mental health problems – suicide, homicide, alcohol, and drug abuse. Extremely high rates of suicide among reservation-based Indian youth are the most tragic manifestation of the psychosocial burden that befalls Indian youth. Virtually all the current statistics and studies have found Indian suicide to be a behavior of younger persons. Of particular concern is the not-so-rare occurrence of suicide among 10- to 14-year-old Indian children. On Indian reservations, suicide rates peak among 15- to 24-year-old youth, whereas in the general United States population suicide rates are relatively steady between 20 and 60 years of age and then increase with age.[2] The vast majority of all American Indians who commit suicide are between the ages of 15 and 39. Sioux suicides are generally between ages 16 and 33.[3]

This is in striking contrast to the general United States population, in which suicide incidence increases as age increases.

Homicide is a growing mental health problem for Indian children. Over the last two decades, homicide rates for American Indians have been approximately two times the national average. Homicide patterns differ for American Indians compared with the general United States population in two ways: firearms are used less often, and family members or acquaintances are more often the perpetrators among American Indians. Generally, Indian Health Service (IHS) areas with high suicide rates also have high homicide rates.[4]

Unintentional injuries are the leading cause of years of production life lost (YPLL) for Indian people. In youth 1 to 20 years of age, unintentional injuries are the leading cause of death.

The excessive rates of homicide, suicide, and injuries among Indian youth and young adults are both symptoms and causes of mental distress. The burden of grief in Indian communities is large and the impact is community-wide. Because many reservation communities are isolated from outside contacts, and are tight-knit with rapid communication networks, children and families are forced to share the tragedies of extended family members and neighbors. This seems to concentrate the effects of bad news within the community. In seeking opportunities to turn challenges into opportunities, one can see how these same insulated communication networks can be used to work positively in community-based interventions.

The Pine Ridge Reservation has a higher rate of diabetes, alcoholism, heart disease, road accidents, and suicide than the Native American population as a whole. The rates are also higher than comparisons with all other groups. Infant mortality and suicide rates are higher than national averages, and the tuberculosis rate is eight times higher. Alcoholism affects nearly every family on the reservation. The Lakota have the lowest life expectancy of any group in America – 45 years according to the Indian Health Service. Children and youth ages 5-19 are assaulted in greater frequencies than any other age group. More than 36% of all assaults occur to children and youth. The overwhelming majority of these involve substance abuse.[5]

It is clear that Pine Ridge residents share a common set of needs that have been identified over time in researching Native American communities. At the most basic level, acute needs exist in terms of many of the essentials of life: housing, transportation, employment, physical safety, as well as other areas of life impacted by the high levels of poverty.

Within families, the care of children has been greatly impacted by poverty, high levels of alcoholism, and inconsistent parenting. The National Indian Child Welfare Association (NICWA) has estimated that between 75 and 90 percent of all Native American child welfare cases are substance abuse related. The ensuing child neglect is often associated with accidents experienced by children. Native American children die

almost three times more often from accidents than other children, and the majority of these accidents are alcohol related.[6]

Documentation exists from many sources on the education deficits of many Native American children due to a variety of factors. These factors include the quality of the schools, the lack of expectations and family support for education, and the emotional issues many young Native American people bring to their educational experience. High dropout rates exist among high school students, along with high numbers of early pregnancies. These appears to be an overall feeling of hopelessness among Native American youth, leading to higher than average suicide rates, and more generally, higher rates of substance abuse and unemployment.

Research at the University of Colorado Health Sciences Center on psychiatric disorders among Native American adolescents concluded that a higher percentage of Northern Plains Indian adolescents manifest significant psychiatric symptoms that warrant treatment. Disorders include disruptive behavior, substance abuse, depression, anxiety, and mood disorders. Unfortunately, there is "an appalling lack of treatment resources in and near reservations."[7] Further, the transition from childhood to adolescence seems to place Native American children at increased risk for emotional disorders, compared to children of other races. Deterioration in academic achievement occurs at the same stage of development as non-Native American children, and suicide rates are two to three times higher.[8]

Circles of Care Report

This report provides a description of the mental health and related services on the Pine Ridge reservation. In sum, the mental health and related services on the reservation are provided by 15 direct service agencies, 18 schools, and 8 traditional healers. The numbers of mental health and related services by sector are:

- Developmental disabilities 3
- Mental Health 3
- General Health/Hospitals 1
- Substance Use 3
- Social Services 4
- Juvenile Justice 1
- Traditional Healers 8 (estimate)
- Self-Help/Advocacy groups 1
- Education 18 schools
- Other- Department of Social Services 1

The majority of these services are located in Pine Ridge, Porcupine, or Kyle. Four districts, Lacreek, Eagle Nest, Medicine Root, and Pass Creek, have been referred to as the forgotten areas because of their remoteness and low populations. Youth from these districts would need to drive an hour or more, one way, to access mental health services in Pine Ridge. In addition, road and weather conditions in the Plains may preclude travel.

