

Department of Health and Human Services

**OFFICE OF
INSPECTOR GENERAL**

**ACCESS TO KIDNEY DIALYSIS
SERVICES AT INDIAN HEALTH
SERVICE AND TRIBAL FACILITIES**



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E X E C U T I V E S U M M A R Y

OBJECTIVE

To determine the extent to which American Indians and Alaska Natives (AI/AN) have access to kidney dialysis services at Indian Health Service (IHS) and tribal facilities.

BACKGROUND

A member of Congress expressed concern about AI/ANs' access to kidney dialysis services and requested that the Office of Inspector General conduct this evaluation.

The incidence rate of end stage renal disease (ESRD) for AI/ANs is the second highest among all racial/ethnic groups. Nationally, the increasing incidence of diabetes and obesity and an aging population have contributed to the rise in chronic kidney disease. Among all racial/ethnic groups, AI/ANs have the highest rates of diabetes (12 percent) and obesity (39 percent).

Chronic kidney disease occurs when the kidneys gradually lose function. The disease generally progresses in stages; at the final stage—ESRD—patients have almost complete loss of kidney function and require dialysis or a kidney transplant to survive. For patients with ESRD, kidney dialysis replaces the function of the kidneys in removing wastes and excess fluid from the blood.

Medicare is the largest payer of ESRD costs, which include costs for dialysis treatment and kidney transplantation. Under the Medicare ESRD Program, individuals who suffer from ESRD and require regular dialysis—including AI/ANs—are eligible for Medicare, regardless of age. Typically, IHS and tribal facilities refer AI/ANs diagnosed with ESRD and in need of dialysis to a Medicare-certified dialysis facility for treatment. Dialysis facilities must be Medicare certified to qualify for Medicare or Medicaid payment. Medicare-certified facilities may or may not be affiliated with a tribal or IHS health care facility.

Our findings are based primarily on a survey of IHS and tribal facilities that provided health care services from January 2008 to June 2009. The survey response rate was 85 percent (506 of 598 facilities). We also conducted onsite interviews at a sample of 98 facilities and at all IHS Area Offices.

FINDINGS

Only 20 of 506 IHS and tribal facilities reported that dialysis services are provided at their facilities; most reported that other facilities provide these services.

In surveys and interviews, 20 of 506 IHS and tribal facilities reported that they provide kidney dialysis services at their facilities. Of these 20 facilities, 3 have tribally operated dialysis facilities and 17 provide dialysis services through an independent for-profit or nonprofit company. Approximately two-thirds of the facilities that do not provide dialysis services (337 of 486 facilities) reported that other facilities provide these services to their patients. Typically these other facilities are neither IHS operated nor tribally operated.

The remoteness of IHS and tribal dialysis facilities can affect the availability of services and create hardships for AI/ANs.

For the 20 communities that have IHS or tribal dialysis facilities, the facilities' remoteness can affect service delivery. The demands of getting to and from facilities can reduce patients' quality of life. Providers highlighted that their patients endure hardships getting to and from dialysis. Transportation, the time involved in travel and treatment, and weather conditions create barriers that affect patients' health.

Most IHS and tribal facilities do not provide kidney dialysis services because of a lack of resources and small patient populations.

Seventy-two percent of the facilities that do not provide dialysis (352 of 486 facilities) reported that they lack the funds, staff, and/or space to provide the services. Eighty percent of IHS and tribal facilities (389 of 486) reported that they do not provide dialysis because the services are outside the facilities' capability. IHS reported that there are too few dialysis patients in most of these communities to support a dialysis facility.

Many IHS and tribal facilities assist tribal members in accessing dialysis services by providing transportation and expanding access to specialists.

More than one-third of facilities that refer patients to dialysis services reported that they assist them with transportation alternatives. Some tribes that operate health care facilities have self-funded transportation systems to transport their members to dialysis facilities. IHS and tribal providers also expand access through innovative programs. For example, access to nephrologists can be difficult in rural communities; Alaska has only seven nephrologists to treat all ESRD patients in the State. Some IHS

and tribal providers strive to expand AI/ANs' access to nephrology services; one tribal hospital reported that it does not provide dialysis services but does provide an onsite nephrologist as part of a diabetes program. In addition, telemedicine is being used by a former IHS physician who provides nephrology services to his AI/AN patients via video conferencing.

RECOMMENDATIONS

Only 20 IHS and tribal facilities reported that they provide dialysis services at their facilities. The remoteness of these facilities affects their ability to provide dialysis services and creates hardships for patients trying to access the services. Most IHS and tribal facilities are unable to provide dialysis services because of small patient populations and the lack of resources to cover operating costs. However, most facilities that do not provide dialysis services refer patients to Medicare-certified facilities, and some assist patients by providing transportation. Some facilities also provide innovative programs to help patients access nephrology services.

When we conducted this study, IHS could not provide a complete and accurate list of all IHS and tribal health care facilities. Therefore, we have no assurance that we have a database that represents all such facilities.

To address these issues, we recommend that IHS:

Develop a plan and provide expertise to assist tribes in expanding dialysis services.

Develop guidance and technical assistance resources to help IHS and tribal facilities offer alternative treatments for dialysis services.

Develop a plan to create a single database of all IHS and tribal health care facilities.

E X E C U T I V E S U M M A R Y

AGENCY COMMENTS AND OFFICE OF INSPECTOR GENERAL RESPONSE

IHS concurred with all of our recommendations. We did not make any changes in the report based on IHS's comments. For the full text of those comments, see Appendix B.

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OBJECTIVE

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BACKGROUND

A member of Congress expressed concern about AI/ANs' access to kidney dialysis services and requested that the Office of Inspector General (OIG) conduct this evaluation.

