
Assessment of the National Library of Medicine's health disparities plan: a focus on Native American outreach*

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Objectives: Overcoming health disparities between majority and minority populations is a significant national challenge. This paper assesses outreach to Native Americans (American Indians, Alaska Natives, and Native Hawaiians) by the National Library of Medicine (NLM). A companion paper details NLM's portfolio of Native American outreach projects.

Method: NLM's Native American outreach is assessed in light of the presentations at a community-based health information outreach symposium and the goals set by NLM's plan to reduce health disparities.

Results: NLM's current portfolio of Native American outreach projects appears most advanced in meeting the goal set in area 1 of the health disparities plan, "Promote use of health information by health professionals and the public." NLM's portfolio also shows significant strength and good progress regarding area 2 of the plan, "Expand partnerships among various types of libraries and community-based organizations." The portfolio is weaker in area 3, "Conduct and support informatics research." More knowledge-building efforts would benefit NLM, the National Network of Libraries of Medicine, and Native American and community-based organizations.

Implications: The current Native American outreach portfolio should be continued, but new approaches are needed for evaluating Native American outreach and for forging collaborations with Native American groups, approaches grounded in consultation and mutual understanding of needs and perspectives.

INTRODUCTION AND OVERVIEW

The "Symposium on Community-based Health Information Outreach" was conceived to encourage the nation's health sciences libraries to explore new outreach models, extend library services beyond traditional boundaries, and forge new partnerships with community-based organizations. The symposium invited a mix of grassroots community organizers, evaluators, communications scholars, and other stakeholders. Participants shared experiences and identified best practices and the tools necessary to measure performance outcomes. The National Library of Medicine's (NLM's) health disparities plan and its outreach projects for Native Americans were evaluated against these benchmarks in a work session following the symposium.

Overcoming health disparities remains a significant challenge throughout the United States. The approach taken by the National Institutes of Health (NIH) is primarily research driven, consistent with the fundamental nature of NIH's strength as America's premier research institution seeking to advance understanding of disease and disability. The NIH Strategic Plan To Reduce and Ultimately Eliminate Health Disparities has three major goals [1]:

- **Research:** to advance the understanding of the development and progression of diseases and disabilities that contribute to minority health and other health disparities
- **Research Infrastructure:** to increase minority health and health disparity research training, career development, and institutional capacity (intramural and extramural)
- **Public Information and Community Outreach:** to ensure that the public, health care professionals, and research communities are informed and educated about the latest advances in minority health and health disparities research

Public information and community outreach is the principal goal around which NLM's Strategic Plan for Addressing Health Disparities 2004–2008 is structured [2]. It mirrors the most recent iteration of NLM's Long Range Plan 2000–2005, especially the outreach goals and objectives [3].

At the core of NLM's health disparities plan is the belief that improving access to affordable and easy-to-use health-related information and health technology could address some of the challenges of the nation's

health disparities. A multidimensional approach has been taken, grounded in NLM's strengths. NLM is the world's largest medical library; it also manages the 5,000-member-strong National Network of Libraries of Medicine (NN/LM). NLM also is a recognized leader in new information technology (IT) innovation and transfer and is a committed public institution that embraces the principle that free and open access to information is at the heart of a vibrant and healthy society.

In the parlance of the NIH plan, NLM identified three *areas of emphasis* that have characterized its efforts:

1. promote use of health information by health professionals and the public
2. expand partnerships among various types of libraries and community-based organizations, with the goal of forming community coalitions to improve access to health information for members of minority and underserved populations as well as health professionals serving these populations
3. conduct and support informatics research

The underlying strategies include:

- improving the information infrastructure and communications capabilities of minority communities and academic institutions
- employing communication methods that are racially sensitive and culturally appropriate
- increasing the scope of information products and services to include cultural, psychological, behavioral, social, gender-based, and environmental influences
- training minority health professionals, information professionals, and community members to use quality health information resources
- building effective partnerships with community-based and professional organizations

The community-based outreach symposium convened by NLM on December 2 and 3, 2004, addressed the need to develop and explore new models and approaches to build partnerships with community-based groups. It also provided an ideal opportunity to seek public review and comment on NLM's health disparities plan and the projects that had been developed to accomplish its objectives. Specifically, NLM hoped to answer the following key questions:

- Are the areas of emphasis and objectives properly framed?
- Are the strategies targeted to achieve the maximum benefits consistent with available resources?
- Has NLM initiated the right kinds of projects?
- Is the overall portfolio of projects appropriate?
- Does NLM have the right partners?
- Is NLM sensitive to their needs?
- Is NLM making a difference?

* This paper is based on a presentation at the "Symposium on Community-based Health Information Outreach"; National Library of Medicine, Bethesda, Maryland; December 2, 2004, and a subsequent work session held the afternoon of December 3, 2004.

In the interest of making this assessment task manageable within the confines of a working symposium, the assessment was limited to those projects addressing the needs of American Indians, Alaska Natives, and Native Hawaiians.