Social workers and other service providers may be willing to provide home visits to remote areas but funding is not always available for them.[9]

The Casey Native American Child Welfare Needs Assessment Project

This report recognizes the need for mental health services provided to Native American children in their own homes. It also sees a need for better integration and coordination among the various family services and agencies. Unfortunately, while there are many examples of committed creative individuals in the Native American communities throughout the U.S. who have developed culturally relevant programs and initiatives to address the needs of Native American people, they are lacking on the Pine Ridge reservation.[10]

- *Wakanyeja Pawicayapi (The Children First), Inc.* addresses young people with serious emotional problems through a wrap-around service delivery model. This program is spiritually based on traditional virtues and values of the Lakota people. The wraparound feature provides much better collaboration between mental health agencies, schools, healers, and other services. It receives funding from Substance Abuse and Mental Health Services Administration (SAHMSA) and is a project under the Oglala Sioux Tribe.[11]

- The *Oglala Nation Tiospaye Resource and Advocacy Center (ONTRAC)* program provides case advocacy for children involved with Indian Child Welfare Act (ICWA) proceedings, as well as services for children.

- *Pine Ridge Multidisciplinary Team* goals involve training in identification of child abuse and neglect, providing parenting classes, addressing reservation-wide reporting policy on child abuse and neglect, and building an interagency network to protect children and preserve families.

- *The Casey Family Programs (TCFP)* has been involved since 1995 in a transformation process, which fosters the coordination and expansion of services to children and families into an inclusive and culturally appropriate model system of care. TCFP is contributing to the development of a more integrated child welfare system across many entities and is rooted in Native American culture. The transformation project is aimed at the development of a centralized community of care agency.

- *Head Start* programs serve to educate and care for preschoolers and provide support services for parents and families.

Of these services, The Children First, Inc. is the only community based mental health program. The NICWA indicates that effective programs in child welfare Native American communities are those characterized by strong outreach, coordination among service providers, and an "in-depth understanding of cultural considerations of clients."

These reports show that there is 1) a lack of mental health services and providers on the reservation and 2) a need for a community-based culturally sensitive program.

Chapter 2: The Need for Community and Culture

To understand the lives of Indian children and their families an ecologic approach is necessary to define the confluence of factors that have precipitated mental health risks, and to identify the indigenous strengths within Indian communities on which to build or enhance existing mental health systems. Child and adolescent psychiatrists and allied mental health professionals can play the following roles: (1) as direct service providers; (2) as consultants who can aid in the development of more comprehensive, cost-efficient mental services that reflect that reflect tribal understanding of mental health; and (3) as consultants to the community regarding the public health policies that affect the mental health of American Indian children and families. If we are successful, children and families with mental health problems will receive high-quality mental health care, and communities will create their own policies and practices that promote mental health and prevent the serious psychosocial problems that currently affect American Indian children.

Problems Faced By American Indian Children and Their Families

Indian children, especially those on reservations, appear to be at higher risk than other United States racial or ethnic groups for mental health problems, including depression, substance abuse, suicide, and homicide. These mental health problems can be viewed as an outcome of various historical and contemporary factors. First, a long history of federal policies and treaties has resulted in the loss of tribal lands and degradation of Indian political and economic systems, languages, traditions and cultures, in essence destroying the social fabric of Indian communities. Second, but not unrelated, day-to-day life for Indian families is difficult. Indian children grow up in communities with high rates of unemployment, poverty, outdated and often irrelevant educational systems, and stressful home lives plagued by broken nuclear and extended family networks. Faced with the magnitude of compounding environmental pressures, it is understandable that American Indian children and their families exhibit the kinds of problems that they do. In short, reservation life is a microcosm of what is known about the effect of adverse life circumstances on communities, families, and children.[12]

Although federal support for local control of health and mental health programs is very positive, outside technical assistance in health planning, delivery, and management remains critical to Indian communities, as they are still challenged by a paucity of Indian peoples skilled in health professions, particularly mental health, health policy, and management. Thus, mental health care providers and institutions across the country who have concerned themselves with the welfare of Indian tribes have increased responsibility at this time to help tribes transition to more culturally relevant, cost-efficient, and effective community-based mental health systems that can be locally run and operated.

The long-term success of technical or academic partnerships in reservation settings today depends on tapping local strengths, inspiring greater tribal autonomy, and melding existing western and traditional resources to service Indian youth.