The incidence rate of end stage renal disease (ESRD) for AI/ANs is the second highest among all racial/ethnic groups.¹ Nationally, the increasing incidence of diabetes and obesity and an aging population have contributed to the rise in chronic kidney disease.² Among all racial/ethnic groups, AI/ANs have the highest rates of diabetes (12 percent) and obesity (39 percent).³ Diabetes often precedes chronic kidney disease,⁴ and more than 80 percent of people with type II diabetes are overweight.⁵

The Federal Government first authorized appropriations for AI/AN health care in 1921 under the Snyder Act, which provided for “relief of distress and conservation of health.”⁶ The Indian Health Care Improvement Act (IHCIA) was enacted in 1976 to improve the services and facilities of Federal AI/AN health care programs.⁷ The IHCIA expired in 2000, but Congress continued to appropriate funds annually for AI/AN health care. In 2010, the President signed the Patient

¹ United States Renal Data System, *An Introduction to End-Stage Renal Disease in the United States*, 2010. Accessed at http://www.usrds.org/2010/pdf/v2_02.pdf on December 29, 2010.

² J. Coresh, E. Selvin, L. Stevens, et al., “Prevalence of Chronic Kidney Disease in the United States.” *Journal of the American Medical Association*, 2007; 298(17):2038–2047.

³ Cara James, Karyn Schwartz, and Julia Berndt, *Race, Ethnicity & Health Care Issue Brief: A Profile of American Indians and Alaska Natives and Their Health Coverage*, September 2009. Accessed at <http://www.kff.org/minorityhealth/upload/7977.pdf> on February 12, 2010.

⁴ A.S. Narva and T.D. Sequist, “Reducing Health Disparities in American Indians with Chronic Kidney Disease.” *Seminars in Nephrology*, January 2010; 30(1):19–25.

⁵ Healthy Americans, *F as in Fat: How Obesity Policies are Failing in America 2006*. Accessed on <http://healthyamericans.org/reports/obesity2006/Obesity2006Report.pdf> on December 27, 2010.

⁶ Snyder Act, 1921, P.L. 67-85 § 13, 42 Stat. 208, 25 U.S.C. § 13.

⁷ IHCIA, P.L. 94-437, 25 U.S.C. 1602.

Protection and Affordable Care Act of 2010 (ACA),⁸ which reauthorized appropriations for the IHCA and stated that “it is the policy of this Nation, in fulfillment of its special trust responsibilities and legal obligations to Indians—to ensure the highest possible health status for Indians and urban Indians and to provide all resources necessary to effect that policy....”⁹

IHS-Funded Health Services

IHS is an agency in the Department of Health and Human Services (HHS) responsible for providing Federal health services to AI/ANs. Headquartered in Rockville, Maryland, the agency operates from 12 IHS Area Offices across the country; these offices oversee the delivery of health services and provide administrative and technical support. IHS’s mission is to raise AI/ANs’ “physical, mental, social, and spiritual health to the highest level.”¹⁰ Members of the 564 federally recognized tribes are eligible for IHS health care. In partnership with the tribes, IHS provides services to 1.9 million¹¹ of the approximately 4.3 million AI/ANs living in the U.S.¹²

Indian Self-Determination and Education Assistance Act. In accordance with the Indian Self-Determination and Education Assistance Act (ISDEAA) (1975), as amended, there are three options for IHS-funded health services.¹³

1. Tribes, independently or through tribal organizations or tribal consortiums, may choose to have IHS continue to provide health services directly to their members.
2. Through Title I, tribes can receive a share of money that IHS would have used to administer and operate health services. Under this option, commonly known as “638 contracting,” tribes negotiate with IHS for funds to provide health services directly

⁸ ACA, P.L. 111-148.

⁹ ACA, Title X Part III § 10221, S. 1790 Title 1 § 103.

¹⁰ IHS, *Indian Health Service Fact Sheets: Indian Health Service*. Accessed at http://www.ihs.gov/PublicInfo/PublicAffairs/Welcome_Info/ThisFacts.asp on February 15, 2009.

¹¹ The remainder of AI/ANs may receive health care coverage through other sources, such as employer-provided health benefits, veterans’ health services, or Medicare and Medicaid.

¹² U.S. Census Bureau, *We the People: American Indian and Alaska Natives in the United States*, February 2006. Accessed at <http://www.census.gov/population/www/socdemo/race/censr-28.pdf> on May 9, 2011.

¹³ ISDEAA, P.L. 93-638, as amended.

to their members, and IHS retains a measure of oversight and supervision.

3. Under Title V, self-governance compacts allow tribes to receive their share of money from IHS to provide direct health services and to assume greater control over the administrative functions that support the delivery of the services and tailor services to the needs of their communities.¹⁴ Self-governance compacts offer tribes a greater degree of autonomy than does 638 contracting.

Direct Care Services. AI/ANs receive direct care services from IHS-operated or tribally operated facilities, generally hospitals, health centers, or health stations that provide direct health care services. In some situations, IHS and tribal programs share a building or hospital in which they operate their respective programs. Tribes, tribal consortiums, and IHS also may enter into arrangements with independent providers for specific services to be performed at their facilities. These may dialysis and dialysis services, mobile diagnostic services, and psychiatric services.

Contract Health Services Program. When an IHS or tribal facility cannot provide required services, IHS and tribes rely on the Contract Health Services (CHS) program, which contracts with private providers, such as hospitals and physicians, to deliver services. The CHS program is the payer of last resort and often defers or denies lower priority services.¹⁵ According to IHS, the CHS program can typically fund only the highest priority, or Level I, health services. The highest of the four priority levels, Level I services—“Emergent/Acutely Urgent Care Services”—are “necessary to prevent immediate death or serious impairment.” These services include kidney dialysis and transplant services.¹⁶

Kidney Disease and Dialysis

Healthy kidneys remove wastes and excess fluid from the blood, typically processing approximately 200 liters of blood a day and

¹⁴ IHS, *IHS Fact Sheets: Tribal Self-Governance*, January 2009. Accessed at <http://info.ihs.gov/TrblSfDtrm.asp> on January 14, 2009.

