Forty Years in Partnership: The American Academy of Pediatrics and the Indian Health Service

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ABSTRACT

Fifty years ago, American Indian and Alaska Native children faced an overwhelming burden of disease, especially infectious diseases such as pneumonia, meningitis, tuberculosis, hepatitis A and B, and gastrointestinal disease. Death rates of American Indian/Alaska Native infants between 1 month and 1 year were much higher than in the US population as a whole, largely because of these infectious diseases.

The health care of American Indian/Alaska Native patients was transferred to the Department of Health, Education, and Welfare in 1955 and placed under the administration of an agency soon to be known as the Indian Health Service. The few early pediatricians in the Indian Health Service recognized the severity of the challenges facing American Indian/Alaska Native children and asked for help. The American Academy of Pediatrics responded by creating the Committee on Indian Health in 1965.

In 1986 the Committee on Native American Child Health replaced the Committee on Indian Health. Through the involved activity of these committees, the American Academy of Pediatrics participated in and influenced Indian Health Service policies and services and, combined with improved transportation, sanitation, and access to vaccines and direct services, led to vast improvements in the health of American Indian/Alaska Native children. In 1965, American Indian/Alaska Native postneonatal mortality was more than 3 times that of the general population of the United States. It is still more than twice as high as in other races but has decreased 89% since 1965. Infectious diseases, which caused almost one fourth of all American Indian/Alaska Native child deaths in 1965, now cause <1%.

The Indian Health Service and tribal health programs, authorized by the Indian Self-Determination and Education Assistance Act of 1976 (Pub L. 93-638), continue to seek American Academy of Pediatrics review and assistance through the Committee on Native American Child Health to find and implement interventions for emerging child health problems related to pervasive poverty of many American
Indian/Alaska Native communities. Acute infectious diseases that once were responsible for excess morbidity and mortality now are replaced by excess rates resulting from harmful behaviors, substance use, obesity, and injuries (unintentional and intentional). Through strong working partnerships such as that of the American Academy of Pediatrics and the Indian Health Service, progress hopefully will occur to address this “new morbidity.”

In this article we document the history of the Indian Health Service and the American Academy of Pediatrics committees that have worked with it and present certain statistics related to American Indian/Alaska Native child health that show the severity of the health-status disparities challenging American Indian/Alaska Native children and youth.

FORMATION OF THE IHS
Health services for AI/AN are a federal responsibility that dates to the early 19th century, the result of a series of treaties executed between the federal government and various tribes. The federal agency responsible for providing these health services was the Department of Interior until 1955, when the responsibility was transferred to the Department of Health, Education and Welfare as the Division of Indian Health. Soon, however, the organization was renamed the Indian Health Service (IHS), its present designation. The IHS is a national program for federally recognized Indian tribes. Here we discuss the special relationship between the AAP and the IHS to address important health needs of AI/AN children and their families.

AAP INVOLVEMENT IN INDIAN HEALTH
In the 1960s, the AAP became involved in Indian health as a result of overlapping interests between IHS officials and AAP leaders. One of the earliest priorities of the first IHS director, James R. Shaw, MD, a remarkable visionary, was maternal and child health. Emphasis on maternal and child health advanced further when Carruth Wagner, MD, who succeeded Dr Shaw as director, made a presentation on Indian health at the 1964 spring session of the AAP. Dr Wagner impressed the delegates with his description of the urgent need for pediatricians in the IHS and practice opportunities in health programs serving the AI population (C. J. Wagner, Some Opportunities for Pediatricians in Government Agencies, unpublished manuscript [located in the AAP archives], 1964). This presentation opened the door for development of a partnership that could focus specific attention on the overwhelming health needs experienced by AI/AN infants and children and to provide an opportunity for the IHS to draw assistance and advice from the AAP on standards and improvements in AI/AN child health care. At that time, generalists, who often entered the service with only 1 year of postgraduate training, provided virtually all health care for Indian children. At the time, only 21 pediatricians were in the professional staff serving all the national IHS programs. With AAP assistance, by 1970, the IHS had begun to recruit more pediatricians at many of its sites.