The IHS remains the primary entity responsible for Indian health care. In the federal provision of health services, mental health services have been and continue to be the larges unmet need with the poorest stream of funding. The Mental Health Programs Branch (MHPB) of the Indian Health Service remains the agency most directly responsible for providing mental health services for federally recognized tribes. Its financial resources are inadequate, however, particularly based on the identified needs of American Indian children. In fiscal year 1988, the per capita budget for mental health services for the IHS service population was less than $12 per year. Less than 9% of the IHS mental health professionals had training to work with children and adolescents, even though youth less than 20 years of age accounted for about 43% of the service population. The provider-to-patient ratio is equally discouraging: in 1988 there were 0.43 trained mental health professionals to serve every 10,000 children. In four of the 12 IHS service areas, there are not any child or adolescent mental health professionals. In 1997, the total IHS mental health budget was $33 million, or $23 per person.[13]

Due to this need and lack of IHS funding, other agencies – federal, state, tribal, private foundations and national nonprofits – are attempting to meet the mental health care needs for Indian nations. As a result, reservation mental health services today consist of a patchwork of IHS resources, tribally initiated health programs, local Native healers and traditional groups, the BIA, urban Indian health programs, and national, state, and local service agencies. Philosophical and historical differences among these organizations contribute to extremely fragmented and uncoordinated systems of mental health care on tribal lands. Adding to the fragmentation, non-Indian mental health professionals working on Indian reservations have a high turnover rate due to isolation, difficult work conditions, and cultural differences. Furthermore, a paucity of trained Indian mental health professionals to serve their communities stands in the way of greater tribal autonomy in providing mental health services. A recent IHS Office of Health Program Development paper indicated that only 3% of tribal health staff work in mental services.[14]

Tribal Programs

There are some promising reports of programs developed by local Indian peoples to prevent mental health problems and to promote general well-being on their reservations. An Office of Substance Abuse Prevention technical report (1990) reviewing existing tribal programs linked to behavioral health clinics reveals significant tribal creativity in employing paraprofessionals outreach workers and integrating local traditional approaches in health promotion programs. An Office of Technology Assessment (OTA) report cites increasing collaboration between health care providers and traditional healers, and the promising use of traditional approaches, such as the sweat lodge, to assist emotional well-being and act as adjuncts to clinical care.[15,16]

Approaches to integrating western and traditional approaches are still exceptions to the rule. As the OTA report acknowledges, "The IHS has not fared well in past efforts to admit traditional Indian psychotherapeutic interventions into daily operations."[17] The dilemma is, western medical acceptance of the benefits of traditional Indian approaches to mental health promotion is essential to expedite improvements in tribal children's mental health status.

Traditional Indian concepts of health different significantly from the western understanding. To be more effective, tribal mental health care delivery systems must reflect Indians' care-seeking behavior, which is predicated on Indian belief systems about mental health and health in general. IHS service utilization data over the past four decades suggest that western medical approaches to the causes of and treatments for physical illnesses have been increasingly accepted and employed by Indian people (i.e., emergency care, obstetrics, dialysis treatments). However, diagnosis, treatment, and prevention of mental illness remain either unaddressed or more solidly in the realm of traditional care. While there is a lack of available western psychiatric or psychological resources for Indian people, those services that do exist are frequently underutilized.[18] In a study of American Indian and white youth in Appalachia, rates of service use were lower for American Indian than for White youth with public insurance. Even among children with a current psychiatric disorder, only about one American Indian child in seven had seen a mental health care professional in the past 3 months, in comparison with one in four White youth with a disorder and public insurance. Specialized child mental health services were scarce on the reservation, and these services, whether on or off the reservation, were used only reluctantly by families.[19]

It is important to make the connection that while the growing number of tragic incidents among children and adolescents at Pine Ridge is partly due to insufficient funds at IHS and the State, an increase in funding alone, thereby raising the number of service providers, will not address the entire problem. Even when mental health services are available, they are underutilized or used reluctantly by American Indian families. Thus, the need for a tribally run service that incorporates culturally sensitive methods.

It may be that the traditional Indian understanding of mental illness as the imbalance of multiple and interrelating social, economic, genetic, environmental, and spiritual factors is a more powerful influence on how Indian people seek care on reservations today than sheer access to clinical services. For example, a tribally initiated suicide intervention team composed of traditional healers and indigenous outreach workers in one Southwestern tribe was more frequently accessed than IHS behavioral health clinical staff. There were important differences in how the modes of traditional and western care were delivered. The traditional healers were lifetime residents of the reservation, were on call 24 hours a day, and were dispatched by the local tribal police department. When called, they made immediate home visits and consulted with the entire family, including extended family members. All family members were included in the treatment. The consultation was generally in the Native language and could include prayer and spiritual ceremonies that were aimed at bringing the entire family back into balance. The healers would stay as long as was deemed necessary, which could be

several hours. In contrast, the clinical mental health providers were generally non-Indian and lived off the reservation. They provided counseling during set clinical hours for limited blocks of time. Clinical counseling sessions were individualized and other family members were inadvertently shut out. The clinic itself was in poor condition, was overused by tribal members in need of detoxification, and, in the authors' estimation, was a difficult place to visit, especially for a child or adolescent.[20]