¹⁵ 42 CFR § 136.61.

¹⁶ IHS, *Contract Health Services, Requirements—Priorities of Care*. Accessed at http://www.ihs.gov/NonMedicalPrograms/chs/index.cfm?module=chs_requirements_priorities_of_care on April 8, 2010.

producing 2 liters of urine.¹⁷ Chronic kidney disease occurs when the kidneys gradually lose function. The disease generally progresses in stages over months or years. In the last stage—ESRD—patients have almost complete loss of kidney function and require dialysis or a kidney transplant to survive.¹⁸

Kidney dialysis replaces the function of the kidneys in removing wastes and excess fluid from the blood. The most commonly used method, hemodialysis, requires blood to be circulated through a filter on a dialysis machine.¹⁹ Hemodialysis is usually done three times a week for 3 to 5 hours per treatment in a renal dialysis facility. The other major dialysis method is peritoneal dialysis, which uses the lining of the abdomen (peritoneum) as a filter to remove wastes and excess fluid from the blood. Peritoneal dialysis can be performed by patients in their homes.²⁰ For most ESRD patients, dialysis services are coordinated by nephrologists, internal medicine specialists educated and trained in kidney diseases and dialysis therapy.

ESRD Networks support the Medicare End Stage Renal Disease Program. In 1972, the Social Security Act (the Act) was amended to create the Medicare End Stage Renal Disease Program (ESRD Program), which extends Medicare benefits to most people with irreversible kidney failure.²¹ To provide access for patients in need of dialysis services, Congress authorized the Secretary of Health, Education, and Welfare²² to establish ESRD Network Organizations to support the ESRD Program.²³ These organizations contract with the Centers for Medicare & Medicaid Services (CMS) to monitor and improve the quality of care of dialysis providers and kidney transplant programs within a given geographic area. Currently there

¹⁷ National Institutes of Health (NIH), *Kidney Failure: Choosing a Treatment That's Right for You*. Accessed at <http://kidney.niddk.nih.gov/kudiseases/pubs/choosingtreatment/> on December 31, 2008.

¹⁸ Definition accessed at <http://www.nlm.nih.gov/medlineplus/ency/article/000471.htm> on March 31, 2011.

¹⁹ NIH, *Kidney Failure: Choosing a Treatment That's Right for You*. Accessed at <http://kidney.niddk.nih.gov/kudiseases/pubs/choosingtreatment/> on December 15, 2008.

²⁰ Ibid.

²¹ Section 299I of P.L. 92-603, amending section 226 of the Act.

²² Before the Department of Education was created in 1979 as a separate Federal entity, HHS was called the Department of Health, Education, and Welfare.

²³ Section 299I of P.L. 95-292, adding section 1881 of the Act.

are 18 ESRD Network Organizations covering all 50 States, the U.S. territories, and the District of Columbia.²⁴

Along with performing other statute-identified activities, the ESRD Networks conduct onsite reviews of facilities, identify facilities and providers that are not complying with applicable standards, and report deficient facilities and providers to HHS. HHS then has the authority to terminate or withhold Medicare certification.²⁵ IHS and tribal facilities that meet the applicable standards can become Medicare certified. Dialysis facilities must be Medicare certified in order to qualify for Medicare or Medicaid payment.²⁶ Individuals, including AI/ANs, may go to any Medicare-certified dialysis facility.

A dialysis facility may be a freestanding unit or be located in a hospital or other health facility.²⁷ CMS lists more than 5,400 dialysis facilities in its Dialysis Facility Compare database.²⁸

Medicare is the largest payer for kidney dialysis services.

Medicare is the largest payer of ESRD costs. Under the Medicare ESRD Program, individuals—including AI/ANs—who have ESRD and require regular dialysis are eligible for Medicare, regardless of age, beginning with the third month after the month in which they initiate a regular course of renal dialysis.²⁹ Individuals—including AI/ANs—who receive dialysis prior to becoming eligible for Medicare may receive financial assistance from State programs, veterans' benefits, or private plan benefits. AI/ANs may also receive assistance from some community tribal organizations. In addition, AI/ANs may qualify for funds from the CHS program (the payer of last resort)³⁰ if the services are not covered by another plan.

Typically, facilities refer individuals—including AI/ANs—who have been diagnosed with ESRD and need dialysis to a dialysis facility for treatment. The dialysis facility may or may not be affiliated with a

²⁴ CMS's overview of ESRD Network Organizations. Accessed at <https://www.cms.gov/esrdnetworkorganizations/> on March 31, 2011.

²⁵ Section 1881(c)(2) and (c)(3) of the Act.

²⁶ 42 CFR §§ 413.20 and 441.40.

²⁷ 42 CFR § 405.2102; CMS, *Medicare Benefit Manual*, Pub. 100-02, ch. 11, § 10.B.

²⁸ CMS, *Medicare Dialysis Facility Compare*, December 2008. Accessed at <http://www.medicare.gov/Dialysis/Static/DataDownload.asp?dest=NAV|Home|DataDetails|DataDownload#TabTop> on October 27, 2010.

²⁹ Section 226A(a) of the Act, 42 U.S.C. § 426-1(a).

³⁰ AI/ANs eligible for alternate resources may not receive CHS funds. 42 CFR § 136.61.

tribal or IHS health care facility. AI/ANs who receive treatment at Medicare-certified dialysis facilities, which can include IHS-operated or tribally operated facilities, are eligible for Medicare assistance.³¹ The referring IHS or tribal health care facility or the dialysis facility may provide financial counselors to help the AI/AN qualify for Medicare payment. To bridge the 3-month gap between when a patient begins treatment and when he or she qualifies for Medicare, the facilities may help the AI/AN identify other potential payment resources. One alternative available to AI/ANs is the CHS program; other alternatives might include tribal organizations, State programs, community organizations, or private plan benefits.

