LONG TERM CARE IN INDIAN COUNTRY

New Opportunities and New Ideas

REPORT of the CONFERENCE

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Long Term Care in Indian Country: New Opportunities and New Ideas

Monday and Tuesday, November 1 and 2, 2010, Washington Marriot Wardman Park, Washington, DC

REPORT of the CONFERENCE

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Section 1: INTRODUCTION

Over the course of two days, from November 1 to November 2, 2010, 174 individuals gathered in Washington, DC, to participate in a meeting titled *Long Term Care in Indian Country: New Opportunities and New Ideas*. This conference was designed to begin the conversation in Indian Country about how to further support the development of long term services and supports in light of the new authorities for long term care in the permanently reauthorized Indian Health Care Improvement Act (IHCIA).

Indian Health Service (IHS) Director Dr. Yvette Roubideaux challenged participants to explore the future of long term care supports and services in Indian Country and to identify some of the major ideas and promising pathways for action in the coming months. The ideas generated at this meeting are a precursor to and will inform Tribal Consultation on implementation of the IHCIA.

The conference was shaped around a series of presentations followed by plenary and breakout discussions, with extensive and detailed note-taking during the discussions. While formal presentations served to frame the discussion and provide participants with information and insight into long term care nationally and in Indian Country, the participant discussion was the heart of the meeting. In the vigorous, wide-ranging, and insightful discussions following the plenary presentations and during focused breakout sessions, participants shared experience, expertise, and critical, on-the-ground perspectives about the needs and opportunities for further development of longterm services and supports for American Indian and Alaska Native (AI/AN) people. They highlighted the questions that must be answered as IHS moves in partnership with the Tribes and Urban Indian Health Programs to take full advantage of the new authorities contained in the IHCIA. The conference did not include a formal consensus development process (e.g., resolutions); the conference's purpose was to bring forth a rich set of ideas. This report captures the participant discussion following plenary presentations and in the critical issues breakout sessions as well as the formal presentations that framed the discussion. The content is organized to reflect and document the flow of ideas at the conference.

This is the beginning of the conversation on long term care. Formal Tribal Consultation will follow and will shape the priorities of the IHS. Together, the IHS, Tribes, and Urban Indian Health programs will continue to explore new opportunities and ideas that will expand the availability of long term services and supports for AI/AN people.

Section 2: EXECUTIVE SUMMARY – Major Themes and Key First Steps

The following is a summary of the major themes that arose during the meeting and some of the key first steps the IHS and other federal agencies can take to expand long term services and supports in Indian Country.

Major Themes

1. Tribes and Urban Indian communities should retain control, leadership, and ownership of long term services and supports.
    - IHS direct services can and should be a partner in the delivery of care.
    - Tribes should have the option of managing all aspects of long term care provided to Tribal members.

2. The Tribal long term care programs that are successfully operating demonstrate that there is a business model for long term care in Indian Country.

3. It is useful to distinguish between the funding needed to support development and initiation of programs and the funding needed to support ongoing operations of these programs.

4. The IHS and Tribes need to further explore how best to use and enhance the resources available (financial and workforce) at the Tribal and community level to provide long term services and supports. This might include:
    - sharing of services between health programs (either direct federal or Tribal) and Tribal long term care programs;
    - integrating services funded and designed to support individuals with disabilities with those targeting support of elders; and
    - coordinating services funded by the Administration on Aging (AoA), IHS, and the Veterans Administration (VA).

Key First Steps

1. The IHS and other Federal Agencies should:
    - Address the complicated jurisdiction for services across states
    - Explore centralized licensure, certification, and regulation with Centers for Medicare and Medicaid Services (CMS), including a possible role for IHS in certification and licensure
    - Coordinate between the IHS and the VA to (1) increase access to long term care services for veterans, (2) increase the purchase of long term care services from Tribal programs, and (3) clarify the meaning of "Payer of Last Resort" language in the IHCIA

2. Explore with CMS the development of a reimbursement mechanism and rate-setting methodology specific for long term care services and supports provided by federal and Tribal providers.

3. Clarify the following issues that arise with inclusion of long term care in Annual Funding Agreements (AFA).
    - Federal Tort Claims Act (FTCA) coverage
    - Reimbursement rates for federal and Tribal providers of long term care
    - Model draft language for Tribes that desire inclusion of long term care services in AFA

4. Identify training and workforce development needs.
    - Identify training needs for both Tribal and IHS staff providing long term care and hospice services
    - Develop training opportunities for IHS and Tribal staff delivering long term care and hospice services
    - Address the huge need for training for family caregivers
    - Create consistency between IHS (direct federal) positions that may provide long term care or hospice services and the staff certification requirements for CMS or state-certified long term care services; this will facilitate licensure, certification, and reimbursement for services provided by IHS and Tribal programs

5. Determine funding needs.
    - For feasibility or demonstration projects
    - For the development and initiation of programs

6. Explore technical assistance needs.
    - Create opportunities for Tribal and IHS long term care programs to share learning with each other
    - Provide or facilitate state-specific training and technical assistance, especially for small and frontier rural Tribes, to allow for planning and program development based on state requirements
7. Identify the Health Information Technology (HIT) requirements for IHS and Tribal long term care programs and integrate these requirements into the IHS HIT development cycle.

8. Open discussions with Tribes to explore the value and feasibility of sharing services and underutilized space for long term care.

9. Create or facilitate opportunities for education and training about hospice and palliative care, including basic, plain language education about what they are, why they are part of the continuum of care, and the creative ways that some IHS and Tribal programs are successfully providing this care.

10. Provide access to best practices and guides for long term care facility design with construction and operational cost estimates.

11. Develop partnerships and collaborations to address the housing modifications needed so that elders and persons with disabilities can remain in their homes.

Section 3: GENERAL SESSION

Opening prayers were provided by Clayton Old Elk with the Crow Indian Tribe of Montana on Day 1 and by Andy Joseph of the Confederated Tribes of the Colville Reservation on Day 2.

Day 1: Morning Session

Welcome and Keynote Address

Update on Indian Health Reform and the New Authorities for Long Term Care in the Indian Health Care Improvement Act

Yvette Roubideaux, MD, MPH, Director, IHS

Dr. Roubideaux welcomed participants and provided an update on Health Care Reform and its impact on long term care in Indian Country. She gave an update on current IHS priorities and on reform efforts within IHS and reviewed the long term care provisions of the IHCIA. She challenged the participants to explore the future of long term services and supports in Indian Country and to identify some of the major ideas and promising pathways for action in the coming months so that these ideas can inform Tribal Consultation on implementation of the IHCIA.

Full text of Dr. Roubideaux's speech is found on page 24.

The Future of Long Term Care and the Aging Network

Cindy Padilla, Principal Deputy Assistant Secretary for Aging, AoA

Ms. Padilla offered a vision of the future of long term care and the Aging Network that embraces the very principles of the Older Americans Act, which honor dignity, independence, and personal choice. Ms. Padilla also expressed her enthusiasm that these principles can be incorporated into a long term care partnership between AoA and IHS to bridge health care services with long term services and supports.

Full text of Ms.Padilla's speech is found on page 37.

Advancing Independence through Long Term Care

Henry Claypool, Director, Health and Human Services Office on Disability

Mr. Claypool shared the perspective of people living with disabilities and explored the theme of advancing independence through long term services and supports. The efforts of those living with physical disabilities, developmental and intellectual disabilities, and disabilities related to mental health continue to change the long term care delivery system in the country. Mr. Claypool reviewed movements toward individual self-determination (the individual's right to direct care for themselves), the Americans with Disabilities Act (ADA), the Olmstead Decision, and the effect on the shift of state Medicaid resources from institutional care to care in the community, targeted toward the needs of the individual.

Notes taken from Mr. Claypool's presentation are found on page 41.

A Strong Foundation for System Transformation

Barbara Coulter Edwards, Director, Disabled and Elderly Health Programs Group, CMS

Ms. Edwards shared information on Medicaid changes that will take place as part of the Affordable Care Act. With the passage of Health Care Reform, health care coverage will expand toward universal coverage. The Affordable Care Act also includes a number of important opportunities to improve the care and services available to individuals with disabilities, individuals with chronic conditions, and individuals who are aging.

Notes from Ms. Edwards' presentation are found on page 43.

Questions and Comments from Participants

- We are concerned with the lack of mental health care professionals in the IHS. The Tribe feels AI/ANs experience high unemployment rates and asked, "Is being poor a disability?"Our Tribe is concerned with Fetal Alcohol Effect (FAE), Fetal Alcohol Syndrome (FAS), alcohol and drug abuse, domestic violence, suicide survivors and families, and car crash survivors who may become quadriplegic. The Tribe also has several people suffering from Post-Traumatic Stress Syndrome. We want to know how the American Counseling Association can help a Tribe like ours that has a Contract Health Services (CHS) Program and is trying to get services to people in their homes.
- A Tribe in Montana is concerned about reimbursements. While the Tribe can appreciate the lack of funding nationwide for services, the Tribal member said this is

nothing new in Indian Country. There is no cost to the state when Tribes provide services. If services are not included in the state plan, Tribes should be reimbursed; however, they are often not reimbursed for services provided. Is there room within the IHS to have special waivers to deal with Tribal concerns? The Tribal representative noted that Montana has a Director of Health Services who is a very good advocate for Indian services.