Other Models Needed

The most common model is a crisis-oriented outpatient service. Current models employed by western child and adolescent psychiatry to identify children or adolescents at high risk for suicide may work for Indians, but at this time there are insufficient data to be certain. Because suicide is much less frequent among non-Indian youth, using these models in community-based prevention programs has been considered to be an ineffective use of resources. The constellation of risk factors and the high rates of suicide among Indian youth, however, suggest that a more systematic community-based public health approach might be very effective in reducing the suicide rate among Indian children. Indeed, many of the tribally initiated programs against youth suicide epidemics that can be found in the literature reflect holistic preventive models, and often employ and circular model for illustrating a continuum of care to protect individuals, families, and communities.[21]

Spiritual Empowerment

Tribes have utilized traditional healing ceremonies which have a natural therapeutic and cathartic effect. The *inipi* (Lakota purification ceremony) is spiritually, physically, and emotionally healing. Participants are able to share their pain and pray for the good of others as well as their own individual healing. Many individuals maintain sobriety only after they resume or begin regular involvement in traditional spiritual practices. Siver and Wilson (1999) describe the therapeutic psychological effects of the inipi for Vietnam veterans with post-traumatic stress disorder (PTSD).[22]

Self-determination

Simple explanations or solutions for American Indian suicide and other self-destructive behavior are not possible. Any attempt to deal with self-destruction among tribes with a high incidence of suicide, alcoholism, and violent death would require efforts to bolster the existing sociocultural system and especially the family. In the past, many of the traditional functions of some American Indian societies have been usurped by Western culture or taken over by the federal government. This has led to social disintegration that needs to be reversed by various means.

Emphasis needs to be placed on accepting an active role in deciding or influencing the future. Government programs have made some efforts towards encouraging American Indians to be active in policy making concerning education, community programs, and some other areas. These efforts need to be continued. The

increased self-determination of American Indians should serve to provide gradual stimulus for restructuring societies in which this is needed. It could affect all levels of these societies and permit new roles, norms, and values to emerge.

In the interim, it is necessary to treat those who have serious mental health needs. Emphasis in these programs should be not only on therapy for the clients but also on assistance and training of indigenous workers to perform mental health services on their own and determine program direction. Generally, treatment performed by indigenous tribal members in a traditional context is probably more successful and advances the idea of self-determination.[23]

Life in the United States has been characterized by a great deal of change and resulting ambiguity of social meaning and values, with a corresponding rise in national statistics on suicide. Some American Indian groups are examples of this type of phenomenon, undergoing forced and rapid social change that results in symptoms of self-destruction. Meaningfulness of life and a strong social system to provide direction and minimize stress are necessary for any group of people.

Examples of Indian Community-Based Traditional Programs

- The Apache Tribal Guidance Center was initiated by and receives its largest grant (40% of the budget) from the Northern Arizona Comprehensive Guidance Center. The Bureau of Indian Affairs contracts for 25%. Indian Health Service covers 30% and local monies supply the remaining 5%. With this money, they field a staff of 20 and offer a complete line of services with the exception of inpatient facilities. One of their special programs offers services to "families at risk" in which each family is treated by a small team of workers who handle both individual and group problems.[24]

- The Indian Children's Program, part of the Office of Mental Health programs at IHS headquarters in Albuquerque, NM, has a large, diverse professional staff supplied from several sources. It provides diagnostic, treatment, and consultation services throughout large sections of the country and offers a model of effective interaction with emotionally handicapped children. On the other hand, the mental health/social services program of the Cheyenne River Sioux, Eagle Butte, SD, with a small staff, interacts with 75 to 100 different agencies per month.[25]

- Part of the Mental health program on the Flathead reservation in Montana (a blend of Indian Health Service and tribal employees) can be found in a mountain retreat of teepees and camp sites some 20 miles from St. Ignatius. Here, through dancing, story telling, and traditional practices handed down from elders, services are provided away from the clinical setting, balancing crisis intervention with the promotion of mental health education and Indian lore that has sustained the tribe for many years.[26]

- The Tohono O'odham (Papago) Indian tribe runs and controls a fully indigenous mental health program (See Appendix). The program functions in a crisis intervention model, but a whole range of disorders and ages are seen. Traditional Medicine Men and Women are often used as consultants, as are some professionals. The main problems now are child sex abuse, suicide, and abuse of drugs among youth are prominent problems. In its 17 year history, the service believes that it has helped bring into focus the pervasive and destructive influence of the widespread use of drugs and alcohol. The program has coped with, and perhaps prevented, many suicides and has counseled with and supported many teenagers with school problems, delinquents, and individuals caught up in family programs and family disruptions. The program shows that a technical-professional service field can be administered with basic technical services provided by indigenous mental health workers. Its services are rendered with cultural understanding and sensitivity and has reached many people in need. Further, the program demonstrates the skill and ability of the indigenous persons in such helping roles. The O'odham mental health workers are also role models for other O'odham people. They demonstrate that O'odhams can perform relevant technical services for their people and demonstrate a meaningful way of gaining economic self-sufficiency.