The ACA addressed dialysis services in the reauthorized IHCA. Under the ACA, the IHCA was reauthorized with key changes related to AI/AN health services. Section 204 of the ACA, “Diabetes Prevention, Treatment, and Control,” authorizes the Secretary to provide dialysis programs directly through IHS, tribes, and tribal organizations. Dialysis programs include the purchase of dialysis equipment and necessary staffing.³² Although IHS has had the authority to provide dialysis services under prior enactments, section 204 reflects the first time that Congress has specified dialysis services in a statute. Furthermore, section 313 of the IHCA also authorizes a “Mobile Health Stations Demonstration Program,” which allows tribes to apply for funding for specialty-services mobile health stations. These include any service relating to dialysis, surgery, dentistry, and any other specialty service.³³

Related Reports

In 2005, the Government Accountability Office (GAO) visited 13 IHS facilities to determine the extent to which AI/ANs had access to health care.³⁴ GAO found that most facilities offered primary care and dental and vision services, but that access was not always assured because of waiting times and lack of transportation. GAO also found that certain ancillary and specialty services were not

³¹ IHCA, P.L. 94-437 § 401, 25 U.S.C. 1602, as amended.

³² New IHS and tribal dialysis facilities that meet Medicare certification standards will be able to bill Medicare for providing services to qualified individuals. Ibid.

³³ Ibid.

³⁴ GAO, *Indian Health Service: Health Care Services Are Not Always Available to Native Americans*, GAO-05-789, August 2005.

routinely available to clients because the facilities lacked staff or equipment. GAO did not focus on kidney dialysis services.

In 2009, OIG examined the extent to which IHS and tribes paid for CHS hospital claims above the required Medicare rate from January to March 2008. The study found that IHS and tribes paid above the Medicare rate for 22 percent of hospital claims, resulting in \$1 million in overpayments. If payments for nonhospital claims were capped at the Medicare rate, IHS could have saved as much as \$13 million.³⁵

In 2010, Senator Byron Dorgan, Chairman of the Senate Committee on Indian Affairs, released a report citing problems with credentialing and licensure of providers, accountability of controlled substances, and management of CHS program funds, among other issues, in the region covered by the IHS Area Office in Aberdeen, South Dakota.³⁶

Companion Report

This report is one of two on AI/ANs' access to health care. The companion report is *Access to Mental Health Services at Indian Health Service and Tribal Facilities* (OEI-09-08-00580).

METHODOLOGY

Scope

This evaluation determined the extent to which AI/ANs had access to kidney dialysis services at IHS and tribal facilities between January 2008 and November 2009. We conducted this evaluation concurrently with our evaluation of AI/ANs' access to mental health services.

We did not review the quality and medical necessity of dialysis services or review whether IHS paid appropriately for the services in accordance with Federal laws and regulations. We did not determine whether the facilities were Medicare certified or at what time following their diagnoses the AI/ANs accessed the services.

Survey and Fieldwork

Stage 1: Survey of IHS and tribal facilities. To identify all IHS and tribal health facilities, we took the following steps:

³⁵ OIG, *IHS Contract Health Services Program: Overpayment and Potential Savings*, OEI-05-08-00410, September 2009.

³⁶ U.S. Senate Committee on Indian Affairs, *In Critical Condition: The Urgent Need to Reform the Indian Health Service's Aberdeen Area*, December 28, 2010.

I N T R O D U C T I O N

- To create one master list of IHS and tribal facilities, we combined the multiple lists that IHS provided to us, removing all duplicates.
- Because the list was missing information (e.g., names of current representatives of the facilities), we conducted research online and used an HHS employee directory to confirm information about facilities and their representatives. We also confirmed this information with IHS and tribal staff.
- We then attempted to contact each facility's representative to confirm the name and type of facility and confirm whether it was IHS operated or tribally operated.

We identified 777 IHS and tribal facilities that were providing health care services from June 2009 to November 2009.³⁷ For the purposes of this report, we excluded 179 facilities that either provided mental health services only or were school health centers, because dialysis services were not within their scope of services.³⁸ Therefore, this report is based on 598 IHS and tribal facilities.

We sent one survey per facility to the contact person we had identified. Some contacts were responsible for multiple facilities. We asked them to complete one survey for each facility so that we could attribute each response to the appropriate facility. We made a minimum of three attempts by email and/or telephone to ensure that all contact people submitted their surveys. We received completed surveys from 506 of the 598 facilities, for a response rate of 85 percent.

Stage 2: Fieldwork at 98 IHS and tribal facilities. We visited 98 IHS and tribal facilities, including 9 dialysis facilities, in 51 AI/AN communities and reservations. These facilities offered a range of health services, including inpatient and outpatient services and primary and specialty care. We also visited 11 of 12 IHS Area Offices in person and interviewed IHS officials at the remaining Area Office by telephone. We used standardized interview guides and interviewed 436 IHS and tribal administrators, providers, and clients.

³⁷ We sent surveys to all IHS and tribal facilities beginning in June 2009 and continued to receive responses for 6 months, until November 2009.

³⁸ Excluded mental health facilities include: alcohol and substance abuse treatment facilities, residential treatment centers, behavioral health facilities, and wellness centers.

I N T R O D U C T I O N

Analysis

We based our findings on the synthesis of survey data, interviews, and observational fieldwork. The data we collected during the onsite work supplemented the survey data. Using SAS software, we analyzed the data collected through our survey and fieldwork.