- A large, land-based Tribe is concerned about the trauma-care system and how it relates to providing care to elders.
- A Tribe from Arizona is concerned with the care of the elderly on their reservation. This Tribe has state-contracted individuals on the reservation through an urban program in Phoenix, AZ. The contractors are Tribal members, but they are supervised by a person from Phoenix who comes once a month. Care continues to be poor, and the Tribe lacks the authority to make positive change. Will states (and their contractors) be involved in improving long term care on reservations?
- For a California Tribe, the county is the public authority. This California Tribe asked how they can become their own public authority and tap into state funds and manage their own long term care services. The Tribe also wanted to know how that would work in the current environment.
- Another Tribal member noted that for long term care to be successful in Tribal communities, Tribes need to be able to provide continuum of care services. All tribes can provide some level of long term care services, no matter what size they are. The Center for Medicare and Medicaid Services (CMS) consults with Tribes, and states must consult with the Tribes when they change policies. The same is not true with AoA. Through AoA, Tribes must meet criteria to get funding, but often the Tribes cannot meet the criteria. Also, some funding comes in silos (earmarked for certain needs). How can AoA help in getting flexible funding to Tribes? What can AoA do at the federal and state level to require Tribal consultation?
- A Tribal member asked how Alaska Natives can incorporate end-of-life services. The Tribe is unaware of a single Alaska Native elder who is able to access the Medicare Hospice benefit because Tribal organizations are unable to meet the requirements to provide services.
- Currently, the translation of the changes in the Affordable Care Act through the states to Indian programs will take about 5 to 10 years. A Tribe from New Mexico asked how to get the translation of the changes through the Affordable Care Act from states to Tribes more quickly (education, dissemination of information, etc.).
- A member of a California Tribe said the states pick and choose what to reimburse. Clinics in California need technical assistance and guidance about best practices. The state does not have a case management wellness plan for Tribal elders.

Day 1: Afternoon Session

A Review of the Continuum of Long Term Care

Bruce Finke, MD, IHS and Nashville Area Elder Health Consultant

Dr. Finke shared definitions regarding long term care that were used throughout the conference, emphasizing that it is about services, not setting. He reviewed the continuum of long term services and supports and observed that existing services and programs are often defined by funding and regulatory requirements and do not always match the needs in the Tribes and communities. Dr. Finke asked participants to help IHS understand what services are needed and how IHS can help facilitate those services.

A National Survey of Long Term Care for Older American Indians and Alaska Natives

R. Turner Goins, PhD, Associate Professor, University of West Virginia

Dr. Goins discussed a survey of long term care in Indian Country conducted between 2005 and 2007 with the support of the Health Resources and Services Administration (HRSA). Dr. Goins shared the findings explaining that there was strong interest in long term care among Tribal programs; the highest percentage of programs and services available were those funded by AoA under Title VI of the Older Americans Act; the Medicaid program was the most common source of funding for other long term care services; and the most commonly cited barriers to the delivery of long term care services and supports were a lack of funding for development and ongoing operations of those services.

Tribal Long Term Care: Programs on the Ground

Kay Branch, Elder Planner, Alaska Native Tribal Health Consortium

Ms. Branch provided a number of examples of currently operating Tribal long term care programs, providing a sense of the specifics of the delivery of long term care in Indian Country. These programs covered the full range of services from home- and community-based to facility-based services. She shared a vision of a network of shared learning among Tribal long term care programs with Tribal organizations learning from each other how to provide better services to their own elders.

Notes taken from Ms. Branch's presentation are found on page 45.

Discussion Content from the Critical Issues Breakouts

In these Critical Issues breakout sessions, participants were asked to share their ideas and thoughts about specific topics of importance in Tribal long term care identified by the Steering Committee. In some cases, these are summaries provided by the participants; in other cases, they are transcriptions of individual comments.

Breakout 1: *Long Term Care and Indian Self-Determination*

Facilitator: Jim Roberts – Policy Analyst, Northwest Portland Area Indian Health Board

- Indian self-determination does not just mean contract/compacts; there should also be direct service to Tribes.
- It is more culturally appropriate to keep elders in their homes.
- Regarding the regulatory environment associated with providing long term care, there is a need to develop more flexible licensing and certification systems.
- Regarding funding issues, more technical assistance is needed from Medicaid and AoA to help Tribes understand how these systems are organized in their respective state.
- More workforce training and technical assistance around long term care is needed; this conference is a good demonstration of how Tribes can come together and discuss needs and how they are organizing long term care in their communities.
- Tribes want to know how they can be reimbursed for long term care services (e.g., fee-for-service).
- Current rate setting structures do not work for Tribes; reimbursement is needed that covers true costs for providing long term care.
- There should be sharing arrangements around long term care (e.g., staff coming to tribal facilities).
- Tribal control is essential; flexibility of services is needed to meet the needs of the community.
- Consultation with how to establish long term care in Indian Country is crucial and needs to continue into the future.
- Regarding self-determination, it is important for Tribes to get answers to some things.
- In regard to the IHCIA, Tribes want to know if there is FTCA coverage included in the funding agreement; this issue needs to be clarified for tribes.
- Training and technical assistance is needed to determine how long term care is developed in the states.

- Financing issues are critical; reimbursement issues and licensure certification issues need to be clarified.
- Tribes need a way to negotiate long term care with states.
- Better venues are needed to provide cross-training for long term care.

Breakout 2: *The Family in Long Term Care*

Facilitator: Margaret (Meg) Graves

In *The Family in Long Term Care Session*, the group focused on how IHS can help create dialogue and professional perspective for long term care, and they identified areas of funding and discussed the need for a method of sharing information on long term care.

- The IHS is following the Tribes as they lead long term care dialogues, and the Tribes appreciate IHS participating in this dialogue and fully expect their input to emphasize that Tribes are leading the dialogue. The Tribes expect IHS to help them create an environment of safety.
- Areas of funding and co-training expected from IHS are listed below.
    - Training (dementia, depression, housing, physical care of elders, elder emotions, different interpretations of elders and privacy, inter-generational family dynamics, elder abuse/elder rights, addictions, and transportation)
    - Caregiver support
- IHS should set up a system on the Internet to share dialogue about what the different Tribes are doing in long term care.
- Tribes will provide cultural competence in long term care. IHS should provide professional perspective. Tribes want to emphasize that they know what they are doing, know their communities, and can help IHS.

Breakout 3: *Ensuring quality, Integrated Long Term Care; the Regulatory Environment*

Facilitator: Margaret Moss

The group looked at three areas associated with long term care in regard to ensuring quality, integrated long term care, and the regulatory environment. The areas include quality, access, and cost.

Quality

- Now that there is authority for long term care within the IHS, honor the elders by making good programs that are developed with a lot of input from Tribes.

- IHS should provide educational opportunities for sharing comments on new regulations and help shape what this long term care program looks like.
- More flexibility is needed in nursing home licensing. Currently, it is almost impossible to mix skill levels (e.g., mixing skilled facility patients with assisted living patients and adult day care clients). The system artificially segregates elders instead of caring for them across service lines.
- Facilities should also be able to relax rules. For example, in one nursing home, if an elder misses 15 days from their bed, they currently lose their spot. This works against the elders maintaining their roles in the communities.
- Dr. Roubideaux talked about inter-agency/inter-departmental collaboration. There needs to be more information about states as they interact with the IHS.
- There is a need for culture/spirituality as a focus in long term care.

Access

- Although no one likes to be in facility care, AI/AN elders will always need this care.
- Tribes could partner with non-profit facilities to provide care.

Cost

- There are funding and licensure issues associated with long term care.
- There are jurisdictional issues regarding long term care, especially for Tribes who must cross state lines to receive care, and there is a problem with licensure for long term care services that are provided for those receiving care in states other than their own. The group recommended that CMS have regional AI/AN representatives look into these issues.

Breakout 4: *Identifying the Funding Streams to Support Long Term Care in Indian Country*

Facilitator: Turner Goins

Participants in this session shared their thoughts on funding streams to support long term care in Indian Country. They also touched on other issues such as training, housing, and education.

- Funding should be directly accessible to Tribes, so Tribes do not have to go through states to access federal dollars. Too many restrictions come with funding.
- IHS should offer training for long term health care providers and front-line workers.

- Tribes need a clear picture of where to get construction and operating funds to support long term care facilities.
- Substandard housing is an issue. Tribes are concerned that their housing doesnot meet the standards to properly house and care for the elderly. Funding needs to be sought to address this issue.
- Recurring dollars: often, funding is only available for a few years to address an elder issue or health issue, and when funding is gone, the program peters out.
- Tribes and IHS need to create a mechanism to hear what elders want.
- Funding is needed for feasibility studies.
- The IHS should engage in training, education, and retention.

Day 2: Morning Session

Federal Resources to Support the Development of Tribal Long Term Care – A Federal Panel

A panel of representatives from various federal agencies with important contributions to the development of long term services and supports in Indian Country discussed their programs and resources.

Office of Minority Health

Commander David Dietz, Senior Public Health Advisor

David Dietz addressed long term services and supports through the lens of health disparity and health equity and invited attendees to participate in the National Partnership for Action (NPA). The purpose of NPA is to establish a nationwide comprehensive, community-driven, sustained approach to ending health disparities. Components of the NPA include the National Action Plan, regional blueprints, initiatives, and campaigns.

Notes taken from Commander Dietz' presentation are found on page 47.

Lillian Sparks, Commissioner, Administration for Native Americans (ANA), Administration for Children and Families (ACF)

Lillian Sparks, a member of the Rosebud Sioux Tribe and a descendant of the Oglala Sioux Tribe, explained the role of ANA, a division of the Department of Health and Human Services, and how it can supplement existing long term care programs. ANA is an agency

that offers a highly competitive, discretionary grant program that provides funding for a variety of programs and services, including social and economic development strategies, environmental regulatory enhancement, and Native language preservation.

Notes taken from Ms. Sparks presentation are found on page 49.