A sentinel event in this collaboration was a 1965 letter from Harris Riley Jr, MD, to the editor of Pediatrics announcing the formation of a new AAP committee on Indian health in response to a request from Dr Wagner (AAP archives on Indian health). Dr Riley noted the remarkable improvement in the health status of AI/AN children after 1955: a 36% decline in overall infant mortality and 43% decline in postneonatal mortality among Indians. Significant observations noted by Dr Riley included:
• The AI/AN neonatal mortality rate of 19.2 per 1000 live births was comparable to the rate of 18.7 per 1000 live births for all races; however, AI/AN postneonatal mortality was at least 3½ times that for all races.

• Most postneonatal deaths were a result of “respiratory disorders, communicable diseases, and diseases of the gastroenteric type.”

• Diseases that affected Indian children, such as trachoma and kwashiorkor, were nearly extinct in the general population. The prevalence of trachoma was as high as 60% among some southwest Indian communities.

This first AAP committee, referred to as the Advisory Committee on Indian Health, focused its early attention on the above-noted disparities. Under Dr Riley’s leadership, the AAP began to make regular on-site visits of IHS facilities and programs and provided reports to the IHS leadership with specific observations and recommendations. The AAP’s activities soon took on a dual focus: (1) providing evaluation, consultation, and advice to the IHS and tribal providers regarding Indian child health and (2) federal advocacy for increased attention and resources necessary to improve AI/AN infant and child health.

The 1970s

The AAP’s consultative functions were the result of pediatricians who were willing to volunteer time and attention and visit, examine, and study conditions in remote IHS facilities. This on-site field work, funded under contract with the IHS, began in the 1970s and has been the hallmark of the AAP’s attention to AI/AN infant and child health. Reports and recommendations generated from these site visits were provided for the director of the IHS.

The on-site field work continues to be a central part of AAP activities. The IHS selects the sites, and planning for visits begins 6 to 9 months in advance. Team leaders make direct contact with key professionals and tribal leaders at the sites to discuss the purpose of the visit and learn about important local needs and child health issues. The consultation visit requires at least a full day, including a tour of the facility and meeting and listening to child health workers, administrators, and tribal leaders. An approved continuing medical education presentation by an AAP member is included in the visit agenda. Efforts to maintain contact by telephone over the following year or two are part of the overall consultative process.

The AAP noted inadequate services to AI/AN children and lagging improvements in health status in the 1970s that were attributed to insufficient funding for needed services and programs. However, although health-status trends among AI/AN children clearly showed significant improvements, it became clear that chronic and behavioral health issues were now more evident and excessive when compared with the general population. In addition, wide regional differences in health status, generally related to levels of poverty, existed among AI/AN children.

After Dr Riley’s tenure as chairman ended in 1972, Sidney R. Kemberling, MD, provided leadership for the committee from 1972 to 1977, and Alice H. Cushing, MD, led the committee from 1977 to 1980. The importance of AAP advocacy during the 1970s is well illustrated by testimony offered by Dr Kemberling and Philip Calcagno, MD, chairman of the Georgetown University Medical Center Department of Pediatrics during congressional hearings on the proposed Indian Health Care Improvement Act of 1976 (Pub L. 94-437). 4

Dr Kemberling described the many activities of the AAP, including committee meetings held in local Indian communities and urban areas, and provided first-hand information about local conditions. Such first-hand knowledge, unique to the AAP committee, provided an authoritative voice in advocating for improved conditions. Dr Kemberling provided an in-depth review of each of the several titles of the proposed legislation, pointing out special concerns related to Indian health. The extent of his knowledge of the various services provided by the IHS was impressive. It is not surprising that considerable attention was given to the need for additional health professionals. One recommendation was to make scholarships available beginning in high school rather than in college. He suggested that the resulting 12 years of payback would have obvious value.

Additional testimony was offered by Edward Zimmerman, MD, of the American College of Obstetricians and Gynecologists (ACOG). Such joint efforts between the 2 professional organizations proved to have important synergistic effects.

Dr Calcagno, a highly respected pediatrician and founder of the academic Georgetown University Department of Pediatrics, provided similar testimony on behalf of the AAP at hearings before the Subcommittee on Indian Affairs of the US House of Representatives Committee on Interior and Insular Affairs. He reiterated the points made at the previous Senate hearings, again reviewing the many needs of Indian children and importance of the proposed legislation. The testimony offered at these hearings attests to the impact that the AAP had on ultimate passage of this legislation with its many revolutionary provisions. Such advocacy proved to be a very important adjunct to the committee’s field activities and its IHS consultations.