Limitations

The findings in this report are not projected to all IHS and tribal facilities, but are limited to the 506 survey respondents, which did not include facilities that provided mental health services only or school health centers. We conducted the interviews concurrently with our evaluation of AI/ANs' access to mental health services. Therefore, not all of the 436 interviews specifically addressed access to dialysis services.

Standards

This study was conducted in accordance with the *Quality Standards for Inspection and Evaluation* issued by the Council of the Inspectors General on Integrity and Efficiency.

► FINDINGS

Only 20 of 506 IHS and tribal facilities reported that dialysis services are provided at their facilities; most reported that other facilities provide these services

Twenty³⁹ of the five hundred six IHS and tribal facilities reported in surveys and interviews that they provide dialysis services at their facilities. Three of these facilities

operate dialysis services in their communities through tribally created dialysis organizations. Seventeen facilities offer dialysis services at their facilities through separate, nontribal for-profit or nonprofit companies. Several facilities indicated that the services were provided through national dialysis providers (e.g., Davita and Fresenius) or independent dialysis providers (e.g., regional providers). The 20 facilities reported that they provided hemodialysis services to approximately 816 patients from January 2008 to November 2009.

Approximately two-thirds of the facilities that do not provide dialysis services (337 of 486 facilities) reported that other facilities provide these services to their patients. Typically these other facilities are neither IHS operated nor tribally operated. Of those facilities that do not provide dialysis, 56 percent (272 of 486) reported that they assist in referring their patients to other facilities, both IHS/tribal and non-IHS/nontribal. The remaining 149 facilities did not indicate whether or where their clients may receive dialysis services.

The remoteness of IHS and tribal dialysis facilities can affect the availability of services and create hardships for AI/ANs

In some situations, the remoteness of the dialysis facilities may affect their ability to provide services. Patients living

in remote areas have difficulties accessing the services because of distance, weather, and road conditions.

³⁹ The Medicare Dialysis Facility Compare Web site lists additional dialysis facilities in or near AI/AN communities. However, the responses that we received from the IHS/tribal health care facilities located near these additional dialysis facilities did not indicate that there were any relationships between the IHS/tribal facilities and the dialysis facilities. Accessed at

<http://www.medicare.gov/Dialysis/Static/DataDownload.asp?dest=NAV|Home|DataDetails|DataDownload#TabTop> on October 27, 2010.

Remoteness of locations of the 20 communities with IHS and tribal dialysis facilities can affect service delivery

IHS and tribal dialysis facilities are limited by their remoteness. The 20 IHS and tribal facilities that provide dialysis services are in nonurban areas. See map of the 20 facilities in Appendix A. These facilities reported that being in remote locations causes staff shortages or limits in essential public utilities and that both factors can affect the availability of dialysis services.

At six of the nine dialysis facilities that we visited, staff reported that it is difficult to recruit and retain qualified staff partly because of the remoteness of the facilities. For example, one facility relied on one employee, who was near retirement, to repair and service its dialysis equipment. Because the community was very remote, the facility feared it could not attract another qualified technician. Instead, the facility would incur additional expenses transporting and paying a contractor to maintain its aging equipment. Another facility relies on contract nurses who commute 120 miles per day to operate the dialysis facility.

During onsite interviews, providers at IHS and tribal health care facilities reported that access to dialysis services was limited because of the operating hours and lack of available appointment times caused by staff shortages. This, according to the facilities, represents a barrier for their clients' access to dialysis services.

Two remote facilities reported having to occasionally cut short their patients' dialysis treatment or close their facilities completely because of interruptions in their water service. During our visit, one of the dialysis facilities was close to depleting its water supply. Until the water service was restored, the facility was preparing to stop treatment early.

Of the three tribally operated dialysis facilities, two are in remote areas and serve a limited client base. As a result, they are unable to generate adequate revenue and experience budget deficits. One of these two facilities reported that its dialysis facility had an annual deficit of \$200,000. However, the third is in a semirural/suburban area and anticipates an increased incidence of ESRD in the community. To meet the need, the tribe that operates the facility recently expanded to a 40-station dialysis facility. At the time of our visit, the facility was not fully staffed or operational because its expansion had just been completed.

Small rural dialysis facilities face challenges providing services. A 2010 Medicare Payment Advisory Commission report on dialysis

providers found that facilities that closed had less capacity than those that remained open, suggesting that it is more difficult for smaller capacity dialysis facilities to generate enough revenue to remain in business. The report also found that the Medicare financial operating margins were lower in rural areas.⁴⁰ Lower wages in rural areas could affect recruitment of staff for remote IHS and tribal facilities.

The demands of getting to and from dialysis facilities can reduce AI/AN dialysis patients' quality of life

Providers at 5 of the 20 IHS and tribal facilities emphasized that their patients endure hardships getting to and from dialysis facilities. Some of these patients travel on rural roads for 4 hours per day, or longer, three times a week. Dialysis services range in duration, from 3 to 5 hours per treatment. Consequently, dialysis treatment can consume 3 entire days per patient, per week. Patients at one facility leave home as early as 3 a.m. to travel to the nearest dialysis facility, more than 45 miles away by mountainous two-lane roads. Two facilities reported that their dialysis patients often are nauseated and exhausted as a result of the journey. Following treatment, some patients choose to stay overnight near the dialysis facility, which incurs them additional expenses and takes them away from their families and communities. Providers at three IHS and tribal facilities reported that in rare cases, patients have chosen to stop dialysis or not begin it at all, partly because of the toll these hardships can take on their quality of life.

Occasionally, weather conditions are severe enough to close roads and cause delays that can interrupt the patients' care. One dialysis facility reported to us that during the previous winter, it was closed for 6 days because of weather. One tribal facility reported that "the nearest dialysis services are located approximately 75 miles one way, and the snow and closure of roads either north or south of our remote location can be very challenging for patients needing the service."