- The White Earth Suicide Intervention Team (WESIT) was created in 1990 in response to an extraordinarily high rate of suicide attempts and completions on the White Earth Reservation. The all-volunteer team, comprised of IHS and Tribal Mental Health staffers, concerned community members, and clergy and spiritual leaders, provides many services previously absent or lacking, including 24-hour support for the attempter and the family, encouragement of voluntary or involuntary hospital admission for all attempters, referrals to mental health services and suicide education. With regards to funding, WESIT is low cost because it is a fully volunteer.

Chapter 3: The Federal Trust Responsibility

Recounting the history of tribal mental health services is important to illustrate the political and legal barriers that still preclude meaningful collaboration among existing agencies who share the responsibility for delivering mental to tribes. It also demonstrates that until now few formal efforts have been aimed at helping tribes gain control or receive appropriate training to develop and manage their mental health systems. The lack of coordination between local service agencies and the local Indian communities will require that mental health consultants be involved at the earliest stage of planning so that appropriate and relevant mental health care can be provided.

This chapter will demonstrate that the inadequacy of the current services, with a shifting of responsibility to the state as a result of changes in the health care system, calls for direct billing with the federal government.

Sources of Health Care for American Indians

American Indians and Alaska Natives access health care services through a variety of sources depending on eligibility requirements. These services include both Indian health programs and other sources of health care.

Indian Health Programs

The federal government has a trust responsibility to provide health care for American Indians from federally recognized tribes. That responsibility is based on numerous treaties, court decisions, and legislative acts. For many years, the Indian Health Service was the primary source of health care for American Indians. However, due to recent changes in legislation and the health needs of the population, the Indian health care system consists of three major types of health programs.

The Indian Health Service (IHS). An agency of the United States Department of Health and Human Services (DHHS) that provides a comprehensive health service delivery system for American Indians and Alaska Natives who are members of federally recognized tribes. Patients access this system of hospitals, clinics, and health programs on or near reservations for direct health care services, or are referred to non-IHS providers for specialty care under the Contract Health Services program if they meet eligibility requirements. The IHS provides health services for approximately 1.4 million of the nation's two million American Indians and Alaska Natives.[27]

Tribal Health Programs. The Indian Self Determination and Educational Assistance Act of 1975 (P.L. 93-638) allows federally recognized tribes to contract with the federal government to assume management of part or all of their health care programs (Title I). And since the amendments to P.L. 93-638 in 1988, tribes can compact with the federal government to assume more independence in the management of their health programs (Title III). American Indians and Alaska Natives can receive health care at these tribally managed facilities also if they meet eligibility requirements. Approximately one third of all American Indians and Alaska Natives eligible for IHS care receive their health care directly from tribal health programs under P.L. 93-638.[28]

Urban Indian Health Programs. Currently 34 urban Indian programs receive federal funding under Title V of the Indian Health Care Improvement Act to provide health care services for American Indians and Alaska Natives who reside in urban areas and who meet eligibility requirements. Even though estimates indicate that over half of the American Indian population in this country lives in urban areas, less than one percent of the Indian Health Service budget is dedicated to urban Indian health programs. The services provided in these programs are heavily dependent of other sources of funding, such as Medicaid reimbursement, grants, and contracts.[29]

Collectively, these three programs are referred to as the I/T/U system.

Other Sources of Health Care

American Indians and Alaska Natives may be eligible for other sources of health care based on their income, work records, health status, ability to purchase private insurance, or tribal/community resources. These other sources of health care include:

Medicaid. American Indians and Alaska Natives can obtain health services under the Medicaid program if they meet eligibility requirements, which vary from state to state. Medicaid is intended to provide basic health care service to the poor and needy, which includes such groups as recipients of AFDC/TANF, SSI (blind, disabled), and pregnant women and children who meet income requirements, usually below 133 percent of the federal poverty level, although some states may set this level higher. The scope of services provided and eligibility requirements vary from state to state, depending on whether the state participates in a "program (1915b)" or "research and demonstration (1115)" waiver. American Indians and Alaska Natives must apply for benefits under the Medicaid program, and must visit health care providers who are approved for reimbursement by the Medicaid program.[30]

State Child Health Insurance Program (SCHIP). The Balanced Budget Act of 1997 created SCHIP to allow states to offer health coverage to uninsured children of working parents who have family incomes too high to qualify for Medicaid coverage and who cannot afford private insurance. States are allowed to raise eligible income levels for their Medicaid programs and/or can create a new low-cost insurance program. Eligibility and access to these programs varies from state to state, and American Indians and Alaska Native children must enroll in these programs and meet eligibility requirements.[31]

Medicare. American Indian and Alaska Natives either can obtain health services under the Medicare program if they are at least 65 years old, disabled, or have the diagnosis of end state renal disease. Individuals must apply for this coverage and may be required to pay certain deductibles (Part A: hospitalizations) and premiums (Part B: physician, outpatient, and ancillary services) unless otherwise covered by Indian health programs. Many American Indian and Alaska Natives do not purchase Part B coverage because of the cost and their belief that they are already covered by the IHS.