Following the example set by the AAP, the ACOG established their Committee on American Indian Affairs in 1970. Chairman Edward Zimmermann, MD, and the AAP Committee on Indian Health forged a cooperative effort to address issues of Indian maternal and child health and health care needs. Collaboration with the
ACOG led to creation and implementation of yearly maternal/newborn workshops in Denver, Colorado, for IHS and tribal maternal and child health professionals. These well-attended workshops provided basic information and skills for physicians from remote sites who faced the need to provide acute obstetrical and neonatal care with minimal resources and, often, for quick referral for specialty care. Together these committees sponsored a study of maternal and infant health care of Indian and Native Alaskan Americans and submitted a report on July 15, 1974. This work set newer directions for the IHS to meet serious health needs of AI/AN mothers and children (unpublished report [available in the ACOG archives], 1974).

The 1980s
In 1980, William B. Weil Jr, MD, assumed the duty of chairman of the AAP Committee on Indian Health. One of the most significant developments in the 1980s was the tightening of resources available to the growing AI/AN populations. Budgetary constraints experienced by the IHS resulted in diminution of support for the committee. This and other factors influenced a decline of the AAP’s attention to Indian health, leading the AAP to decommit the Committee on Indian Health in December 1981 and transfer its activities to the Committee on Community Health Services, ending Dr Weil’s tenure as chairman.

In 1986, the AAP’s involvement in AI/AN child health rejuvenated. Through additional interest and funding support from the IHS, along with the farsighted leadership of Kenneth Fleshman, MD, FAAP, and David Kaplan, MD, FAAP, the Subcommittee on Indian Health was formed under the AAP Committee on Community Health Services. At an April 1986 meeting in Albuquerque, New Mexico, the subcommittee identified as priorities chronic illnesses, adolescent pregnancy, drug and alcohol abuse, and high injury rates among AI/AN children and youth. The AAP strengthened its involvement in Indian child health issues and made its resources more available to pediatricians and other child health professionals serving IHS and tribal health programs. This increased attention led to a progression of actions that, once again, resulted in a full committee dedicated to AI/AN child health issues.

The 1990s
As the 1980s drew to a close, Lance Chilton, MD, assumed greater responsibility along with Dr Kaplan, and served as chairperson of the Subcommittee on Indian Health until 1993. He held this position through subsequent committee reorganizations, as chairperson of the Provisional Committee on Native American Child Health, and, finally, as chairperson of the CONACH. After this productive term of leadership, David Grossman, MD, assumed CONACH leadership in 1999, followed by George Brenneman, MD, in 2003.

During this decade, the most extensive development in Indian health was the progression of Indian self-determination to the new concept of Indian self-governance. As the name implies, tribes authorized by Congress to enter into compacts with the IHS gained even greater authority to design and implement programs for their members.

As more tribes took advantage of the authority to manage their own health programs and services, the AAP expanded its scope to include reviews and evaluations of tribal and urban AI/AN health programs. Health status and services among Indian youth in Bureau of Indian Affairs boarding schools also received substantial attention.

Through its renewed committee work in the late 1980s and through the 1990s, the AAP continued to focus on changes in health services delivery and the continuing need for more pediatricians on clinical staffs at Indian health facilities. Since the Committee on Indian Health began its work in 1965, the total number of pediatricians serving AI/AN communities had increased from 21 to ∼150 in 2005 (S. Holve, MD, FAAP, Chief Clinical Consultant for Pediatrics, IHS, written communication, 2005). AAP efforts have assisted pediatricians in the Indian health programs to achieve a strong and respected voice in the development and implementation of programs and services for Indian children throughout Indian country. From its earliest involvement, the AAP has continued to provide strong support to IHS pediatricians, who often work in isolation in very remote locations. In recognition of important contributions that pediatricians and other child health professionals make to AI/AN child health, in 1995 the AAP established the Native American Child Advocacy Award, awarded each year at the annual AAP National Conference and Exhibition.

HEALTH-STATUS CHANGES
Over the past 40 years, changes in the health status of AI/AN children have been remarkable. Although it is not possible to directly measure the effect that the AAP has had on these improvements, the consensus is that its various efforts have been important and helped to make a difference.