⁴⁰ *Report to Congress: Medicare Payment Policy*, Section 2F, Outpatient Dialysis Services, March 2010. Accessed at http://www.medpac.gov/chapters/Mar10_Ch02D.pdf on January 13, 2011.

Most IHS and tribal facilities do not provide kidney dialysis services because of lack of resources and small patient populations

Seventy-two percent of the facilities that do not provide dialysis (352 of 486 facilities)

reported that they lack the funds, staff, and/or space to provide the services. According to IHS Area Office staff, many tribes have asked IHS for funds to provide dialysis services. However, the tribes lack additional funds, and given the small population of dialysis patients, Medicare reimbursement would not be sufficient to subsidize the sizable annual budget required to operate a dialysis facility.⁴¹ For example, administrators at two facilities reported that their efforts to establish a local dialysis facility stalled because they lacked resources. In an earlier effort in the 1990s, a tribe considered building and independently operating a dialysis facility. However, after determining the facility would likely operate with an annual deficit of \$200,000 to \$250,000, the tribe decided not to build it. One tribe reported that it is “cost prohibitive” to support a dialysis facility with trained staff and resources.

Eighty percent of the IHS and tribal facilities that do not provide dialysis services (389 of 486) reported that the reason they do not provide such services is that they are beyond the facilities’ capability. Generally, these facilities are in small communities and they serve relatively few patients. According to the survey, the median community size per facility is 1,600 people and 78 percent of the facilities serve fewer than 5,000 health care patients each. A tribe that manages more than 40 small clinics in remote locations explained that it cannot provide dialysis services onsite:

[T]he overwhelming factor is that this service is well beyond the scope appropriate to a frontier location [Our facilities are] small and lack the basic infrastructure to support provision of dialysis services. In addition, the population is small and would not produce adequate demand to support this service.

⁴¹ IHS funds can be provided to tribes either through ISDEAA 638 contracts or self-governance compacts. However, neither the ISDEAA funds allocated to a tribe nor the additional Medicare reimbursement would be sufficient to cover the operating costs of providing dialysis services to few tribal members. Therefore, to meet the operating costs of a dialysis center, most tribes would be required to provide supplemental tribal funds beyond the IHS funds allocated under the ISDEAA.

According to IHS Area Office staff, many tribes have too few dialysis patients to justify a dialysis facility.⁴² The medical director at one tribal facility reported that although the tribe had discussed establishing its own dialysis facility, it chose not to do so, instead deciding to take a preventive approach against chronic kidney disease. The tribe invests in prevention and education programs, despite the likelihood that at least 200 of its members will need dialysis within the next 10 to 15 years, according to the medical director.

Many IHS and tribal facilities assist tribal members in accessing dialysis services by providing transportation and expanding access to specialists

The physical condition of dialysis patients makes self-transport difficult, and patients must look to other resources for assistance.

One facility reported that access to dialysis services is limited for 85 percent of its dialysis patients because of patients' lack of transportation.⁴³ Although most tribes do not provide dialysis services, some tribes are providing innovative access to nephrology and using telemedicine applications to meet their needs.

More than one-third of facilities that refer patients to dialysis services reported that they assist them with transportation alternatives

Thirty-eight percent of the facilities that refer patients to dialysis services (102 of 272 facilities) reported that local tribes, volunteers, and nonprofit organizations assist in transporting patients to and from the nearest accessible dialysis facilities.

During interviews, several tribes said that they have self-funded transportation systems and/or use their Community Health

⁴² Oklahoma State University at Stillwater, Department of Agricultural Economics, *A Systems Guide for a Kidney Dialysis Center*, August 2003. Accessed at http://www.ruralhealthworks.org/downloads/Additional/Renal_Dialysis_Guidebook.pdf on May 9, 2011. Experienced managers reported that a small dialysis center with 6 to 10 stations may need at least 14 to 15 patients on a 3-day week to break even, assuming adequate staffing is available. In addition, the capital costs range from \$35,000 to \$70,000 per station, and the facility should not expect to make a profit in the first 3 years of business.

⁴³ According to *Medicare Coverage of Kidney Dialysis and Kidney Transplant Services*, Medicare covers round-trip ambulance service only if other forms of transportation would be harmful to the health of the patient. Accessed at <http://www.medicare.gov/Publications/Pubs/pdf/10128.pdf> on June 9, 2011.

Representative (CHR) programs⁴⁴ to transport their members to dialysis facilities. For example, CHRs at one tribe we visited transport several dialysis patients 3 times per week, including one patient who lives

60 miles from the dialysis facility. Another tribe said it leases a van and has hired a driver to transport tribal members to dialysis appointments, because the only private transportation provider that served its community no longer transports Medicaid patients since the State's Medicaid program reduced its reimbursement for nonemergency transportation.

IHS and tribal providers expand access through innovative programs

Access to nephrologists can be limited in rural communities.⁴⁵ For example, Alaska has only seven nephrologists to treat all ESRD patients—both AI/AN and non-AI/AN—in the State, and all seven are in Anchorage. The State has a total of six dialysis facilities spread over the cities of Anchorage, Fairbanks, Juneau, and Soldotna. According to facility staff, AI/AN dialysis patients usually travel or relocate to one of these cities for treatment and most travel to Anchorage to see a nephrologist. AI/ANs in Wyoming face similar challenges.⁴⁶ There, the State has three nephrologists and nine dialysis facilities. In some communities, however, itinerant specialists visit two to four times per month to provide nephrology services at the facilities.