This paper provides a historical context for NLM's health disparities plan, including the nation's health disparities challenge and the roles taken by NLM and NIH. The paper notes NN/LM's very special contributions. The paper, then, provides an assessment of NLM's Native American outreach projects as discussed by symposium participants, who were mindful of NLM's health disparities plan. The paper concludes with discussion of some key issues and thoughts on possible future directions. A detailed portfolio of NLM's Native American outreach projects is presented in the accompanying paper.

HISTORICAL CONTEXT AND EVOLUTION OF THE NATIONAL LIBRARY OF MEDICINE'S (NLM'S) HEALTH DISPARITIES PLAN

Health disparities as a national challenge

Medical and scientific advances continue to provide opportunities for improving the health of many Americans. Despite improvements in the overall health of the general population, an alarming and disproportionate burden of disease, disability, and premature death is borne by racial, ethnic minorities, and medically underserved populations.

Data documenting the existence of health disparities date back almost 20 years, with the 1986 publication of the *Report of the Secretary's Task Force on Black and Minority Health*, the first, comprehensive national minority health study, which was published by the US Department of Health and Human Services [4]. The report suggested that 6 problem areas together accounted for more than 80% of high mortality rates among minorities from 1979 to 1981: cancer; cardiovascular diseases and stroke; chemical dependency; diabetes; homicides, suicides, and unintentional injuries; and infant mortality. HIV/AIDS was later added to this list. Since the 1986 report, numerous findings have corroborated the disparities in health care among the same populations.

The elimination of health disparities is now a recognized national health crisis. *Healthy People*, the 1979 surgeon general's report, provided a foundation for a national prevention agenda [5]. The 1980 *Promoting Health/Preventing Disease: Objectives for the Nation* [6] and *Healthy People 2000: National Health Promotion and Disease Prevention Objectives* [7] both established national health objectives and served as the basis for the development of state and community plans. Since the recent release of *Healthy People 2010*, the current prevention agenda for the nation, NLM has experienced a resurgence of interest in addressing health disparities [8]. *Healthy People 2010* identified the most significant preventable barriers to improved health and established a national goal of reducing obstacles, among them the elimination of health disparities.

The 2003 Institute of Medicine (IOM) report *Unequal Treatment* provided extensive documentation that the sources of health disparities are complex and "rooted in historic and contemporary inequities, and involve many participants at several levels" [9]. Therefore, "a comprehensive, multi-level strategy is needed to eliminate these disparities." The report also identified some of the medical, social, and economic implications of health disparities:

- For health professionals, racial and ethnic disparities in health care pose moral and ethical dilemmas as they face a complex set of societal expectations.
- Health care as a resource is tied to social justice, opportunity, and quality of life for individuals and groups.
- Racial and ethnic disparities in health care threaten to hamper efforts to improve the nation's health.
- The costs of inadequate care may have significant implications for overall health care expenditures.
- Health disparities pose a significant dilemma for a society that is still wrestling with a legacy of racial discrimination.
- Racial and ethnic disparities raise concerns about the overall quality of health care in the United States. [9]

The *National Healthcare Disparities Report* by the Agency for Healthcare Research and Quality complemented the IOM study by examining the ability of Americans to access health care and the quality of health care [10]. The key findings of this report were that (1) inequality in quality exists; (2) disparities occur at a personal and societal price; (3) differential access may lead to disparities in quality; (4) opportunities to provide preventive care are frequently missed; (5) knowledge of why disparities exist is limited; (6) improvement is possible; and (7) time limitations hinder targeted improvement efforts.

The 2004 Sullivan Commission report, *Missing Persons: Minorities in the Health Professions*, reflecting 18 months of fieldwork that focused on diversity in America's health workforce, also corroborated the need to augment the capacity of health care providers to address health disparity [11]. The Sullivan Commission report revealed that African Americans, Hispanic Americans, and American Indians combined make up more than 25% of the US population. Yet only 9% of the nation's nurses, 6% of its physicians, and 5% of its dentists are African American, Hispanic American, or American Indian. The Sullivan Commission report added that the nation's medical school graduating classes for 2007 included only 2,197 African Americans, Hispanic Americans, and Native Americans from a cohort of more than 16,000 students—while these groups are still underrepresented, 14% is a significant improvement.

Approach to research and outreach on health disparities of the National Institutes of Health (NIH)

In response to the recognition of health disparities as a national health crisis, Congress passed the Minority

Health and Health Disparities Research and Education Act of 2000 [12]. While the act is comprehensive and includes six titles, title I specifically designates NIH's responsibilities to improve minority health and reduce health disparities. The act established the National Center on Minority Health and Health Disparities, which authorized NIH to develop a strategic plan for how NIH could contribute to reducing health disparities. NIH's mission was "to support and promote biomedical and behavioral research, research training, research capacity, and research information dissemination, with the goal of improving the health status of minorities and other health disparity populations." Each NIH institute and center developed a strategic plan for health disparities within the broader framework of NIH's Strategic Plan [1], which included three major goals, as described above: research, research infrastructure, and public information and community outreach.