Private Insurance/Managed Care. American Indians and Alaska Natives who work can purchase private medical insurance policies offered by their employers and can therefore access hospitals and clinics outside the Indian health system. In addition, some tribes with income from economic activities now purchase private insurance for their employees or members. Choices regarding private insurance options often include managed care options, such as PPOs and HMOs, and individuals, tribes, and Indian health programs must deal with issues related to coverage, reimbursement, referral authorizations, and administrative requirements when choosing to interact with a

managed care plan. Managed care plans are now options in the Medicaid and Medicare systems as well.

Traditional Indian Medicine. American Indians and Alaska Natives often still use traditional Indian medicine and practices to promote their overall health and well-being. The use of traditional Indian medicine varies by tribe and individual preferences, and patients often do not tell their health care providers about their use of traditional medicines and practices. The role of traditional Indian medicine in the Indian health care system has not been well-defined, although some programs have considered reimbursement for traditional healers.

Summary of Key Indian Health Legislation

A number of important legislative acts reaffirm the federal government's trust responsibility to provide health care for American Indians and Alaska Natives and have created many of the key components of the current Indian health care system[32]

The Snyder Act of 1921. The Federal Government agreed to provide health care and other services. Congress was given authority to appropriate money from "time to time" for the "relief of stress and the conservation of health" of American Indians. This Act is significant because it was the first legislation by Congress that provided funding for American Indian health; however, it establishes this funding as an "appropriation," not an entitlement.

The Miriam Report in 1928. Recommended removing health care from auspices of the Bureau of Internal Affairs.

The Transfer Act of 1954. This Act transferred the responsibility for Indian health from the Bureau of Indian Affairs to the Public Health Service that led to the creation of the Indian Health Service in 1955. This Act allowed for a significant expansion of the number of staff, facilities, and preventive services to meet the needs of the rapidly growing population of American Indians and Alaska Natives in the United States.

The Indian Self-Determination and Educational Assistance Act of 1975 (P.L. 93-638). This Act allows federally recognized tribes to assume the management of any or all of their health programs and services form Indian Health Service. Title I of this Act allows tribes to enter into contracts with the federal government to manage all or part of their health programs with continued federal oversight. Title III of this Act allows for compacting, which gives tribes greater independence and control in the management of their health programs (Tribal Self-Governance). Subsequent amendments have clarified the contracting and compacting process. The 1988 amendments led to the removal of financial barriers. The 1990 amendments resulted in the removal of additional barriers. And the 1994 amendments let to compacting in health care. The number of tribes entering into contracts and compacts is increasing, and a recent survey of elected tribal leaders by the National Indian Health Board demonstrated a clear trend towards contracting and compacting in the future, according to predictions by tribal leaders.[33]

The Indian Health Care Improvement Act of 1976 (P.L. 94-347). The purpose of this act was to increase the number of Indian health professionals, to eliminate deficiencies in health status and resources, to improve health facilities, to increase access to health services with Medicare/Medicaid, and to provide health care services for urban Indians. It is credited with markedly improving health care services for American Indians in the last 20 years. The last major reauthorization was in 1992, and the next reauthorization is due in the year 2000. It is the basis for a large amount of funding for specific Indian health programs, including the Indian Health Service Scholarship Program and Urban Indian Health Programs. The original Indian Health Care Improvement Act in 1976 included the following:[34]

INDIAN HEALTH CARE IMPROVEMENT ACT 1976 : P.L. 94-437

Title I: Indian Health Manpower – Indian Health Professions Scholarship Program
Title II: Indian Health Services – expanded services in patient care, field health, dental care, mental health
Title III: Indian Health Facilities – construction of hospitals, health centers/stations
Title IV: Access to Health Services – Indian health facilities eligible for Medicare and Medicaid reimbursement
Title V: Health Services for Urban Indians – funding for urban Indian programs
Title VI: American Indian School of Medicine – feasibility study only
Title VII: Reporting to Congress

The most recent authorization in 1992 included the following:[35]

INDIAN HEALTH CARE IMPROVEMENT ACT AMENDMENTS OF 1992 : P.L. 102-573

Title I: Indian Health Professionals – changes to the scholarship program
Title II: Indian Health Service – health promotion and disease prevention services
Title III: Indian Health Facilities – evaluate impact of closure of facilities, other
Title IV: Access to Health Services – Medicare/Medicaid payment issues
Title V: Health Services for Urban Indians – continued grants to urban programs
Title VI: Organizational Improvements – IHS Director appointed by President
Title VII: Substance Abuse Programs – programs for alcohol and substance abuse treatment and prevention
Title VIII: Miscellaneous – specific items
Title IX: Technical Corrections

Recent Changes within the Indian Health Care System

Declining Resources for Indian Health

The most significant factor impacting the Indian health care system has been declining resources for health care services. Congressional appropriations for the Indian Health Service have not increased over the past few years, and the actual amount of funding available for health care services has decreased when the data is adjusted for inflation and population growth. A recent financial analysis of DHHS data by the

National Indian Health Board demonstrated the changes in per capita expenditures on Indian health over the past few years when adjusted for these factors.