Some IHS and tribal health care providers strive to expand and protect AI/ANs' access to nephrology services. We encountered innovative programs and dedicated providers caring for AI/ANs who need dialysis. For example, one tribal hospital reported that it does not provide onsite dialysis services but does provide an onsite nephrologist as part of a

⁴⁴ The CHR program is “a unique community-based outreach program, staffed by a cadre of well-trained, medically-guided, tribal and Native community people, who provide a variety of health services within American Indian and Alaska Native communities.” IHS, *Indian Health Manual*, Part 3, Chapter 16. Accessed at http://www.ihs.gov/ihtm/index.cfm?module=dsp_ihm_pc_p3c16#3-16.1 on September 8, 2010.

⁴⁵ Access to health care continues to be an ongoing problem for many ESRD patients in rural communities. *End-Stage Renal Disease (ESRD) Network 13*. Accessed at <http://www.network13.org/about.asp> on November 9, 2010.

⁴⁶ Reservation-based dialysis has improved the access of patients to renal replacement therapy, but barriers to access remain. These include the rural nature and isolation of locations. A.S. Narva, “Kidney disease in Native Americans.” *Journal of the National Medical Association*, August 2002, 94(8):738–42. Accessed at <http://www.ncbi.nlm.nih.gov/pubmed/12152933> on January 4, 2011.

F I N D I N G S

diabetes program. This nephrologist treats more than 60 dialysis patients at the facility.

Telemedicine is being used in a variety of settings to increase access to professional health care providers. IHS and tribes are successfully using telemedicine in cardiology⁴⁷ and mental health services. In addition, a former IHS physician provides nephrology services to his AI/AN patients via video teleconferencing. This physician manages treatment for 30 AI/AN dialysis patients more than 2,000 miles away with the help of onsite dialysis staff at the patients' facilities.

⁴⁷ IHS, *Native American Cardiology Program*. Accessed at <http://www.ihs.gov/Cardiology/index.cfm?module=telemed> on January 4, 2011.

Only 20 IHS and tribal facilities reported that they provide dialysis services at their facilities. The remoteness of these facilities affects their ability to provide dialysis services and creates hardships for patients trying to access the services. Most IHS and tribal facilities are unable to provide dialysis services because of small patient populations and the lack of resources to cover operating costs. However, most facilities that do not provide dialysis services refer patients to ESRD Network facilities and assist patients by providing transportation and innovative programs to help patients access the services.

When we conducted this study, IHS could not provide a complete and accurate list of all IHS and tribal health care facilities. Although IHS attempts to collect information annually about IHS-funded health services, tribal facilities funded under Title I and Title V of the ISDEAA are not required to report specific information about their facilities. Therefore, IHS was unable to provide a complete, accurate list of all IHS and tribal health care facilities and contact individuals for them.

To address these issues, we recommend that IHS:

Develop a plan and provide expertise to assist tribes in expanding dialysis services

Under the reauthorized IHCLA, the Secretary is authorized explicitly to provide support for IHS and tribal dialysis programs, including funding for equipment and staff. Tribes need effective and efficient ways to coordinate and evaluate the demand for dialysis facilities in their communities. IHS should develop a plan to provide technical expertise and consultation to assist tribes in evaluating the economic feasibility of establishing dialysis facilities.

Develop guidance and technical assistance resources to help IHS and tribal facilities expand alternative treatments for dialysis services

IHS staff should continue to expand IHS's use of telemedicine and seek ways to provide nephrology services and counseling in remote locations using telemedicine. In addition, as part of its plan to expand dialysis services, IHS should continue to collaborate with the national dialysis organizations and kidney disease organizations to increase technical assistance available to IHS and tribal health care facilities. This collaboration should assist facilities in expanding awareness of and education about peritoneal and home hemodialysis as alternatives to facility-based hemodialysis for AI/ANs in remote areas.

Develop a plan to create a single database of all IHS and tribal health care facilities

Our attempts to compile a comprehensive list of all IHS and tribal health care facilities were limited because there is no single database—either in IHS or among tribes and tribal organizations—of all IHS and tribal health care facilities, with the facilities’ addresses and the names of contact people. Although tribes are not required under 638 contracting or self-governance compacting to report information about their facilities to IHS, a single database that identified all health care facilities and the services they offer would help the tribes and IHS to expand services under the reauthorized IHCA. IHS should develop a plan to work with tribes, States, and Federal agencies to create a national database of AI/AN health care facilities, and it should include all such facilities, regardless of funding sources. Such a database would assist the Secretary in meeting the Administration’s mandate to “formulate a comprehensive approach to Indian health care reform” and provide planning information relative to the distribution of health services for AI/ANs throughout the country.