NIH's initial efforts focused on specific racial or ethnic minority populations, including African Americans, Asians, Pacific Islanders, Hispanics, Native Americans, and Alaska Natives. NIH's institutes and centers were expected to (a) target research that would contribute to understanding how diseases and disabilities adversely impact minorities and underserved populations, (b) support the improvement of the research infrastructure to increase and ensure a sustainable research and workforce capacity, and (c) vigorously pursue public awareness and community outreach programs to facilitate the transfer of research findings and the dissemination of information to health care providers as well as the public.

Special NLM resources

Because the issue of health disparities is complex, a multifaceted approach and mix of organizations and individuals was seen by the Sullivan Commission, NIH, and other reports as required to reduce health disparities. NLM is in a unique position regarding the dissemination of biomedical research information to health care providers and the public. NLM-developed resources are foundational to disseminate research findings to the biomedical community and provide authoritative and up-to-date health information to the public. Resources such as MEDLINE, MedlinePlus, ClinicalTrials.gov, TOXNET, AIDSinfo, and Genetics Home Reference provide access to peer-reviewed research reports and quality health information.

In addition to the high-quality health informatics resources it offers, NLM also manages a national network of more than 5,000 health sciences libraries. NN/LM is a critical component of NLM's outreach program and its efforts to help reduce and eliminate health disparities. Partnerships and collaborations are essential to working toward the reduction and elimination of health disparities. NN/LM members have been collaborating and partnering with NLM for 37 years.

A major part of NN/LM's efforts is devoted to developing awareness programs, providing training in

the use of NLM's resources, facilitating and improving the public's access to electronic health information, and developing multi-institutional partnerships with an array of organizations. NN/LM members have conducted collaborative outreach and consumer health efforts with academic health sciences and hospital libraries; state, public, and school libraries; area health education centers; local and state health departments; community health centers; and community- and faith-based organizations. NN/LM members have conducted hundreds of projects aimed at increasing public awareness of high-quality electronic health information resources. These projects have involved a variety of community- and faith-based groups and organizations whose objectives are to improve public access to high-quality health information. NLM's collaboration with NN/LM members is a well-established and effective mechanism to engage organizations and groups whose objectives are to work toward eliminating health disparities. Outreach projects managed or funded by NN/LM complement other important outreach projects conducted or sponsored by NLM's Specialized Information Services Division and Office of Health Information Programs Development.

ASSESSMENT OF NLM'S NATIVE AMERICAN OUTREACH

A major objective of the December 2 and 3, 2004, "Symposium on Community-based Health Information Outreach," and especially a Native American outreach work session held immediately afterward, was to assess NLM's Native American outreach activities. Attendees were asked to evaluate NLM's Native American outreach projects in light of the symposium's presentations and the goals set by NLM's Strategic Plan for Addressing Health Disparities. The results reported below refer directly to NLM's portfolio of Native American outreach projects and initiatives. NLM's capacity to respond to each area and an overall assessment of the relative success of combined efforts are critiqued, with direct reference to some Native American initiatives that NLM and its NN/LM and other partners have advanced. A comprehensive description of NLM's Native American portfolio is provided in a companion paper.

Based on the symposium presentations, work session discussion, and related evaluative activities, NLM's Native American outreach portfolio is assessed below. The results of the ad hoc evaluation are presented in three categories: areas of emphasis in NLM's Strategic Plan for Addressing Health Disparities, strategies underlying the NLM health disparities plan, and key assessment questions posed in the introduction. The results reported below are the opinions of the authors. However, the authors' reporting of results reflects both symposium presentations and discussion and a consensus among the attendees of a work session that immediately followed the symposium. The work session included members of American Indian, Alaska Native, and Native Hawaiian communities and

interested researchers and librarians, all of whom had attended the symposium. John C. Scott, Tlingit Indian and president of the Center for Public Service Communication, prepared a summary of the work session; key elements of the summary are incorporated in this paper.

For the convenience of the reader, the assessment begins with a thumbnail sketch of NLM's portfolio of Native American outreach, because the following discussion refers to the several categories or clusters of outreach projects. See the companion paper for the complete portfolio.