Veterans Administration

Rick Greene, VA Office of Geriatrics and Extended Care

Mr. Greene reviewed the VA Home-based Primary Care Program and shared information about a current VA, IHS, and AoA project that is expanding the reach of this program to serve AI/AN veterans living on Tribal lands. He also reviewed the VA Medical Foster Home Program and VA Hospice and Palliative Care services. He invited attendees to reach out to their local VA medical center or clinic to explore opportunities to serve AI/AN veterans in need of long term services and supports.

Questions and Comments from Participants

- A Tribal member asked if the Tribe can work through Medical Foster Homes with families.
- One Tribal member talked about how important it is to keep children speaking their Native languages. She asked if there is an opportunity to develop cartoons that speak Native languages or if there are other language programs for young children.
- Tribes also wanted to know how they can seek cooperation between themselves and the IHS, as well as with other organizations.
- A member of a Pueblo Tribe said ANA funding has been monumental in restoring the Pueblo Tribe, and they would like to see Tribal Consultation with the VA.
- A Tribal member said that during his Tribe's Health Board meeting, they declared it the year of the veteran. He said his Tribe needs assistance for veterans and their children. Children are often strongly affected by their parents' experiences and problems.

Medicaid Home- and Community-based Long Term Care: New Opportunities

Anita Yuskauskas, PhD, Technical Director, CMS

Dr. Yuskauskas reviewed the current role of Medicaid in home- and community-based services and summarized recent legislation and trends affecting these services, with a special

focus on the new opportunities provided by the Affordable Care Act. Taken together, these represent an acceleration of the trend in recent years toward more home- and community-based services and person-directed care.

Tribal Perspectives on Home- and Community-based Care

Rick Richards, CEO, Cherokee Home and Health Services

Mr. Richards shared the Cherokee Nation's experience in providing home- and community-based services through Cherokee Home and Health Services, a totally self-supporting agency. Mr. Richards also discussed the Nation's Program of All-Inclusive Care for the Elderly (PACE), the first ever Tribal PACE program and one of the very first rural PACE programs in the country.

Notes from Mr. Richards' presentation can be found on page 49.

Peg Blakely, Director, Leech Lake Band of Ojibwe Elders Program

Peg Blakely shared lessons learned by Leech Lake Band of Ojibwe in developing and delivering home- and community-based care in northern Minnesota.

Notes taken from Ms. Blakely's presentation are found on page 50.

Pat Butler, Director, White Earth Community Center

Ms. Butler shared the experience of the White Earth Home and Community Health Agency in delivery of long term services and supports through the Minnesota Medicaid Waiver program since 2003. She encouraged Tribes to be persistent in building partnerships and to not quit.

Questions and Comments from Participants

- Tribes want to know if the Cherokee facility is its own corporation or a one-stop-shop for long term care.
- Another Tribal representative said it sounded like the Cherokee facility was able to coordinate all services.

- A Tribe from Arizona said they are reaching the limits of communication with the IHS and wanted to know how that can be improved.
- Another Tribe is facing issues with recertification for its Community Health Resources (CHR) program, which needs nurses and paramedics. They also asked if these programs go as far as billing emergency medical technicians (EMTs) through the Medicaid program.
- One Tribe needs federal assistance to develop 911 (e.g., tracking ability). The Tribe needs to renegotiate contracts to be able to assist in training and funding.

New Ideas and Tribal Perspectives in Facility-based Long Term Care

Kay Branch, Elder Planner, Alaska Native Tribal Health Consortium (ANTHC)

Ms. Branch facilitated a discussion of new ideas and Tribal perspectives on facility-based long term care. These models emphasize a more home-like environment and person-centered care with maximum resident control over their daily lives and activities. She also shared the interest of the ANTHC in the Green House model of care, designed to encourage and support resident function with smaller units (10 to 12 residents in each) and team-based care.

More information about the Green House model can be found at www.thegreenhouseproject.org.

Jane Smith and David Larson, Oneida Tribe of Indians of Wisconsin

Ms. Smith and Mr. Larson discussed the success of the Anna John Nursing Home, a 30-year-old facility in the Oneida Nation. Several years ago, the nursing home began to explore replacing its aging facility, but the Oneida Nation also wanted to make good decisions, knowing that there were good ideas and good research available to validate their process. Their presentation summarizes some of what they have learned.

Lee Olitzky, Administrator, Tohono O'odham Nursing Care Authority (TONCA)

Mr. Olitzky presented on behalf of Ms. Frances Stout, Chairwoman, TONCA. The presentation discussed TONCA, which was formed 15 years ago to meet the needs of elders and younger individuals living with disability. TONCA provides long term care within the Archie Hendricks Sr. skilled nursing facility, as well as post-hospital care, wound care, rehabilitation, hospice, and other services. They are working toward integrating home- and community-based services within their facility-based services.

Full text of Mr. Olitzky's speech is found on page 51.

Vickie Bradley and David Hunt, Tsali Care Center, Eastern Band of Cherokee Indians

Ms. Bradley and Mr. Hunt discussed the challenges and opportunities in operating a Triballyowned nursing home since 1996. Though the facility has great community support, it lacks the funding needed to bring it up to date. The facility offers residents as much flexibility as possible, and incorporates traditional foods and community participation into the care.

Notes taken from Ms. Bradley and Mr. Hunt's presentation are found on page 54.

Questions and Comments from Participants

- One Tribe said they are trying to integrate the IHS and Resource and Patient Management Systems (RPMS) to have good referral systems and medical records. They asked panelists if they had any experience with integrating Indian long term care and IHS systems.

Moving Beyond Paradigm Paralysis: Care at End of Life

Dave Baldridge, Director, National Indian Project Center

Mr. Baldridge challenged commonly held assumptions about cultural barriers to discussing preferences for care at end of life with AI/AN people. He presented four very different programs that have successfully met the need for palliative care in Native communities, reducing unnecessary pain and suffering at end of life.

Notes taken from Mr. Baldridge's presentation are found on page 55.

Day 2: Afternoon Session

Shared Services: What are the Possibilities?

Bruce Finke, MD, IHS and Nashville Area Elder Health Consultant

Dr. Finke reviewed the language of the IHCIA that refers to "shared services for long-term care" and provided an example of shared services between the Red Lake Service Unit and the Jourdain/Perpich Extended Care Center.

Read the full text of the IHCIA.

Discussion Content from the Critical Issues Breakouts, Day 2

In these Critical Issues breakout sessions, participants were asked to share their ideas and thoughts about specific topics of importance in Tribal long term care, identified by the Steering Committee. In some cases, these are summaries provided by the participants; in other cases they are transcriptions of individual comments.

Breakout 1 – Sharing of Services

This group discussed sharing of services between Tribes, IHS, CMS, and other agencies.

- Tribes should maintain control and leadership of long term services and supports.
- IHS facilities should open discussion with Tribes about shared services and underutilized space for long term care supports and services.
- It is important to distinguish between funding needs for startup versus long term operation – both are needed. Funding for demonstration projects should not be overlooked.

- A rate-setting methodology needs to be developed for reimbursement rates.
- This is an opportunity to rethink relationships between IHS and direct service Tribes. It does not have to be an either/or situation, both can share services.
- Tribes should be able to work with CMS and IHS directly.
- This group suggested that IHS propose model draft language for inclusion of long term care in AFA.

Breakout 2 – Increasing Access to Hospice and Palliative Care

This group of participants discussed the need for hospice and palliative care to be factored into the long term care discussion.

- It is important to note the distinction between hospice and palliative care. Tribes want to know how they can best provide those services to their elders.
- There must be education and community buy-in, especially in areas where geography is an issue.
- Some facilities discourage traditional medicine, which can be problematic, especially at the end of life.
- PACE in South Carolina is trying to include palliative and end-of-life care, so people do not have to leave PACE if they want end-of-life care.
- Coordination and collaboration is needed when thinking about end-of-life care and how to make it a part of the long term care continuum.
- People should think of end-of-life care as normative, as one aspect of long term care. End-of-life care does not need to be stigmatized.
- Tribes should honor the wishes of the individual.

Breakout 3 – Next Steps to Support AI/AN Long Term Care

This group discussed a myriad of next steps the IHS should take when it comes to supporting AI/ANs in offering long term care services.

- IHS should coordinate with other federal agencies.
- IHS should serve in a policy role when it comes to licensure, certification, and regulation.
- IHS should help in solving the jurisdictional issues across state borders.
- IHS should partner with the VA to increase long term care services for veterans.
- IHS should have more consistency in its business practices.
- Long term care should be included in AFAs with the IHS.
- IHS should offer assistance with reimbursement rates (there are many rates that could be problematic).

- Tribes are looking for 100% Federal Medical Assistance Percentage reimbursement for any Medicaid services.
- IHS should be working toward a cost-based system that would account for geographic location, cultural issues, and spiritual activities.
- IHS should assist in training and workforce development.
- IHS should provide supports and training for family caregivers, including technical support.
- IHS should move away from a reactive system and toward a preventative system.
- IHS funding is needed for feasibility projects.
- Any Tribe or group should be able to write their own home- and community-based services program.
- Tribes need technical assistance.
- Tribes should share things they learn among themselves and help each other out.
- Tribes need a network for asking and responding to questions as needed.
- IHS should establish an office specific to long term care.
- There is a need for start-up programs.
- Tribes want true funding that is cost-based, with the ability to use CHR.
- The provider, IHS, and Tribal positions should be aligned.
- The IHS should form an Elders Advisory Council.

Breakout 4 – Facilities Issues Related to Long Term Care

This group focused on facilities issues related to long term care and the needs in Indian Country.