Increased Reliance on Third Party Reimbursements

This decline in congressional funding for Indian health care has forced Indian health programs to increasingly rely on third party reimbursements to attempt to maintain their current level of services. Indian health programs also must actively encourage their eligible patients to enroll in Medicaid, Medicare, and private insurance/managed care plans with Indian health facilities as approved providers in order to maximize third party collections. Reimbursements from these sources are providing an increasing proportion of the overall budgets for Indian health programs. For some urban Indian health programs, 40 percent of the budget comes from Medicaid reimbursement.[36] If Indian health programs cannot meet the administrative requirements or become approved providers in these programs, then they lose an important source of revenue for their health care budget.

Federal Downsizing/Reorganization

In response to decreasing resources for health care, federal downsizing efforts, and changes in the overall health care system, the Indian Health Service is currently undergoing a major reorganization intended to transfer functions, staff, and resources to the local levels. In 1995, the Indian Health Design Team was changed with the task of restructuring the Indian health care system with tribal and local community input. The Indian Health Design Team has released two reports with recommendations for restructuring the Indian Health Service, and these recommendations include:

- A streamlined headquarters organizational structure with major reductions in offices, divisions, staff, and core functions, and
- An area office restructuring that includes determining key support services that will remain at the area level and a transfer of all other functions, resources, and management/program authorities to the local levels (I/T/Us).

The headquarters restructuring has been implemented over the last two years with the following changes:

- Consolidation of the eight major offices into three offices: the Office of the Director, the Office of Public Health, and the Office of Management Support;
- Consolidation of divisions and branches from 132 to less than 50;
- A reduction in headquarters staff by over 200 positions;
- A plan to decentralize control of resources to the area and local levels, with 17 percent of current funding to remain under headquarters management.

The area office restructuring is currently in progress; however, many serious issues have been raised, including:

- Continued inadequate funding for Indian health programs,
- Capacity of local I/T/U programs to assume more responsibility and risk in the management of their health programs,
- Continued ability of the downsized Indian Health Service infrastructure to support Indian health programs, and
- Concerns over a reduction or undermining of the federal trust responsibility to tribes with downsizing/restructuring,
- Concerns over the impacts on Urban Indian health programs, which are seriously underfunded.

Increased Contracting and Compacting by Tribes

As previously stated, the number of tribes choosing to manage their own health programs, under contracts or compacts through P.L. 93-638 and its amendments is increasing. In 1996, $282 million was transferred to tribes through self-governance compacts/annual funding agreements, and $332 million was transferred to tribes under self-determination contracts. The total Indian Health Service budget was approximately $2 billion during that year. The Indian Health Service budget will support tribally managed health programs in the next three to five years.[37]

Under compacting, tribes can receive more of their "share" of the overall Indian Health Service budget to manage their health programs by claiming the funds to assume administrative functions that were previously managed by the headquarters or area level. The amount of these "shares" is determined through a formula, and as each tribe establishes their compacts and annual funding agreements, these shares are taken from the overall Indian Health Service budget. The transfer of these administrative funds has created concerns over potential negative impacts on the rest of the Indian health system, as the funding for many administrative functions within the Indian Health Service, especially at the headquarters level, has decreased. However, this transfer of resources and responsibilities to tribes is consistent with the overall Indian health design team restructuring to transfer resources and functions to the local levels.[38]

Recent Changes in the U.S. Health Care System Affecting Indian Health

In addition to the changes within the Indian health system, recent changes in the U.S. health care system have also created challenges for tribes and Indian health programs, such as:[39]

Transfer of Health and Welfare Program Authority from the Federal Government to the States

Recent legislation has transferred the authority for certain health and welfare programs to the states. The states gain the authority and flexibility to change the structure of these programs, including eligibility requirements and levels of service. This

transfer or "devolution" of these resources to the states has created new challenges for the Indian health system. Tribes and Indian health programs must now interact and develop new relationships with states to ensure that American Indians and Alaska Natives receive the services for which they are eligible. State programs that impact significant numbers of American Indians include the following:

- *Medicaid.* Many American Indians are eligible for these services based on low income levels and disabilities and may use these services as a primary source of health care or as an occasional alternative to the Indian health care system. Indian health programs can benefit from the Medicaid program because of the potential for reimbursement of services delivered to Medicaid beneficiaries in Indian health facilities. However, there is much variation from state to state in the eligibility requirements, levels of services, and reimbursement requirements, with no national standard to ensure equal protections for American Indians and Alaska Natives. In addition, under the Medicaid waiver program, states are allowed greater flexibility in the management of their Medicaid programs, and many states include managed care programs as options for their beneficiaries. A recent study by the National Indian Health Board reviewed the practices of 9 state Medicaid Managed Care Programs, and found a wide variation in practices, including the following:[40]

    - Differing approaches to tribal consultation,
    - Unclear role of HCFA (now CMS) in the waiver review process,
    - Enrollment issues, including Fee-for-Service vs. Managed Care options,
    - Payment for "off-plan services" in Indian health facilities,
    - Reimbursement issues involving clarification of the HIS/HCFA MOA payment options,
    - Dual eligibility for Medicare and Medicaid,
    - Concerns over cultural competence of services,
    - Participation of IHS, Tribal Health Programs, and Urban Indian Health Programs as providers in Medicaid managed care plans, and
    - Continuity of care issues, including choice of providers and access to specialists.