Thumbnail sketch: NLM's Native American outreach portfolio

- **Tribal Connections I (1998–2000, Pacific Northwest) and II (2000–2001, Pacific Southwest):** conduct technical needs assessments, improve IT infrastructure and Internet connections, carry out on-site health information training, develop partnerships for sustainability
- **Tribal Connections III (2001–2003, Pacific Northwest):** conduct tribal community-based outreach, integrate Regional Medical Library (RML) outreach with tribal health promotion activities, include evaluator on outreach team
- **Tribal Connections IV (2003–ongoing, Four Corners Region [Arizona, New Mexico, Utah, Colorado]):** build collaborative tribal outreach relationships among RMLs and Resource Libraries (RLs) in the Four Corners Region, conduct tribal health information outreach needs assessments, build tribal contacts database, build lessons learned database, contribute tribal health information to regional Go Local, include evaluator on project team
- **Native Internship Pilot Project, Sacred Root (2002–ongoing, Mandan, Hidatsa, and Arikara [MHA] Nation [Three Affiliated Tribes], North Dakota; Nez Perce Tribe, Idaho; Papa Ola Lokahi, Hawai'i):** provide training and education for midlevel tribal professionals, strengthen skills needed for tribal health information programs, enhance people and organizational networking, fund pilot projects at each participating tribal location
- **Tribal college outreach and librarianship projects (2001–ongoing, tribal colleges in North Dakota, South Dakota, Arizona/New Mexico, Kansas):** increase awareness of NLM's health information resources, strengthen health-related curriculum and training programs, enhance IT infrastructure where needed, support health sciences internships for Native Americans
- **Collaboration with inter-tribal and national tribal organizations (2001–ongoing, various locations):** participate in meetings of the Association of American Indian Physicians, National Tribal Environmental Council, and National Congress of American Indians (NCAI); support and participate in NCAI President's Task Force on Health Information and Technology
- **Participation in Native American Powwows (2001–ongoing, mid-Atlantic, New Mexico, and elsewhere):**

conduct health information outreach at select powwows, minority recruitment, cross-cultural experience for NLM staff

- **Native American Listening Circle Project (2003–ongoing, Dakotas, Hawai'i, Alaska to date):** encourage open dialogue between tribal and NLM leadership, share perspectives and needs, identify opportunities for collaboration in follow-on projects and activities
- **Tribal economic development and job creation (2004–ongoing, North Dakota):** provide equipment and training support for a tribal small business in the IT/scanning market, provide NLM materials suitable for scanning
- **Native American health information (1998–ongoing):** develop Websites and pages with health and health-related information relevant to Native Americans; Websites include Tribal Connections <www.tribalconnections.org> (since 1998), Native American Health on MedlinePlus <<http://www.nlm.nih.gov/medlineplus/nativeamericanhealth.html>> (since 2000), Arctic Health <www.arctichealth.org> (since 2002), and American Indian Health <<http://americanindianhealth.nlm.nih.gov>> (since 2004)
- **Other Native American outreach projects (ongoing):** conduct various other projects involving Native Americans at locations around the country

Areas of emphasis

With regard to the three areas of emphasis in NLM's Strategic Plan for Addressing Health Disparities, the work session participants concluded that the current portfolio of Native American outreach projects appears most advanced in area 1, "Promote Use of Health Information by Health Professionals and the Public." All the major elements of NLM's portfolio, with the exception of tribal economic development and job creation, were seen as providing significant attention to promoting health information use by health professionals who serve Native Americans and/or directly by Native community members. Workshop attendees and symposium presenters also noted that the goals of area 1 have been embedded in almost all NLM- and NN/LM-sponsored Native American outreach projects, and NLM has the most extensive experience in this area.

The portfolio was seen as advanced and progressing significantly in area 2, "Expand Partnerships among Various Types of Libraries and Community-based Organizations with the Goal of Forming Community Coalitions to Improve Access to Health Information by Members of Minority and Underserved Populations as well as Health Professionals Serving These Populations." The following NLM portfolio elements were seen as particularly well matched with area 2: Tribal Connections IV (Four Corners), Native American internship, tribal colleges and tribal librarianship, collaboration with inter-tribal and national organizations, Native American Listening Circle Project, and select other Native American outreach projects. Some work session participants noted that NLM should take more

advantage of opportunities to strengthen the role of partnerships and diffuse NLM's knowledgebase about effective partnering, across its spectrum of Native American outreach initiatives.

NLM's portfolio was seen as more limited with regard to area 3, "Conduct and Support Informatics Research." NLM has a reasonably extensive history with satellite-based telemedicine projects with Alaska Natives. More recently, two now-completed telemedicine projects with the University of Alaska at Anchorage and the University of Washington at Seattle featured significant Native American involvement. NLM's Listening Circle Project identified some new opportunities for informatics projects, including possible Native telemedicine projects in Hawai'i and Alaska, with potentially stronger evaluative components. The symposium highlighted the need to develop more relevant evaluation models for projects involving minority and underserved populations, including Native communities. NLM was charged to think more creatively about informatics research projects involving Native communities.