- Consultation and information is needed from IHS on how to access funding for these services.
- IHS should develop guidelines or standards for designs and plans for developing long term care facilities.
- Improvements should be made to homes of elders (especially for those who have difficulty standing up, bathing, showering, etc.).
- More facilities and services should be provided in the community, bringing it closer to home.
- Tribes want to know how to make long term care facilities self-supporting.
- A demonstration project for long term care is needed. Tribes want to know how and where these facilities and programs would be most helpful.
- Tribes also want assistance in determining the real cost of facilities and how to sustain them.

Section 4: FULL PRESENTATIONS

The following pages include prepared statements, notes, and presentations from speakers at the Long Term Care in Indian Country: New Opportunities and New Ideas *Conference held November 1 and 2, 2010, in Washington, DC.*

Welcome and Update on Indian Health Reform

Yvette Roubideaux, MD, MPH, Director, Indian Health Service

Please see following page for Dr. Roubideaux's complete presentation.

Long-Term Care Meeting

November 1, 2010

Update on Indian Health Reform

by

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

Director, Indian Health Service

Good Morning. It's pleasure to be here today to help address the important issue of long-term care in Indian Country. With the permanent reauthorization of the Indian Health Care Improvement Act (IHCIA) and the passage of the Affordable Care Act, we are facing historic health care changes, as Americans and as Native people. I am grateful for this opportunity to speak about some of these important changes that will have a positive impact on our ability to provide quality health care to American Indian and Alaska Native (AI/AN) people, including our elders and those in our communities who are living with disabilities.

I will be giving you an update today on Indian Health Service (IHS) Reform, the Affordable Care Act, and the IHCIA, and what it all means to Tribes, AI/AN patients, and the Indian health care system. This includes the major provisions of the IHCIA that deal

The text is the basis of Dr. Roubideaux's oral remarks at the Long-Term Care Meeting on November 1, 2010. It should be used with the understanding that some material may have been added or omitted during presentation.

with long-term care.

This meeting is a first step. It is the beginning of a critical conversation on how we use the authorities of IHCIA to support and enhance the delivery of long-term care services in our communities.

To put the conversation about long-term care into context, I want to take a few minutes to review for you where we are in the IHS, and where we are going. There is a lot happening in the IHS these days, and we need to consider this as we think about how we could begin the work of implementing long-term care services in this context.

In terms of how we are changing and improving the IHS, I set four priorities for the IHS to guide our work over the next few years:

- The first priority is to renew and strengthen our partnership with Tribes;
- Our second priority is, in the context of national health insurance reform, to bring internal reform to IHS;
- The third priority is to improve the quality of and access to care for patients who are served by IHS; and
- The fourth priority is to have everything we do be as transparent, accountable, fair, and inclusive as possible.

We are making some progress on these priorities; however, much of this work involves fundamental changes in how we do business in the organization, so the change will take some time. Long-term care would certainly fit into the third priority.

Our first priority is to renew and strengthen our partnership with Tribes. I truly believe that the only way we're going to improve the health of our communities is to work in partnership with them. The IHS cannot do its work in isolation – we have evidence throughout our system that we work better in partnership with our communities.

I am grateful for my public health training because it helped me see that the solutions to our communities' health problems will not be solved with efforts that just focus on our clinics or hospitals. Look at some of the biggest problems we face – suicide, domestic violence, obesity, cancer, mental health issues – all are influenced by factors in our communities such as education, unemployment, law enforcement, housing, etc. IHS cannot solve these problems alone.

Our Tribes, as sovereign nations, are responsible for the health and well-being of their members, and we can accomplish so much more if we work in partnership with them. So I am grateful that with this new administration, tribal consultation is a priority. It is clear that Tribes have been the leaders in long-term care services in Indian Country. I am anxious to hear the lessons learned they have to bring to the conversation today and in the coming months to years.

President Obama signed the Executive Order on Tribal Consultation at the first-ever White House Tribal Nations conference in November 2009, which supports our partnership in health with Tribes. Secretary Sebelius has also demonstrated her commitment to tribal consultation and partnership by meeting with Tribes on several occasions so far, including an historic moment when the Secretary held a private meeting with tribal leaders in her office on March 3, 2010. These are examples of this administration's dedication to tribal consultation.

In the past year, we have consulted with Tribes on improving the tribal consultation process, improving the Contract Health Services (CHS) program, priorities for health reform, implementation of the IHCIA, and the fiscal year (FY) 2012 budget. We are beginning to implement some of the recommendations from these consultations.

For example, we're improving the consultation process by making the information on consultations more widely available, giving more time for response, considering options to ensure consultation with all Tribes, and building a website to document progress on our consultation activities and workgroups.

The CHS consultation, listening sessions, and best practices meetings are generating a lot of great ideas to improve the way we do business in CHS.

I plan to formally consult on other topics this year, including the Indian Healthcare Improvement Fund, health care facilities construction, and my third priority on improving the quality of and access to care. And we will consult on implementation of long-term care in IHS as we move forward. Today is not a consultation – it is an opportunity to begin to discuss how we could implement. We will formally consult with Tribes as a next step. All of these consultations are opportunities to partner with Tribes.

I have also held extensive listening sessions with Tribes and have conducted more than 270 Tribal Delegation Meetings at IHS headquarters and at national meetings since being sworn in over a year ago. And I am in the process of visiting all 12 IHS Areas to consult with Tribes, which was one of the recommendations from our consultation last year. I have visited 11 of 12 Areas so far. I will meet with the Navajo Area once their elections are completed.

I have found these visits to be very helpful in understanding broad themes as well as specific Area and tribal needs. Because not all Tribes can afford to travel to Washington, D.C., these Area visits are critical to ensuring that all voices are heard.

It's important that we strengthen our partnership and that Tribes help create the vision for IHS reform. For every decision I make, I always consider the input I have received from Tribes.

In addition to meeting with the entire group during the Area listening sessions, I also met individually with tribal leaders to hear about their priority issues and recommendations from a local perspective. I am grateful that these busy tribal leaders are taking the time to meet with me on health issues. It helps us see how we can move forward in partnership. We

all want the same thing – better health care for our patients and our communities. It's important that we find more ways to work in partnership together.

And I appreciate your coming to this meeting today to discuss how we can work together to build the system of long-term care we need in our communities. In light of the new authorities of the IHCIA, this is an opportune time to begin this conversation.

My director's workgroup on tribal consultation met last month and developed some additional recommendations. I also met with the tribal leaders diabetes committee just last week. They are working on a strategic plan to further their work to advise and advocate for diabetes treatment and prevention. And I met with the Tribal Self-Governance Advisory Group this summer and in October. We talked about how we can help advance some of their issues in partnership by helping each other.

We are also developing a policy to confer with urban Indian programs – this is a new provision in the IHCIA. The first meeting of the workgroup was held last month.

And I held a CHS listening session and best practices session in September. In addition to the need for more CHS funding, we heard recommendations on how to improve the way we do business in CHS, such as how we refer patients, negotiate rates, and collect third-party reimbursements. I know CHS is a very important topic to Tribes and improving how we do business is a top priority for the IHS.

My second priority is "in the context of national health insurance reform, to bring reform to IHS." This priority has two parts – and as you all know by now, the first part includes passage of the health reform law, the Affordable Care Act, and the IHCIA.

We are grateful for passage of the Affordable Care Act because it will make quality, affordable healthcare accessible to all Americans, including our First Americans. It is designed to increase access to health insurance, help those who have insurance, and reduce healthcare costs. It also contains the permanent reauthorization of the IHCIA, which provides new and expanded authorities for a variety of healthcare services.

Both laws have the potential to benefit all of the Indian health system. We will be holding ongoing consultations with Tribes on the implementation of these new laws, and we will let you know about these consultation opportunities along the way. The Department of Health and Human Services (HHS) and IHS sent a letter to Tribes in May initiating consultation efforts. I still encourage you to send your input to the email address consultation@ihs.gov.

We are working quickly to implement tribal priorities among the many provisions in these laws. I recently sent out a letter to Tribes with information on some provisions that are self-implementing, or that were in effect with passage of the law and require little or no implementation activities. I will be sending regular updates to Tribes.

We conducted planning consultation activities in October on topics such as the Access to Federal Insurance Provision and the special provisions related to the Insurance Exchanges in the Affordable Care Act. More information will be sent to Tribes shortly.

Don't worry, we are consulting with Tribes and will be doing more to make sure you have input before decisions are made.

One of the most common questions we get is, "How will health care reform help American Indians and Alaska Natives?" Health care reform is mostly about increasing access to affordable health insurance. While many AI/ANs are covered by IHS, many do not have access to IHS, especially in urban areas, or some may want to purchase insurance as an alternative to IHS services.

The new law means that individuals and small businesses will have more affordable options for health insurance through the creation of state-based Exchanges by 2014. They will be able to compare health insurance plans in their state and purchase more affordable insurance. This should result in 32 million more Americans being covered.

And it means that AI/AN individuals or small businesses that want to purchase health insurance will have more affordable options than they do now. This is particularly important for those who do not have access to IHS coverage and/or do not have access to insurance with their job.

Also, there will be no cost sharing for insurance purchased through the exchanges – that means no co-pays or deductibles – for Indian patients who incomes are less than 300% of the poverty level. And AI/ANs are exempt from tax assessments for not enrolling in an exchange plan. This was the first provision in the health reform law that the President publicly supported for AI/ANs – they are exempt from the penalty due to health care being "owed to them."

Another provision in the Affordable Care Act will expand Medicaid coverage to individuals with incomes up to 133% of poverty level starting in 2014. This should help many AI/ANs in our communities.

All of these provisions mean that our patients, American Indians and Alaska Natives, will have more choices – to use IHS, and/or to purchase more affordable health insurance. It does not mean that the IHS will go away. That was a myth.