AGENCY COMMENTS AND OFFICE OF INSPECTOR GENERAL RESPONSE

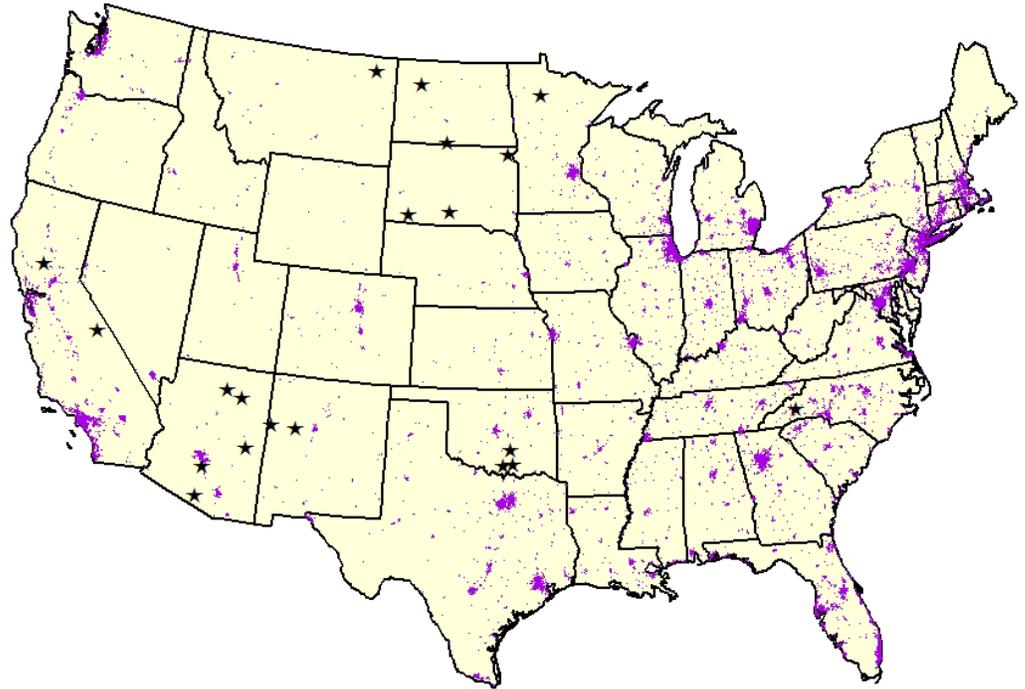
IHS concurred with all three of our recommendations. In response to our first and second recommendations—that IHS develop a plan and provide expertise to assist tribes in expanding dialysis services and that IHS develop guidance and technical assistance resources to help IHS and tribal facilities offer alternative treatments for dialysis services—IHS stated that it will conduct a tribal consultation process to determine whether tribes need increased centralized IHS assistance in expanding dialysis services and offering alternative treatments for dialysis services. If the process identifies needs for assistance in those areas, IHS should be prepared to support IHS and tribal dialysis programs, including providing funding for equipment and staff under the reauthorized IHCA. As part of our second recommendation, we said that IHS should continue to collaborate with the national dialysis organizations and kidney disease organizations to increase technical assistance available to IHS and tribal health care facilities. Although IHS did not address this portion of our recommendation in its response, we support IHS’s continued collaborations with these organizations.

In response to our third recommendation—that IHS develop a plan to create a single database of all IHS and tribal health care facilities—IHS stated that it will work with tribes, States, and Federal agencies to create a database of AI/AN health care facilities to include physical locations, contact information, and available services.

We did not make any changes in the report based on IHS's comments. For the full text of IHS's comments, see Appendix B.

▶ A P P E N D I X ~ A

Map of the 20 Indian Health Service and Tribal Facilities That Provide Dialysis Services⁴⁸



⁴⁸ The star symbol represents an Indian Health Service (IHS) or tribal dialysis facility. Shaded areas represent urban areas according to the U.S. Census Bureau's 2009 TIGER/Line Shapefiles, nation-based shapefiles (Corrected Census 2000). Alaska and Hawaii are not shown; neither State has IHS or tribal facilities that provide dialysis services.

▶ A P P E N D I X ~ B

Agency Comments



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Indian Health Service
Rockville MD 20852

AUG 19 2011

TO: Inspector General

FROM: Director

SUBJECT: Comments by the Indian Health Service on the OIG Draft Report *Access to Kidney Dialysis Services at Indian Health Service and Tribal Facilities*, (Report No. OEI-09-08-00581)

Please accept the following responses to your June 23 memorandum transmitting the Office of Inspector General (OIG) draft report entitled *Access to Kidney Dialysis Services at Indian Health Service and Tribal Facilities*, (Report No. OEI-09-08-00581). I appreciate the opportunity to address the recommendations to improve access to services in the Indian Health Service (IHS) and Tribal health systems.

IHS Response to the OIG Draft Recommendations

1. Develop a plan and provide expertise to assist Tribes in expanding dialysis services.

The IHS concurs with this recommendation. Tribes are primarily involved in setting up dialysis service access; therefore, IHS will conduct a Tribal consultation process to determine if Tribes need increased centralized IHS assistance in this area and, if so, what types of support would be most useful. Indian health programs often develop partnerships locally and/or regionally to provide dialysis services so it is necessary to determine whether Tribes have access to the advice they need about dialysis from their local nephrology consultants in the private sector. Implementation of the recommendations will be considered during the budget formulation process as IHS does not currently have the required staff or funding to fully implement.

2. Develop guidance and technical assistance resources to help IHS and Tribal facilities offer alternative treatments for dialysis services.

The IHS concurs with this recommendation. As with recommendation #1 above, IHS will conduct a Tribal consultation process to determine if Tribes need increased centralized IHS assistance in this area and, if so, what types of support would be most useful.

3. Develop a plan to create a single database of all IHS and Tribal health care facilities.

The IHS concurs with this recommendation. IHS will develop a plan to create a single data base that identifies all IHS and Tribal health care facilities to better assist Tribes and IHS in identifying and expanding services. IHS will collaborate with Tribes, States, and Federal agencies to create a single database of IHS and Tribal health care facilities to include physical location, contact information, and available services.

A P P E N D I X ~ B

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Thank you for providing IHS the opportunity to comment on the OIG's draft report. The IHS is committed to improving our health care delivery system and increasing access to those requiring our services. We will continue to work in partnership with our Tribal health system to assist them in their ongoing efforts.

/S/

Yvette Roubideaux, M.D., M.P.H.



A C K N O W L E D G M E N T S

This report was prepared under the direction of Timothy S. Brady, Regional Inspector General for Evaluation and Inspections in the San Francisco regional office, and Michael Henry, Deputy Regional Inspector General.

Steven Zerebecki served as the team leader for this study. Other principal Office of Evaluation and Inspections staff from the San Francisco regional office who contributed to the report include: Loul Alvarez, Veronica Gonzalez, Camille Harper, Cynthia Lemesh, Christina Lester, Linda Min, China Tantameng, and Marcia Wong. Central office staff who contributed include Ruth Davis, Melinda Golub, Amitava “Jay” Mazumdar, and Talisha Searcy.

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