Underlying strategies

The introductory section listed the strategies that undergird NLM's Strategic Plan for Addressing Health Disparities. In general, the current NLM Native American outreach portfolio appears to parallel many of these strategies:

- Improving the information infrastructure and communications capabilities of minority communities and academic institutions: NLM has developed the following initiatives: Tribal Connections, Native American Internship Project, tribal college outreach and tribal librarianship, tribal economic development, select other Native outreach projects.
- Employing communication methods that are racially sensitive and culturally appropriate: Work session participants found that this strategy was well implemented in most current elements of NLM's portfolio. Despite progress, this strategy was seen as requiring NLM's continued attention and improved implementation.
- Increasing the scope of information products and services to include cultural, psychological, behavioral, social, gender-based, and environmental influences: NLM-sponsored general- and special-purpose Websites cover a range of health and other information relevant to Native Americans. NLM's collaboration with intertribal and national organizations also was seen as directly supporting this strategy.
- Training minority health professionals, information professionals, and community members to use high-quality health information resources: NLM has developed the following initiatives: Native American internship project, tribal college outreach and tribal librarianship. NLM also has initiatives that match this strategy via Tribal Connections, tribal economic development, and some other Native American outreach projects.
- Building effective partnerships with community-

based and professional organizations: NLM initiatives include Tribal Connections, collaboration with intertribal and national organizations, Native American Listening Circle Project and related follow-up projects, and select other Native American outreach projects. Symposium and work group attendees noted that NLM needs to remain mindful of this strategy in almost all of its future Native American outreach projects.

Key assessment questions

The introduction posed a series of evaluative questions. Each question is repeated below, followed by a brief response. All responses summarize the discussion during the symposium and work sessions about each area.

- Are the areas of emphasis properly framed? Participants in the work session suggested that the currently defined areas of emphasis are applicable and complementary as applied to the current NLM Native American outreach portfolio.
- Are the strategies targeted to achieve the maximum benefits consistent with available resources? Symposium and work session discussions noted that the current portfolio seems reasonably well balanced, but improved project evaluations will be needed to assess fully whether the deployment of resources is optimal. This will become more important if NIH, NLM, and NN/LM budgets decline. The symposium and work session discussions identified some new or enhanced areas that warrant consideration (see "Suggestions for Future Directions").
- Has NLM initiated the right kind of projects? Is the overall portfolio of projects appropriate? The symposium and work session discussions concluded that NLM's current array of projects is appropriate and should be continued, but new directions that deserve consideration were identified (see "Suggestions for Future Directions").
- Does NLM have the right partners? Overall, the discussion indicated that NLM is on the right track in developing diverse Native American partners, but this effort needs to be enhanced. The different types of partners identified included Native American health care professionals (including community health aides or the equivalent) and other health professionals serving Native communities; Native and non-Native outreach and related professionals serving Native Americans; librarians and libraries that serve Native American communities; Native and non-Native educators and teachers (and their educational institutions) that serve Native students of all ages (K-12 through adult); local Native and tribal leaders and elders in communities involved or likely to be involved with NLM outreach projects; the national Native American leadership and advocacy community (including such groups as the National Congress of American Indians, National Indian Health Board, Association of American Indian Physicians, National Indian Council on Aging, and Native American Journalists Association); Native health writers and journalists; and Native American

health information consumer activists and advocates in the participating Native communities.

NLM appears to have made substantial progress during the last eight years with all of these groups except, perhaps, for the last two. To better reach the Native media, a special Native Writers Project has been suggested. To better engage Native activists, project planning could give greater attention to including Native community-level health-related advocates in outreach projects.

■ Is NLM sensitive to their (the partners') needs? The Native American Listening Circle Project, implemented in 2003–2004, was seen as illustrating NLM's understanding of the importance of listening to the Native communities and their leaders, in the true spirit of dialogue and consultation. The original Tribal Connections Phase I Project in the Pacific Northwest helped crystallize the importance of community-level consultation and involvement either at the outset or, preferably, before any project decisions are made. NLM was seen as understanding the importance of consultation with the Native community both at the project-specific level and at the regional or national leadership levels. However, work session participants noted that it will take more time for NLM and its partners to fully translate lessons into planning models, field training, and operational realities.

■ Is NLM making a difference? Symposium and work session participants noted that this was the most difficult evaluative question to answer. Work session participants identified positive short-term impacts from most of the projects in NLM's portfolio, but longer-term and cumulative impacts were seen as more difficult to assess. Symposium sessions emphasized that improved evaluation models are needed at both levels. Overall, the work session suggested the answer to this question is yes: NLM is making a difference at the project level. NLM also is making headway in some regional and national collaborations that appear to serve intended audiences. However, work session participants noted that NLM's Native American future outreach initiatives require more creativity to leverage and partner efforts and to develop improved models for planning, collaboration, evaluation, and knowledge transfer and knowledge building. The symposium and work session provided recommendations to advance NLM and NN/LM's future Native American outreach initiatives. These perspectives and recommendations are reflected in the following sections of this paper.