And it means that the entire Indian health system – Tribes and IHS facilities - may benefit from reduced health care costs, more choices, and better coverage. If more AI/ANs are covered by health insurance and they choose to use IHS, it could mean more third-party reimbursements.

The challenge is that as more patients have the choice of where they can receive their health care, IHS must become more competitive. IHS must demonstrate that it delivers quality health care and provides excellent customer service. So the work IHS is doing to change and improve is even more important now.

HHS is taking the lead on implementation of the Affordable Care Act in general, and IHS is working closely with HHS on the provisions that impact American Indians and Alaska Natives. Provisions already implemented in 2010 include:

- Extended insurance coverage for young adults under 26 years – previously they were not covered and usually could not afford insurance;
- Extended reinsurance for early retirees aged 55-64;
- Access to insurance for those who were uninsured due to pre-existing conditions (Pre-existing Condition Insurance Plan);
- Provision of checks to seniors who reached the Medicare Part D "donut hole" – while only a small proportion of AI/ANs purchase this coverage, it does help;
- Establishment of a new "Patient's Bill of Rights" that includes a number of insurance protections, including
  - No discrimination against children with pre-existing conditions, and
  - Elimination of lifetime limits on insurance coverage
- Small business tax credits
- Efforts to crack down on healthcare fraud; and
- Creation of a website at Healthcare.gov with information on insurance plan choices and other information for consumers. It even references IHS as an option for those who are eligible.

The Affordable Care Act also addresses long-term care in some important ways. I think that over the next couple of days you'll hear more about some of these provisions from our colleagues at Centers for Medicare and Medicaid Services and the Administration on Aging.

And the IHCIA was included in the Affordable Care Act – which is great for Indian Country because this law is the main legislation that authorizes Congress to fund health care services for AI/ANs. And it ***permanently*** reauthorizes the IHCIA.

The IHCIA updates and modernizes the IHS. The provisions are numerous but many of them give IHS new authorities. The IHCIA updates and modernizes the IHS. The provisions are numerous but many of them give IHS new authorities. This includes authorities for the provision of long-term care service, which I will say more about in a moment. But there are also other important provisions that I want to highlight for you, including:

- New and expanded authorities for behavioral health prevention and treatment services;
- New and expanded authorities for urban Indian health programs;
- Authorities for various demonstration projects, including innovative health care facility construction and health professional shortages;
- The authority for provision of dialysis services;
- Authorities to improve the CHS program;

- And authorities to improve facilitation of care between IHS and the Department of Veterans Affairs (VA).

These are just examples of what is in the new law.

Now I want to take a few minutes and walk with you through the language of the IHCIA provisions that are specific to long-term care. We all need to know the language contained in the Act. I won't be interpreting it for you or telling you "what it means." We'll be sorting this out together through our conversations today, through future tribal consultation, and through implementation efforts.

The law defines the terms that it uses, including Assisted Living Services, Home and Community Based Services, Hospice Services, and long-term care Services, usually in terms of other statutes or laws. This is important because these are technical and legal definitions that we'll need to work with and understand as we implement the law.

Given those definitions, the Act specifies that the Secretary of Health and Human Services, acting through the Indian Health Service, can provide funding for these services. And it identifies those individuals who might be eligible for these services.

This is the "authorities" part of the law – it tells the IHS what we can do, either directly or through Tribes and tribal organizations. It's important to realize that while this gives us authority to provide these services, it does **not** actually give us any funding to do so. IHS did not have these authorities before this law passed. However, many Tribes have implemented these types of services on their own, and I am looking forward to learning from their experience.

There is also language in the Act that addresses the sharing of staff, services, and facilities between IHS, Tribes, and tribal organizations. This is really important because it can allow us to think creatively and do more with the resources we already have.

There is some regulatory language in the Act, mostly referring to existing regulatory language already in law that guides the sharing of services.

And finally, it encourages the creative use of facilities and space that may be underutilized to help provide these long-term care services.

So this is basically what the law says. That's where we start – with the authority to provide these services to our patients. But there is much to do – we must see what has been done so far, consult with Tribes on how they want us to implement this provision, and then we have to mobilize the right people and resources to make this happen. This meeting is a good first step.

Another common question about the IHCIA, beyond what is in the new law, is about what IHS plans to do to implement the provisions in it.

IHS is taking the lead on implementation of the IHCIA. It is clear that IHS cannot implement the entire law all at once and that this will need to occur over time. IHS is working very hard on reviewing provisions and developing next steps and timelines. Some provisions are immediate, and some require funding or additional work.

IHS and HHS also must take time to consult with Tribes on this important new law. We must consult in a meaningful but efficient way so implementation can move forward. We are working very quickly, but also very carefully – we want to do this right the first time.

HHS and IHS initiated consultation with Tribes on the Affordable Care Act and the reauthorization of the IHCIA in May with a letter to Tribes requesting input on the process for consultation and priorities for implementation. The input received to date makes it clear that Tribes want to be consulted before policy decisions are made. HHS and IHS will announce plans for regular consultation with Tribes. We will also plan to consult with Tribes on the long-term care provisions – we heard they were a top tribal priority.

We recognize that education and communication are priorities at this time. So we are taking steps to keep everyone informed:

- You can find updates on our implementation process on my Director's Blog at ihs.gov;
- As I mentioned a minute ago, HHS just unveiled a new website – healthcare.gov – that helps the public understand how health reform benefits them.
- We are using *Dear Tribal Leader* Letters to keep you updated. HHS and IHS sent a letter to tribal leaders in May requesting consultation on health reform and the Indian Healthcare Improvement Act. The letter included a fact sheet and tables that summarize the provisions relevant to Indian country.
- In July, IHS sent a letter to Tribes that summarized some provisions that are already in effect or were self-implementing.
- We will be announcing soon more self-implementing provisions and initiating some consultation activities on some topics of great interest, including the Federal Employees Health Benefit program provision and the Special Provisions for Indians related to the State Exchanges.

I encourage you to learn everything you can about this important new law and its impact on Indian health care.

The letter IHS sent to tribal leaders in July explains some provisions in the Indian HealthCare Improvement Act that are self-implementing or require little to no implementation. This is the first in a series of letters to Tribes with this type of information.

An example of a self-implementing provision includes Section 113 – exemption from payment of certain fees. This requires federal agencies to exempt Tribes from paying

licensing, registration, or other fees imposed by federal agencies. Because of this new law, the Drug Enforcement Administration (DEA) will no longer charge tribal providers a fee to prescribe controlled substances. The DEA has already notified its field offices of the new law. So there is nothing else to do to implement this provision; it is self-implementing.

There are numerous other sections that are mentioned. I encourage you to review the letter if you have not already done so.

Section 157, Access to Federal Insurance, was indentified by Tribes as a top priority for implementation. This provision allows Tribes, tribal organizations, or urban Indian organizations to purchase coverage for their employees from the Federal Employees Health Benefits Program. While the authority was present on the day the law was passed, a mechanism needs to be developed to administer this option. IHS is assisting the Office of Personnel Management with implementation of this provision, and Tribes were sent a letter requesting consultation and input this month.

The second part of this priority is about bringing internal reform to the IHS. In order to get the support we dearly need, the IHS must demonstrate a willingness to change and improve. It is clear that Tribes, staff, and our patients want change.

By internal IHS reform, I mean we need to look at what we do well, and be honest about where we need to improve.

I want to thank those of you who provided input last year on your priorities for how to change and improve the IHS. There is so much to do – it really helped me to hear from you about your priorities on where you think we should begin this important work.

Tribal priorities for internal reform included:

- More funding for IHS, including a review of how we allocate funding;
- Improvements in the CHS program; and
- Improvements in the tribal consultation process.

We're working on these priorities, as I have already described. We're also making progress on the top staff priorities for internal IHS reform. Overall, staff emphasized improving the way we do business and how we lead and manage our staff. I can understand this – as a clinician, I just wanted to see and help patients, but the way we were doing business was getting in the way. I imagine many of you have felt this same sort of frustration at one time or another.

To improve the way we do business, we're working with HHS and our Area Directors to improve how we manage and plan our budgets and improve our financial management. We're working to make our business practices more consistent and effective throughout the system.

To improve how we lead and manage staff, we're working on specific activities to improve and streamline the hiring process by making it more efficient and proactive, and less

time-consuming. We're also working on improvements in pay systems and strategies to improve recruitment and retention. Many of you know how difficult it is to recruit and retain healthcare providers. We need to make sure the way we do business is not causing us to lose the opportunity to hire and keep good staff.

We are also responding to the concerns raised in the hearing on the Senate Committee on Indian Affairs investigation of the Aberdeen Area. Some of the issues raised are unacceptable, and we are acting to correct them immediately. We are implementing stronger reforms to ensure that we hire the right people, deal with problem employees rather than shuffle them around, increase security in our pharmacies, and make sure that our providers have updated licenses or else they cannot practice.

Many of these improvements are happening behind the scenes, so you may not be seeing specific improvements yet, but they are fundamental improvements that will pay off over time.

At a recent Human Resources Summit that we held with representatives from all IHS Areas and key staff involved in the hiring process, they came up with some very good recommendations for improving and shortening the hiring process.

I have also sent messages to IHS staff on improving our business and management practices – such as the importance of customer service, ethics, performance management, and professionalism. Many of our staff members want improvements in these areas, and our work starts with a strong message from the top that these are important areas for all of us.

We're also improving our performance management process to include the agency priorities and to make sure we do a better job of rewarding employees who perform well and holding those accountable who do not.

Nothing is more frustrating than working with or being taken care of by someone who is unprofessional, or who does not treat patients or staff well. Our patients – and staff – deserve to be treated with respect and kindness at all times.