Infant Mortality
In 1965 the AI/AN infant mortality rate in the IHS service area was 39 per 1000 live births compared with 24.7 for all races in the United States.* The average AI/AN infant mortality rate in the IHS service area from 1996 to 1998* (latest IHS data available) had decreased

* Statistical data from the IHS use a 3-year moving average to smooth year-to-year changes for a relatively small population. Data from 1996–1998 is the most recent general AVAN data available from the IHS and for the AI/AN populations served by the IHS.
to 8.9 per 1000 live births compared with 7.2 in 1997 for all races in the United States. General AI/AN data, which include AI/AN outside the IHS service area, from the National Center for Health Statistics (NCHS) show an AI/AN infant mortality rate of 8.3 per 1000 live births for 2000 compared with 6.9 for all races.

It is interesting to note that the AI/AN neonatal mortality rate of 15.8 per 1000 live births in 1965 was less than the rate (17.7 per 1000 live births) experienced by all races in the United States. AI/AN neonatal mortality has and continues to be lower or equal to neonatal mortality rates experienced in the general US population. The AI/AN neonatal mortality rate from 1996 to 1998 was 4.4 per 1000 births compared with 4.8 per 1000 births in 1997 for all races in the United States. NCHS data from 2000 show an AI/AN neonatal mortality rate of 4.4 compared with 4.6 per 1000 live births for all races in the United States.

A different picture presents for AI/AN postneonatal death rates. The AI/AN postneonatal mortality rate for 1965–1967 was 23.2 per 1000 live births compared with the rate of 7.0 per 1000 live births for the general population. Postneonatal deaths resulting from respiratory causes were similar between AI/AN and US general populations, but AIs/ANs experienced 7 times the mortality rate for digestive diseases, 2.4 times the rate for "accidents" (unintentional injuries), and 5.3 times the rate for infectious diseases. The excess burden of postneonatal infant mortality experienced by the AI/AN population continues to remain a significant disparity. In 1987, Honigfeld and Kaplan noted rates of AI/AN postneonatal infant mortality in the IHS service area that were twice those of the white US population. The most recent IHS data show that this is still true, with AI/AN postneonatal infant mortality in 1996–1998 at 4.4 per 1000 live births compared with 2.0 per 1000 live births in 1997 for the white US population. In 2000, general AI/AN data show a postneonatal mortality rate of 3.9 compared with 2.3 per 1000 live births for all races in the United States. Over the years, the leading cause of postneonatal infant mortality in the AI/AN and white US population shifted from infections to sudden infant death syndrome.

**Child Mortality**

In 1967, 13.9% of all AI/AN deaths were infant deaths, and 6.8% were children 1 to 14 years of age, compared with 4.3% and 1.6%, respectively, for the same age groups in the general US population. The leading causes of death among AI/AN children 1 to 14 years of age were motor vehicle accidents, other accidents, and pneumonia and other infections at rates 2.2 to 3.3 times the rates among all races in the United States. Infectious diseases other than pneumonia were responsible for 22.2% of all deaths among AI/AN children 1 to 14 years of age compared with 15.6% for the general US population.

IHS data from 1997–1999 show that infectious causes of death, other than pneumonia, were responsible for <1% of all deaths of AI/AN children 1 to 14 years of age. These causes continued to be 1.7 to 2.2 times that of all races in the United States. General mortality data from the NCHS for all AI/AN children 1 to 14 years of age for 2002 reveal rates that are 1.1 to 1.4 times the rates among all races in the United States. Recent mortality data from the IHS for the IHS service area are unavailable at this time, but many IHS health professionals allude to persistent, very high mortality rates resulting from injuries, especially motor vehicle injuries.

**CHALLENGES**

Conditions that adversely affected the health of AI/AN children early in the collaboration between the AAP and IHS responded well to vaccines, antibiotics, sanitation and safe water, improved transportation, and application of medical technology in remote communities. Emerging chronic diseases and conditions related to risk behaviors and lifestyle choices, often associated with poverty, now confront AI/AN communities. The underlying challenge to federal Indian health programs, other public and private agencies, and tribal communities is to find appropriate and effective ways to meet the health needs experienced by AI/AN communities and reduce continuing disparities. Although these health problems and disparities likely have always been present, they have come to the forefront in recent years as access to effective prevention and treatment of acute conditions has become more available. Remaining health disparities affecting many AI/AN communities include:

- approximately double the postneonatal mortality rate as compared with white infants (primary causes are sudden infant death syndrome, congenital anomalies, and injuries);
- lower-respiratory conditions;
- overweight, obesity, and type 2 diabetes; and
- overwhelming mortality and morbidity rates, 3 times those of all races in the United States, resulting from unintentional and intentional injuries.