KEY THEMES

On making a difference

Work session participants noted that a single government agency cannot satisfactorily create and improve the Internet, computer, telecommunications, and other infrastructure—as well as provide for the training, research, and delivery of programs—needed to significantly improve access to and use of health information by health professionals serving Native communities and by members of Native communities. No single

government agency has the infrastructure or financial resources necessary to overcome health disparities and to carry out other initiatives needed in Native American (or other) communities. Nevertheless, one strength of NLM's Native American outreach program was its focus on expanding partnerships among various types of libraries and community-based organizations that serve Native Americans, with the goal of forming community coalitions to leverage scarce resources and involve Native communities in outreach efforts. Additionally, NLM's train-the-trainer strategy, used in many of its outreach programs, has a multiplier effect that, over time, was seen as widely extending the benefits of its programs. The train-the-trainer approach and development of community alliances was seen as similar to the adage: "Give a community a fish and you have fed them for today. Teach a community to fish and you have fed them for a lifetime."

Work session participants noted that NLM can claim more Native American beneficiaries than the numbers of persons who have been formally trained by NLM or partner recent initiatives. Richard Mayer, chief executive officer of the MHA Tribes in Ft. Berthold, North Dakota, who was involved in this multiplier effect, offered an example.

Mayer was one of the first interns in NLM's Sacred Root tribal health information internship program, implemented in cooperation with the NCAI President's Task Force on Health Information and Technology. During his internship, Mayer developed a plan to create a mobile computer lab for the tribe that was subsequently funded by NLM. Part of the funding enabled Bruce Hall, a consultant from the tribe, to travel to Grand Forks, North Dakota, to receive training in the use of NLM databases from Judith Rieke, assistant director of the Library of Health Sciences at the University of North Dakota. When he returned to Ft. Berthold, Hall took the mobile lab to schools and elder programs on the reservation and has since worked with more than 700 children and 400 elders. The tribe then hired Hall on a full-time basis. Currently, in addition to the mobile computer lab, Hall manages the tribe's Sacred Breath diabetes program, another project of the NCAI Task Force in collaboration with NLM and Georgetown University.

In addition, NLM has worked with the NCAI President's Task Force on Health Information and Technology and the US Senate Committee on Indian Affairs to convene statewide Tribal Leaders Summits on Health Information and Technology with Senators Tim Johnson and Mike Crapo in South Dakota and Idaho, respectively. These summits were seen as well received; they provide a model for a national program that was proposed by former US Senator Benighthorse Campbell (Colorado), when he served as chair of the Senate Committee on Indian Affairs.

Symposium and work session participants noted that during the past eight years, NLM's Native American outreach initiatives have evolved into a more programmatic approach. NLM's portfolio includes many types of projects and activities. The symposium and

work session discussions, as well as project evaluations, interviews with various project participants, and comments from outside observers and reviewers, strongly suggest that NLM has met or exceeded expectations in its Native American outreach initiatives. Outside observers have noted that NLM, without having identified it as an objective, may well have developed and funded the largest body of Native American, Alaska Native, and Native Hawaiian health information outreach programs of any federal agency outside of the Indian Health Service. Indeed, NLM's 1995 review of its outreach activities noted the paucity of Native American projects [13]. Certainly, during the past eight years, NLM was seen as advancing its Native American outreach from a few isolated projects into a coherent program [14].

Importance of consultation

Symposium and work session participants emphasized that, like most minority communities, Native Americans rarely have had the opportunity to consult with federally sponsored service and outreach programs, especially regarding health and medical challenges. Symposium and work session participants reiterated general concerns in the Native American community about lack of meaningful consultation, particularly regarding federally sponsored research involving Native populations. Participants noted that consultation with Native American communities probably will be the lynchpin of NLM's future initiatives. For example, symposium presentations noted the reluctance in minority communities to trust outsiders who do not take the time or devote the energy to consult with them before initiating projects. Besides pre-project consulting, symposium presentations stressed that NLM's portfolio demonstrates a flexibility to continue to invest time and financial resources in successful projects that lead to follow-up activities as well as to projects where methods change midstream thanks to consultation with outreach participants.

Symposium and work session participants noted that NLM frequently has listened to Native American communities and leaders from the local to national levels. Listening Circles have proved to be effective means for NLM and NIH to implement American Indian, Alaska Native, and Native Hawaiian community consultation consistent with the Department of Health and Human Services (DHHS) and White House guidance (executive order 13175 of November 6, 2000, "Consultation and Coordination with Indian Tribal Governments"). The NIH director's Council of Public Representatives (COPR) specifically mentioned NLM's Listening Circles as a model to "ensure that senior NIH decision makers receive and fully consider public input" [15]. Also, Surgeon General Richard Carmona in his February 10, 2004, address to NLM's Board of Regents, observed:

NLM's new "Listening Circle" initiative shows that the Library is leading the way to meet with Native American communities on an informal, collegial basis to improve com-

munication; explore ideas, needs, and capabilities; and develop new collaborations. The "Listening Circle" project is consistent with the Administration's commitment to community-based consultation and partnership. [16]

The Listening Circle is a Native American concept that enables an open dialogue and exchange of perspectives and information between people to build mutual understanding and trust on which future collaborations are based. With the benefit of guidance and intermediation from outstanding leaders of the Native community, the NLM Listening Circle Team effort brought NLM Director Donald A. B. Lindberg and senior staff to three Listening Circles convened with tribal leaders and elders in North Dakota, Hawai'i, and Alaska. NIH's Director Elias Zerhouni and members of his staff later went to Alaska as well.