Overall, we need to improve how we do business as an agency – yes, we are a "service" organization with a great mission, but we also have to function as an efficient and effective business to survive, given the challenges we face. And with the Affordable Care Act making insurance coverage more accessible, we need to be as competitive as possible so that our patients will always consider us their first choice for health care. So changing and improving the IHS is more important than ever.

As we do better as a business, you can be assured that as an American Indian physician who has worked in IHS clinics, I will make sure we don't forget that our ultimate focus is on the patient.

In relation to our third priority, to improve the quality of and access to care, I started by identifying the importance of customer service – how we treat our patients and how we treat each other. I am now starting to see activities to improve customer service throughout

the system and am starting to hear stories about some improvements. However, we still have a lot of work to do to improve our customer service.

We also plan to expand the Improving Patient Care (IPC) initiative to 100 more sites over the next 3 years. This is our "medical home" initiative that puts the focus of our healthcare team on serving the patient. We're now beginning phase 3 of the IPC.

And I began collecting best practices in providing quality care last year – we need to avoid reinventing the wheel by doing a better job of sharing what we're doing well and disseminating that information more effectively. We know our programs and facilities are doing some great things, especially in the provision of culturally competent care.

I would like to hear from you about your best practices and ideas to improve quality – you can send them to quality@ihs.gov.

We recently held a quality of care summit with IHS staff – they generated a larger number of recommendations to improve quality.

Other ways we are working to improve quality care include collaborations with other departments and agencies. Given that we have limited resources in Indian health, we have to leverage all resources to improve care for our patients.

For instance, we have been meeting with the Department of Interior on health issues in our communities – I met with Assistant Secretary of Indian Affairs Larry Echohawk, and he understands how we must work together to address some of the most difficult health problems we are facing in tribal communities.

I also am working with other Operating Division heads in HHS to expand availability of resources and services for American Indians and Alaska Natives. For instance, I have worked with Mary Wakefield, Administrator of the Health Resources and Services Administration, on workforce issues, and Pam Hyde, Administrator of the Substance Abuse and Mental Health Services Administration, on suicide and behavioral health efforts.I am grateful for all the HHS leaders who are working with us – and especially those who are willing to help us begin our discussion of implementing long-term care. Some of those leaders are following me on the agenda today. It's clear that we need everyone to help us with this enormous task of implementing long-term care in IHS.

I also met with Secretary Shinseki from the VA. We are working to collaborate on several activities, including coordination of care for veterans who are eligible for both IHS and the VA. We just signed a VA-IHS Memorandum of Understanding (MOU) – updated from the one we signed in 2003 – to help improve how we coordinate care for our veterans and will be consulting with Tribes on implementation shortly. The VA can also help us with understanding how to implement long-term care services because they already provide these services. This is a topic in the updated MOU.

The signing of the Tribal Law and Order Act is an example of a collaborative effort that will help us improve health in our communities by addressing the serious problem of violence against women. Many federal agencies are collaborating on implementation of this

law, and we are involved in those activities. Violence against Indian women is unacceptable, and we all need to work to eliminate it in our communities.

Our fourth priority is to make all our work transparent, accountable, fair, and inclusive. Since I began my tenure as the Director of IHS, I have worked hard to improve our transparency and communication about the work of the agency. This includes working with the media, sending more email messages and *Dear Tribal Leader* letters, holding regular internal meetings, and giving presentations at meetings like this.

We have also enhanced our website with the IHS Reform page, Director's Corner, and Director's Blog, which contain important updates and information about reform activities.

And we're looking at ways to improve IHS-wide communication among Areas, Service Units, and Headquarters. We need to be functioning as **one unit, as a team**, in order to provide the best services possible to our patients. This includes not just federal sites, but our tribal and urban sites as well. We are all a part of the same team.

We're also emphasizing accountability and fairness in the way we do business – by evaluating our programs and focusing on areas of greatest benefit, and by always considering fairness when dealing with staff and making programmatic decisions.

Inclusiveness is a part of these priorities because as the IHS Director, I have to ensure that all my decisions consider the impact on all our patients, whether they are served in an IHS, tribal, or urban Indian health facility. Balancing the needs of the various parts of our healthcare system is a challenge, but inclusiveness is very important as we work to improve the IHS.

As I just mentioned, we have enhanced our IHS website. One addition is my "Director's Corner," which is linked to the IHS home page. There you can get information on presentations, *Dear Tribal Leader* letters, updates on internal IHS reform, and other messages. You will also see an orange "Director's Blog" button that you can click on that will take you to my blog. I plan to use the Director's Blog to post brief updates on our activities and the latest IHS news at least weekly. This is one of many efforts to be more transparent about what we're doing as an agency.

I have posted pictures of many of my consultation and listening session on my blogs, as well as pictures from Tribal Delegation Meetings. I think it's important for the public to know that meeting with Tribes is important to the agency, and putting updates and pictures on the blog helps. This really is the place where you can get the most up-to-date information. I encourage you to check this site every one to two weeks.

So what are our accomplishments so far? Well, we are making progress on IHS reform, but a lot of the work is internal to the organization right now and much of the work to improve the way we do business is in progress. Certainly the most visible progress to date for this new administration is the increases in funding for the IHS:

- The FY 2010 budget with its 13 percent increase has the largest percent increase in over 20 years for IHS. We're just now feeling the impact of this increase. For example, there was a $100 million increase in CHS funding – this meant an increase in the range of 14-30 percent in each IHS Area, which will result in more referrals being paid.
- And this increase included a substantial increase in our Catastrophic Health Emergency Fund, which pays for high cost cases. This year, we may be able to make it to the end of the year and not run out in June, as has been the past experience.
- The FY 2011 President's budget proposed an almost 9 percent increase, and we're waiting to see if Congress decides to keep that increase in the budget.
- The Recovery Act funding provided $590 million for health facilities construction, sanitation facilities construction, maintenance and improvement, equipment, and health information technology. Some of you may be seeing this funding benefiting your communities now. For instance, hospital constructions in Eagle Butte, South Dakota, and Nome, Alaska, are making progress.

Overall, we are beginning to make progress on our priorities and are moving forward on the challenging work to change and improve the IHS. The changes we're working on are fundamental improvements in how we do business as an agency, and I believe they will help address many of the priorities for change as expressed by staff and by Tribes**.**

Our staff, our patients, and the tribal communities we serve need to see that we heard their priorities and their input, that we're committed to changing and improving, and that we're now implementing specific activities to change and improve IHS.

This includes the opportunity to begin creating the kinds of long-term care services and support that are vitally needed in our communities. These services must allow our elders and those in our Tribes and communities living with disability to be active participants in our communities.

I am really looking forward to this conversation with you. With your help, I am confident we can make real progress in improving health care for American Indian and Alaska Native people. Thank you.

The Future of Long Term Care and the Aging Network

Cindy Padilla, Principal Deputy Assistant Secretary for Aging, Administration on Aging

It is truly an honor to be a part of this historic conversation! Thank you Dr. Roubideaux for your leadership and for bringing us together as we set the stage for the future of long term care in Indian Country.

It is a privilege to be here representing Assistant Secretary Kathy Greenlee and the Administration on Aging (AoA). Also here today from AoA is Dr. Yvonne Jackson, Director of our Office of American Indian, Alaska Native, and Native Hawaiian Elders, along with Meg Graves, Cecilia Aldridge, and Leslie Green.

And as November has been proclaimed by President Obama as National Native American Heritage Month, what better time to talk about health care for our elders, many of whom carry the disturbing memories of the dark moments of injustice they experienced…and to also look ahead to the opportunities created under the Indian Health Care Improvement Act as part of the Affordable Care Act that will open new doors for services to our American Indian, Alaska Native, and Native Hawaiian elders are truly exciting.

We know that as we talk about the future of long term care, the future we can create, a future that embraces the very principles of the Older Americans Act – principles of honoring dignity, independence, and personal choice – being a part of the Health and Human Services Department allows for stronger partnerships between all agencies, and especially between AoA and Indian Health Services (IHS).

This partnership is not only critical but essential. As we talk about long term care, first it is important to think about what long term care is. We are talking about the care of all people – our elders or people living with disabilities – many of whom need additional services or supports that sustain that quality of life we in America not only expect but work hard to protect. We are talking about doing this through services and supports that respect and honor our cultural identities.

AoA is the agency entrusted with the responsibility of carrying out the provisions of the Older Americans Act. As I stated earlier, the Older Americans Act has as its very core the focus on dignity, independence, personal choice, and the respect of all cultures. Our priority it to support aging in place, with three key strategies:

- investing in home- and community-based services that help seniors stay at home and support family caregivers;

- build partnerships that leverage additional public and private resources; and
- promote innovations to ensure continuous effective outcomes through health care reform.

Although AoA as an agency is small, the strength of the Act, I believe, lies in the Aging Network, and how it is established in the law. Briefly, the National Aging Network as created by this legislation, is made up of AoA, state units on aging, Tribes, and area agencies on aging. This national network is designed to provide local involvement in the development of a comprehensive and coordinated system, for supportive services, nutrition services, and where appropriate, multi-use senior centers. This network is the very foundations of home- and community-based services and supports that help maintain community living.

The Network is comprised of 56 state units on aging (50 states and 6 territories), 645 area agencies on aging, 246 Tribal organizations, 29,000 providers, 10,000 senior centers, and over 500,000 volunteers. Our Indian Tribal Organizations, as authorized under Title VI of the Older Americans Act:

- Provide a combination of SUA and AAA functions.
- Provide leadership within the Tribe for developing home- and community-based long term care services.
- Provide direct services – meal; transportation; health promotion, such as physical activity programs, mental health programs, chronic disease self-management, and health screenings; in-home services, such as personal care, chores, maintenance, and repair; family support, through caregiver support, intergenerational activities, and spiritual support; assisted living or adult day services; and other supportive services, such as information and assistance, case management, and elder rights.
- In many tribal communities, the Title VI program is the focal point for elderly services and provides the entry point for assessing need for multiple services, determining eligibility and assisting in arranging for the services; or provides home visitation and ombudsman services.
- And also in many tribal communities, provide end of life care through visitation and cultural observances.