- *State Child Health Insurance Program (SCHIP).* States can now offer health insurance to the uninsured children of the working poor by expanding their Medicaid program income-eligibility levels, or by creating new insurance programs. The SCHIP was recently authorized by the Balanced Budget Act, and funding has been distributed to the states. While many American Indians and Alaska Native children are potentially eligible for this program, programs vary from state to state. American Indians are likely to benefit from state programs that raise eligibility levels for their Medicaid programs, but may not enroll in state programs that create new insurance programs requiring cost-sharing (premiums, copays).

In addition, few states have consulted with tribes in the design of their SCHIP programs to ensure coverage of eligible American Indian children. In the National Indian Health Board Medicaid Managed Care study, only four of nine states consulted tribes in the SCHIP planning process.

- *Welfare to Work Grants Program.* The Balanced Budget Act provides block grants to states to create programs that help welfare to recipients obtain employment within 24 months of receiving benefits under the state Temporary Assistance for Needy Families (TANF) Program. Tribes are eligible for these funds if they already operate a TANF or other employment program. However, tribes with high unemployment rates may have difficulty finding employment for their recipients and meeting the requirements for the block grants. Technical amendments to the welfare reform law attempt to address

Federal and state jurisdictional conflicts

The status, rights, and benefits of Indian people are poorly defined in respect to state and federal programs. An often stated misconception held by other government agencies is that the Indian Health Service (IHS) has the primary responsibility to care for the health needs of Indian people. Yet, according to Congress, the IHS is viewed as a residual resource. Too frequently, Indian patients and families suffer while governmental agencies dispute the question as to whose responsibility it is to respond.[41]

Several states have contorted their responsibility for Indian health care, especially for clients 16 years of age or requiring involuntary commitment. The Bureau of Indian Affairs (BIA) and the IHS have often disagreed over client responsibility. Until recently, The National Institute of Mental Health funding also appeared to feed this type of problem.

The fact remains that most Indian people look to and expect the federal government, through the IHS, to make provision for their health needs under circumstances that do not allow for sufficient funding or authority.

Challenges to the Federal Trust Responsibility

Many tribal leaders have raised concerns about the impact of these changes in the Indian health system on the federal trust responsibility to provide health care for American Indians and Alaska Natives. Some are concerned that these changes are steps towards "termination" or a weakening of the federal trust responsibility. The federal trust responsibility and the "government-to-government" relationship between Indian tribes and the federal government are certainly being tested in the following circumstances:[42]

- An IHS budget that does not include adjustments for population growth, inflation, and mandatory costs over time may result in less funding available for direct services;

- Federal downsizing and restructuring of the Indian Health Service that could potentially result in a reduction of support services for local I/T/Us;
- Increased compacting and contracting by tribes could potentially result in fewer resources for the remaining IHS programs;
- Transfer of authority for Indian health programs to the I/T/Us could lead to a perceived reduction in the obligation of the federal government;
- Transfer of authority for health and welfare programs to the states means tribes and Indian health programs must interact and negotiate with states, but does not reduce the federal trust responsibility for oversight;
- Inadequate tribal consultation by government agencies and states creates the potential for policies that do not meet the needs of American Indians and Alaska Natives;
- Increased role of managed care in Indian health may lead to reduced levels of services and less control over the health care of American Indians;
- Incorrect assumptions that all tribes are rich from gaming revenues, create the idea that federal assistance is no longer needed;
- Some members of Congress continue to question the federal trust responsibility and advocate termination.

In his opening statement before the Senate Indian Affairs Committee Budget Oversight Hearing on the FY 1988 Budget request, Dr. Michael Trujillo, the Director of IHS, stated that "the trend toward downsizing the role of the Federal Government cannot be used to abrogate historic treaty and trust obligations." Given the dramatic changes in the Indian health system over the past few years, efforts are needed to ensure that the federal government continues to honor its responsibility to provide health care for Indian people.

There are currently three mechanisms that may qualify Wakanyeja Pawicayapi, Inc. to obtain direct billing with CMS. These are

- ❖ Early and Periodic Screening, Diagnostic, and Treatment (EPSDT),
- ❖ Home and Community-Based Services Waivers, and
- ❖ Targeted Case Management Services.

The following pages provide brief summaries regarding each service.

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