As a result of the Listening Circle consultations, the NLM Listening Circle Team planned and is implementing new collaborative outreach initiatives to reduce health disparities that have significantly exceeded expectations. Some of these projects were introduced during the symposium:

- a pilot program at the MHA Nation of North Dakota (established with guidance from Tex Hall, tribal chief and president of the National Congress of American Indians) to support job creation on the reservation by assisting a Native-owned business to recruit and train tribal members to perform electronic journal scanning for NLM
- improvement of library infrastructure and services at nine tribal colleges that are the principal sources of higher education on Indian reservations in North Dakota and South Dakota
- two innovative pilot projects in remote areas of Hawai'i that serve Native patients at a community health center (Waimanalo) and community library development in Native villages (Miloli'i)
- assessment of health information infrastructure needs and a skills workshop for school staff and community health aides who are the only source of health care in an isolated Native village above the Arctic Circle (Buckland)
- augmentation of NLM's collections and databases with new health information resources that accurately reflect Native cultures, traditions, and healing
- a planned NLM exhibition for the public on Native health

Appropriate evaluation models

NLM has a long-standing commitment to outreach evaluation. However, a 1995 outreach review concluded that NLM's outreach evaluations should be more consistent and better integrated into various stages of each project's planning and development. As a result of the 1995 review, NLM collaborated with the Pacific Northwest RML at the University of Washington to prepare an outreach evaluation field manual [17]. The field manual was developed to parallel the original Tribal Connections project, which implicitly adopted tribal consultation and tribal needs assessment as es-

sential elements. Since its development, the field manual has been applied to a range of NLM and RML outreach projects, including some Native American projects. Consideration is being given to revising, adapting, or extending the field manual to focus more directly on community-based outreach, either as a revision or as a separate extension suitable for community-level use.

Further efforts to enhance NLM's evaluation were the topic of several presentations at the symposium that is the basis of this supplement. Several presentations discussed lessons learned from prior Native American (and other) outreach. While the symposium presentations addressed evaluation in a range of community outreach activities, all the presentations were relevant to Native American outreach. Symposium presenters and discussants reinforced the Key Points of Discussion of the June 1998 NN/LM Project Advisory Panel Meeting, which noted implicitly the importance of participatory approaches to achieve outreach objectives and the need to distinguish between relatively limited and more far-reaching outcomes:

The evaluation process helps the local outreach planner better understand (i.e. research) how health information is most critically needed and most usefully promoted. Thus, in a community such as Alaska Native/American Indians, just tracking user increases of Western-based knowledge resources will ignore other outcomes more important to this community, such as development, control, and/or identification with data relevant to Indian health. Likewise, for local decisions about maintaining library resources in a rural hospital, tracking the increase in document requests may not be as useful an outcome as tracking the ways this information has changed or influenced patient care decisions. [18]

Several symposium speakers also emphasized that NLM and NN/LM should not assume there is a "gold standard" for outcomes research based on traditional outreach models. NLM and NN/LM were advised to be open to new approaches and to engage nontraditional partners.

More important, the symposium and work session participants noted that return visits to communities already engaged in outreach efforts need to be conducted, so that NLM and NN/LM are perceived as long-term trustworthy partners.

Some lessons learned

NLM has drawn some key lessons from outreach projects conducted during the past several years that may be widely applicable to a wide range of Native American (and other community-based) outreach. These lessons add another dimension to the results from NLM's overall Native American outreach portfolio. They were widely discussed or validated during the symposium:

- Consultation with local community leaders and key staff is vital to create a successful project.
- A local needs assessment, conducted early in the project and in a collaborative fashion, helps ensure that scarce resources are applied in a maximally leveraged and responsive manner.

- Site visits by the project team are essential to a successful local needs assessment.
- The site team needs to develop a grassroots understanding of the people and their community.
- Community empowerment is an important key to project success.
- To be most effective, an evaluative component should be included in the project plan from the outset.
- To ensure a good evaluation, the project evaluator should be a key part of the project team and should spend significant time in the field.