I think what you can see is that Title VI of the Older Americans Act is the core of non-medical long term care services and supports in Indian Country.

So what is the future of long term care, and where are we now?

Several months ago, Assistant Secretary Kathy Greenlee and I met with Director Roubideaux to talk about this very subject, and discussed what opportunities exist to

strengthen this partnership and ultimately build on the Aging Network and the work of IHS. We see the future as one that looks to long term care as the opportunity to bridge health care services with social services and supports, a future that is built through collaboration and participation, that addresses and serves the needs of our elders, one that is person centered and builds on a strengthened partnership between AoA and IHS.

What we have is a promising opportunity. It is interesting, too, that wherever we go and we speak to seniors – from all cultures, from all across the country – we find the same core values: **faith, family, community**.

Faith – Deeply important to seniors, deeply personal and reflective of the diversity of our country;
Family – However defined and including extended kin; and
Community – Being from New Mexico, I know these knit together for elders in a very specific and special way. I know I want to remain at home surrounded by my friends and family and participating in the community for as long as possible. I think you do, too.

So as I stated above, we have a healthcare system and a social supports network – and the question is:

- What can we do in Indian Country to weave them together?
- How do we integrate these models?
- What are the best practices among you/us?
- Where are the medical professionals – doctors and nurses – working most closely with seniors at the senior center – for the education and treatment of diabetes, for vaccinations and immunizations?
- Where are the hospital, medical, clinical, and senior programs all contained in the same location?
- Where do the medical providers call a case manager to say, "This person is leaving the hospital, are you arranging for meals and assistance once they get home?"
- Where is it all working together now?
- Can we fund that approach? Can we document our outcomes?

I am not naïve, thinking additional resources will suddenly appear. Instead, growth will be gradual, but hopefully steady.

AoA is also building on our relationship with the Department of Veterans Affairs (VA), a successful partnership started 2 years ago. The VA saw that they operate a nationwide health care system: VA hospitals, nursing homes, and medical services, but they were lacking in home- and community-based support.

Services and supports are currently being provided nationally by and through the Aging Network. We are building the bridge with the VA, the bridge between health care services and services and supports…and we would like to partner with you in a similar way.

As I stated earlier, these services for Tribal elders should be created by you, and through collaboration, the Network can help. We can work with you to promote best practices. We can explore with you the best current models on care coordination and hospital discharge plans. We can struggle together on how to provide support for people with dementia. November is also Alzheimer's Awareness Month. And we can commit ourselves together to the value of supporting family caregivers. And in the area of family caregivers, President Obama has also declared November as National Family Caregivers Month.

Supporting the care given by family members, the countless hours of support and love shared when there is a need, support given to help our loved ones remain at home and in the community. The work of the Middle Class Task Force, led by Vice President Biden, also recognized the needs of the family caregiver, and as such the President's 2011 budget request for AoA included an increase in $102.5 million for the caregiver support programs administered by AoA; this increase includes $50 million for caregiver services, $2 million for Native American caregiver services, $48 million for III-B supportive SVCs, $2 million going to Native Americans, and $2.5 million for lifespan respite services.

We know the challenges ahead – adequate transportation, adequate number of health care and direct care workers – these issues are hard, but must be faced. We believe at AoA that these challenges can be faced, and faced together. As we look to the future of long term care, we can look at these challenges as opportunities.

We know First Americans, like all Americans, are growing older, and we can best honor our elders by finding ways to assist them while respecting their dignity and the right to grow old at home where they belong. We believe that working with IHS and all of you, we can take these opportunities and act on them. We can transform our health care service system not only in Indian Country, but across the nation.

Advancing Independence through Long Term Care

Henry Claypool, Director, Health and Human Services Office on Disability

Notes from the Presentation

These are notes taken by a professional note-taker at the conference and are not a text of the speaker's comments. They do not represent an official statement of the presenter.

Mr. Claypool shared his perspective on people with disabilities as it relates to advancing independence through long term care. Long term care is often thought of as for the elderly and aging and those in nursing homes, but people with disabilities have challenged those assumptions. Whether physical disabilities, developmental and intellectual disabilities, or mental health issues, people with disabilities' efforts have continued to change the long term care delivery system.

There has always been a theme of self-determination within the disabilities community; doubly so within the Native disabilities community.

Mr. Claypool shared information about two movements that have had a great impact on long term care services: the Independent Living Movement, which focuses on people with physical disabilities; and the professional- and family-based movement, which centers on people with developmental and intellectual disabilities. These two movements have shaped the choices elders have in their long term care services.

The Independent Living Movement began in the 1960s with a move to make going to university a more accessible opportunity for people with disabilities. The people involved in this movement plotted to change the way they experienced their education and the way they lived in the community. Through their efforts in the 1960s, the Rehabilitation Act was passed in the 1970s. The act requires non-discrimination for people with disabilities in all programs that receive federal dollars.

Another major challenge for people with disabilities has been access to employment opportunities for people with limited mobility. There is a constant need to improve accessibility and community support, such as transportation and personal care.

Recently, there has been a shift in how long term care is viewed. Society is moving away from facility-based care and toward more home- and community-based care. It is often easier to get home- and community-based services through Medicaid waivers than through states. The waiver movement has transformed long term care, largely thanks to the efforts of the developmental disabilities community.

The Independent Living Movement led to a change in the language used in long term care. For example, the words "personal care" are in the Medicaid statute. People with disabilities have changed those words to "personal assistance services and support." This is a subtle switch, but it is something that is significant. The change allows people with disabilities to direct the types of services they need.

Self-direction is very empowering from a disabilities aspect and allows people with disabilities to take greater control over their situation. It has led to a switch in how long term care is regarded. There has been a move away from facility-based care to community-based services.

Through institutions, people were receiving care 24 hours a day, 7 days a week. But through their advocacy, the home- and community-based services waiver movement came about. Home- and community-based services waivers allow states that participate in Medicaid to develop creative alternatives for individuals who would otherwise require care in a nursing facility or hospital. It is easier to get access to care through waivers than to get basic personal care services through the state plan. People also were able to move out of large institutions and into group homes in the community. There has been a real move from people moving out of group homes into individual situations, where they can live in a more integrated setting.

There are still obstacles and issues in these movements. There is a significant way to go, but they are making progress. People should have greater choices and control of services, and the setting in which to receive those services should not be dictated to them.

There are opportunities in the Medicaid program to have choices in the support and services on which they rely. Mr. Claypool explained that as Medicaid continues to be reformed, hopefully resources will eventually be allocated based on people's needs and not on what they are labeled. There are some significant statutory barriers in the way; however, advocacy groups are trying to bring down these barriers or modify them.

It is really people with disabilities who are making the change. It is the group of younger people who are looking at 20, 30, and 40 years of living with a system that is not meeting their needs who are leading the effort to change how long term care is provided to them.

People with disabilities were also greatly helped by the passage of the ADA in 1990 and the landmark decision in 1999 called the Olmstead Decision. In the Olmstead Decision, two women in Georgia were institutionalized because that was the only place services for people with disabilities were offered. The women argued that their civil rights were being denied because services were only offered in an institution and that they needed to have a choice.

The court agreed. This decision has compelled state Medicaid to change. Resources are being shifted from institutional services into the community. Also, the quality of these services is enhanced, and they are more focused on what individuals need.

People with mental health issues will be eligible for Medicaid services through the expansion of Medicaid through the Affordable Care Act. There is a significant need for services for those with mental health issues. This funding is important because the Substance Abuse and Mental Health Services Administration (SAMHSA), which provides many of the mental health services, has real budgetary restraints.

A Strong Foundation for System Transformation

Barbara Coulter Edwards, Director, Disabled and Elderly Health Programs Group, Centers for Medicare and Medicaid Services

Notes from the Presentation

These are notes taken by a professional note-taker at the conference and are not a text of the speaker's comments. They do not represent an official statement of the presenter.

Ms. Edwards shared information on Medicaid changes that will take place as part of the Affordable Care Act. With the passage of health care reform, health care coverage will expand toward universal coverage. There will not be lifetime limits, and people with pre-existing conditions will be able to get insurance. It also provides the opportunity to improve care and services available to the aging and people with disabilities and chronic conditions.

Employer-provided care will be the primary source of insurance; 159 million people will be covered through employer-offered insurance. Medicaid will become the second largest provider. It will not just be a safety net but also a full partner. Medicaid will be a new program as a result of the Affordable Care Act. It will become a foundation of universal health coverage in the U.S. People may move back and forth between Medicaid and the state-exchanges. Anyone eligible will need to be enrolled, and enrollment should be easier.

Long term care accounts for 32% of Medicaid spending. Some provisions related to long term care in the Affordable Care Act are listed below.

- Children can now receive palliative care and hospice care without giving up their curative treatment options.
- States can offer health homes to people with chronic conditions (care-coordination activities, transitional assistance across care settings, family support, and integration

of behavioral and physical health care services). Health homes become an option for states in 2011.