Social and economic factors contribute to these disparities and become barriers to the effectiveness of health programs and services for children. Pervasive poverty persists among many Indian communities. Some Indian counties in the United States are among those with the highest poverty rates. Indians also experience the highest poverty rate of any ethnic group, with unemployment rates often at 50% to 80%. Second, demographic changes in the AI/AN population have an impact on the access to health care by AI/AN children and their families. More than 50% of the AI/AN population now live in urban counties, where they do not have full access to the IHS delivery system; President
Bush has proposed cutting all support for urban Indian programs as part of his 2007 budget. The IHS system was designed primarily to meet the health needs of AIs/ANs living on or near reservations. A third factor relates to funding levels for AI/AN health programs and services that have not kept pace with health care cost inflation and AI/AN population growth (~1.7% per year).15

COMMENTS/CONCLUSIONS

At a time of greater need for collaborative efforts among health programs, providers, and services, the ongoing AAP-IHS collaboration serves as a successful model. Forty years ago, the AAP accepted the opportunity to become involved as consultant and advisor in the health and health care issues of AI/AN children. Since its involvement in 1965, the health status of AI/AN children has exhibited remarkable improvements. The AAP has played a very important role and had the privilege to be involved in an advisory and consultative capacity regarding programs and services that had a direct impact on the health of AI/AN children. This opportunity has strengthened over the past 40 years into a revised and stronger partnership involving a highly motivated group of pediatricians and other child health professionals dedicated to bringing the best health care possible to AI/AN children and their families. Just as leaders in the past addressed health challenges that confronted AI/AN children, opportunities now remain for the AAP to chart support for ongoing partnerships with IHS, tribal, and urban health programs to address persistent health disparities affecting AI/AN children.

The need for vision is just as strong today as it was in the earliest days of the AAP-IHS partnership. The AAP needs to forge partnerships with tribal leaders to find paths that will bring the resources of the AAP to tribal and urban programs serving AI/AN children outside the direct responsibility of the IHS. This is already beginning. The CONACH has collaborated in advocacy efforts with the National Indian Health Board and in consultation on school health in Indian boarding schools with the Bureau of Indian Affairs. Site reviews now regularly include urban Indian programs. Expansion of these efforts in addition to involvement with review of programs on or near reservations will need to be strengthened to enable the AAP to bring its resources to help meet the health needs of all AI/AN children, youth, and their families.

Contributions made to Indian health by the AAP may not be measurable, but, without question, it made, and continues to make, important contributions through consultation and advocacy. As a nonfederal organization, the AAP is able to speak forcefully and authoritatively to Congress on many issues of AI/AN child health. This is particularly important, because Congress appropriates funds for the operation of the IHS on a yearly basis. It serves as a model for successful collaboration between a professional organization and a federal agency. This success depends to a large degree on the willingness of pediatricians to donate time for travel to remote sites, examine problems, and make recommendations for improvement at local and national levels. The success also depends on the willingness of IHS practitioners and administrators to provide attention and modest resources and especially depends on the receptivity of IHS practitioners to critique and evaluation. It also illustrates the importance of professional organizations comprehensively educating themselves in the complicated fields of Indian health and Indian health services. Only in this way could the AAP have provided itself the basis on which to speak with authority.

Finally, another important development, and one to which the AAP must be given recognition for its foresight and efforts, is the ascendency to leadership positions by pediatricians of American Indian descent such as Bernadette Freelander-Hyde, MD, FAAP (Navajo), James Jarvis, MD, FAAP (Seneca), and Joey Bell, MD, FAAP (Lumbee), who are past and current members of the CONACH. That these and other physicians of American Indian descent have emerged as leaders in Indian health is additional testimony to the importance of the AAP as it completes its 75th year, during 40 of which it has been devoted to betterment of the health of AI/AN infants and children.

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