SUGGESTIONS FOR FUTURE DIRECTIONS

The symposium and work session discussions provided the following suggestions for the possible future directions of NLM's Native American outreach initiatives. While many of these suggestions build on some of the previously discussed initiatives, they also provide a glimpse into the diverse NLM and NN/LM new project possibilities presented during the symposium. The suggestions are clustered into three groups:

Overall thematic directions

- Continue the current balanced portfolio (see accompanying paper for details), but with some modifications and enhancements discussed below.
- Consider emphasizing capacity building in Native communities (to include training in grant writing and administration, as well as technical and human infrastructure). NLM and NN/LM's Tribal Connections and tribal college outreach projects have some capacity-building elements, as does the Tribal Economic Development Project. Many projects have tribal empowerment at least as an implicit goal. But the importance of capacity building and empowerment could be better developed and defined as an outreach priority in the future.
- Continue to emphasize the importance of site visits and direct interactions to establish working relationships with Native American communities.
- Continue to emphasize the importance of partnerships with libraries, health clinics, and community organizations that serve Native American populations.
- Continue to emphasize partnerships with national Native American leadership organizations and participation in conferences where appropriate.
- Consider special health information training and outreach for community health aides and other Native/tribal health workers who directly serve Native populations.
- Consider extension and adaptation of the highly successful Listening Circles Project to include subregional and content-focused variations.
- Continue to develop, improve, and promote NLM-supported Native American-centric Websites, in part through application of Web evaluation methods and metrics to obtain user feedback on content enhancements and design upgrades. Enhance the cross-platform coordination and cross-linking among the family

of NLM-supported Native American-centric Websites and with the Native American Health page of MedlinePlus.

Project-specific directions

- Consider working with Native media, including radio and newspapers, as they are important communication channels in Native communities. A Native Health Writers workshop could strengthen both the communications and media component and health literacy in Native communities.
- Consider strengthening urban Indian outreach initiatives. About half of Native Americans live on or near reservations or villages in remote areas. The other half live in urbanized areas. Urban Indians are in some ways harder to reach because they are dispersed in the general population, but there are organized efforts in some metropolitan areas, such as Los Angeles and New York.
- Strengthen the role of Native youth projects. Limited recent experience with Native youth, combined with the highly successful MedHigh project (using high school peer tutors to reach other students at a magnet health high school in the Lower Rio Grande Valley of Texas; see Cynthia Olney's paper in this supplement), suggests highly leveraged opportunities for Native Youth involvement. Native communities place a high priority on helping their youth to have healthy, successful lives.
- Consider developing models for participation in Native American powwows and health fairs. NLM's and NN/LM's experience suggests that these events are highly leveraged mechanisms to reach Native (and other) populations who would otherwise have little exposure to NLM's health information resource. A national NLM and NN/LM strategy may be warranted.
- Identify informatics project concepts such as telemedicine, electronic patient records, and health provider prescriptions for health information that might be relevant to Native communities and engage in dialogue with select Native groups to assess if these or other concepts could be viable and empowering.

Knowledge building or evaluative directions

- Develop an evaluation package tuned to Native American outreach. The package should include model projects and related training that incorporates suggestions in the symposium presentations. This package should include planning, evaluation, and outreach models.
- Revise and/or extend the outreach planning and evaluation field manual to focus on community-based outreach and, more specifically for the purposes of this paper, on Native American outreach.
- Enhance current mechanisms for exchange of ideas and consolidate the lessons learned from Native American outreach. NLM and NN/LM might consider use of one or more of the Native American-centric Websites as part of this process. NLM and NN/LM appear to be generating useful information and ideas but do

not always capture and diffuse these ideas to new and existing partners.

CONCLUDING THOUGHTS

The symposium and work session reinforced the view that partnering and shared perspectives are key reasons for NLM's and NN/LM's advances in Native American outreach. The concepts of partnering and sharing perspectives are well understood by Native Americans. Both are reflected in various Native philosophies and models, such as the Medicine Wheel concept. In the Medicine Wheel, any idea, object, or activity may be perceived differently by various members of the tribal community.

The understanding of multiple perceptions and various participants embedded in the Medicine Wheel reflects the need to understand the multiple perceptions of participants and stakeholders in Native American outreach. Of course, a diversity of viewpoints sometimes contributes to varying degrees of misunderstanding. To ensure a therapeutic outcome, the Native American approach embodied in the Medicine Wheel (and the Listening Circle) is to ensure that all perspectives are considered and respected. The symposium and work session discussions confirmed the importance of this principle, regardless of wide variations in the specifics of individual outreach projects and activities.

NLM also has been receptive to involvement in varied and sometimes eclectic partnerships, as is the case with Native American outreach. In her keynote address to the community-based outreach symposium, Eugenie Prime, former chair of the NLM Board of Regents and retired manager of corporate libraries at Hewlett-Packard, referred to a need to be receptive to "promiscuous partnerships." She urged NLM and NN/LM to "reach out beyond its traditional constituents" and to choose nontraditional partners, because they can help NLM attain challenging goals, such as overcoming health disparities. Prime challenged NLM to pursue outreach and partnerships with passion and to embrace a disciplined commitment to execution. She suggested a "Manhattan Project" for community-based health information outreach would serve NLM and NN/LM well. NLM's Native American outreach program represents some significant steps toward that end. All the elements are in place and await the availability of sufficient resources.

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