- The Money Follows the Person program has been extended and expanded through 2016. This is an opportunity for states to receive matching funds for moving people from institutional care into community-based care. CMS is working to help states be creative in building new infrastructure for this program.
- The Affordable Care Act requires integration of services for people covered by both Medicare and Medicaid. Currently, there is no coordination. States will also be able to seek 5-year demonstrations that serve dual (Medicare/Medicaid) eligibility.
- 1915(i) is new, and it allows states for the first time to provide waiver-like services through the state plan.
- The Community First Choice State Plan Option is another new program that takes effect in October 2011. It provides community attendant-care services to people who do not need institutional level of care.
- The Balancing Incentives Program is targeted at states that have not done a very good job integrating home- and community-based services; it gives them enhanced matching payments.
- The Affordable Care Act has a triple aim: better health for the population, lower costs through improvement, and better care for individuals.
- Other pieces of legislation driving the transitional transformation of Medicaid are the ADA and the Olmstead Act.

It is a time of great challenges for states, but CMS has to continue to move forward to put the structure and policy in place to move toward community-based care, which is the law of the land.

The strong themes of reform in the Affordable Care Act are person-centered services, individual control, and quality.

This is a great challenge to CMS, but Ms. Edwards said CMS is looking forward to that challenge. She explained that times are tough for states, but that is not a barrier if people keep their eyes on the prize and look at ways to deliver services more efficiently.

Tribal Long Term Care: Programs on the Ground

Kay Branch, Elder Planner, Alaska Native Tribal Health Consortium

Notes from the Presentation

These are notes taken by a professional note-taker at the conference and are not a text of the speaker's comments. They do not represent an official statement of the presenter.

Kay Branch has been involved with long term care in Indian Country for 20 years, and there was not much available when she first began her job. Ms. Branch is a firm believer that "Elders need to be near the river where they were raised," a quote from Rose Gorue.

Ms. Branch said that when she began her job there is a lot going on in long term care, but at that time there was not a lot about it published in journals. In order to get that information, she went to congressional hearings, got information from the White House Conference on Aging and National Indian Council on Aging, and from other sources.

She presented highlights of what is offered through Tribes today and what programs are on the ground.

The Laguna Pueblo Nursing Home was built in 1981. The Laguna nursing home is managed by Laguna Rainbow Corporation and has 58 beds. It is a Medicaid-certified facility, and it does some community-based services with Title VI funding. Laguna offers a continuum of care that begins with the basic types of services such as meals and transportation and goes all the way up to nursing home care. The facility receives federal, state, and private foundation funding and supports programs for community dwelling elders. Laguna incorporates Tribal culture into its care such as following the Navajo tradition of greeting the sun every morning. Laguna is one of 14 Tribal nursing homes currently in operation in the country.
Ms. Branch hopes one of the outcomes of long term care language in the reauthorization of the IHCIA is a network of shared learning so Tribal organizations can work together to learn what each other is doing and provide better services to their own elders.
Tribal home- and community-based care operates within the IHS. The nursing homes are working with the states, other Tribes, and non-Tribal providers in order to meet the needs of their elders.

The Elder Care Initiative Grants support the Tribes, Tribal consortiums, and Urban Indian Health Programs as they build long term care systems and services that meet the needs of the elders and that keep elders engaged and involved in the lives of their families and communities. Fifty-four grants have been awarded. The grant cycle is every 2 years, and the first one was awarded in 2003. The most recent grants were awarded in 2010.

Minnesota and Wisconsin both have an executive order under their governors to recognize Tribes as sovereign governments and require government-to-government relationships.

Below is a sampling of nursing homes in Indian Country.

- Minnesota - White Earth Nation
  - The facility operates through a Tribal Management of Elderly Waiver.
  - White Earth has formed a partnership with the state to directly serve their elder clientele that formerly had to go through the county for service.
  - White Earth serves more people who are Tribal members than ever before because they have this agreement.
  - The Leech Lake Band of Ojibwe came on board and began to bill Medicaid for long term care services as well.
- Wisconsin Tribal Services
  - Wisconsin offers state/Tribal coordination and collaboration, government-to-government consultation, Association of Tribal Aging Directors (2005), state funding for Tribal services and Tribal Technical Assistance Center at the Great Lakes Inter-Tribal Council.
  - The Ho-Chunk Nation has a range of long term care services provided with Tribal funds. It operates through an IHS Elder Care Initiative Grant (needs assessment), and it is increasing third-party revenue to enhance and expand programs.
- Laguna Pueblo Nursing Home
  - The home was established in 1981 with 25 beds. It has since expanded to 58 beds.
  - The home accepts Medicaid and does community-based services with Title VI programs.
  - The home incorporates Tribal culture, such as arranging windows so all residents can greet the sun every morning, according to Navajo tradition.
- Blackfeet Tribe
  - The Blackfeet Tribe has been a Montana Personal Care Program since 1995.
  - The facility employs local Tribal members as personal care assistants.
  - The facility accepts Medicaid, VA, and private pay.
  - The Tribe provides services to the elders and employment to young people.
- Fort Defiance
  - Fort Defiance offers a continuum of care for elders to keep them in their homes and within their community.
  - The facility has comprehensive elder assessment, which offers interdisciplinary support for elders and assesses their needs as well as the needs of family caregivers.

- Southeast Alaska Regional Health Consortium
    - The consortium has an Elder Care Initiative Grant, an extensive network of non-Tribal long term care providers that assesses access, cultural relevance, and gaps.
    - The Consortium serves eight villages in southeastern Alaska.
    - The Consortium has a need for home health and assisted living.
    - The Consortium used the data to apply for and receive a PHN grant.
    - The Consortium created an elder case management position.
- Zuni Elderly Services Adult Day Program
    - Zuni offers the following services: respite, transportation, lunch, exercise, activities, and personal care.
- Cherokee Nation PACE Program
    - The goal of the program is to keep elders in the community.
    - Cherokee Nation PACE serves 70 clients.
    - Cherokee Nation paved the way for PACE programs with the IHS, CMS, and Oklahoma for development of similar services in Indian Country.
- High Looke Lodge Assisted Living (Confederated Tribes of Warm Springs)
    - The facility has 35 assisted living units.
    - Funding for the facility comes from Medicaid and Tribes.
    - Residents of the facility are local and from neighboring Tribes.
- MarrulutEniit Assisted Living
    - MarrulutEniit is a 15-bed assisted living home.
    - A grant funded the building of the facility.
    - Services provided at the facility are paid for by Medicaid and residents.

Federal Resources to Support the Development of Tribal Long Term Care – A Federal Panel

David Dietz, Health and Human Services Officer of Minority Health

Notes from the Presentation

These are notes taken by a professional note-taker at the conference and are not a text of the speaker's comments. They do not represent an official statement of the presenter.

Mr. Dietz told attendees that over the last couple of years his agency, researchers, and other agencies have developed definitions for two important terms: health disparity and health equity. The NPA wants to increase the effectiveness of programs that target elimination of health disparities through the coordination of partners, leaders, and stakeholders committed to action.

The purpose of NPA is to establish a nationwide comprehensive, community-driven, sustained approach to ending health disparities. Components of the NPA include the National Action Plan, Regional Blueprints, initiatives, and campaigns.

The Office of Minority Health is seeking regional board members to participate and provide regional input on needs and strategies. Mr. Dietz encouraged anyone at the conference to consider participating in this capacity.

NPA collaborates from the federal to the state to the community level and provides open lines of communication.

NPA includes a section on older adults called the Older Adults' Strategy. The Strategy's goal is to enable provision of needed services and programs to foster healthy aging through identifying needs, forming partnerships, and linking resources.

For more information on NPA, go to minorityhealth.hhs.gov and search for National Plan of Action.

Lillian Sparks, Commissioner, Administration for Native Americans, Administration for Children and Families

Notes from the Presentation

These are notes taken by a professional note-taker at the conference and are not a text of the speaker's comments. They do not represent an official statement of the presenter.

Lillian Sparks, a member of the Rosebud Sioux Tribe and a descendant of the Oglala Sioux Tribe, explained the role of the American Nurses Association (ANA), a division of the Department of Health and Human Services. ANA is an agency that runs a highly competitive, discretionary grant program that provides funding for a variety of programs and services, including social and economic development strategies, environmental regulatory enhancement, and Native language (e.g., preservation and maintenance as well as emersion programs).Approximately $48 million is appropriated to the agency each year, and $42 million of that goes directly to grants. This year there were 365 grant applications,74 of which were funded.

ANA programs can supplement existing long term care community programs. For example, the agency has a program in Hawaii, which is a 3-year project to provide culturally competent, community-driven support to elders trying to stay in their homes. ANA also

helped the Cherokee Nation get its PACE program started, which was the first PACE program operated by a Tribe in a rural location. This was the first rural PACE program, the first PACE program in Oklahoma, and the first program to be operated by a Native American Tribe.

The Tribal Home Visiting Program is a partnership grant program with the Administration for Children and Families (ACF) and the Health Resources and Services Administration (HRSA). This year, there were 75 grant applications, 13 of which will be funded.

ANA dollars also can be used to jumpstart long-standing programs in communities.

Tribal Perspective on Home- and Community-based Care

Rick Richards, CEO, Cherokee Home and Health Services

Notes from the Presentation

These are notes taken by a professional note-taker at the conference and are not a text of the speaker's comments. They do not represent an official statement of the presenter.

Mr. Richards told attendees that the services offered by Cherokee Home Health Services originally were dependent on government structure, but it too was subject to outside forces. Cherokee started out as a not-for-profit organization in 1981; a home- and community-based services program was started in 1996.

In 1998, Cherokee became a totally self-supporting agency and moved all business functions in-house to be more responsive to their needs. By moving outside the government structure, they were able to recruit, hire, and retain more quickly and meet the needs of their patients. Currently, the home- and community-based program of Cherokee Nation Home Health serves about 440 patients daily. Cherokee admits and discharges 20 to 25 home- and community-based services patients a month.

Some patients are transitioned to PACE. Cherokee provides care for about 30 to 40 PACE patients in the home. The home- and community-based program also contracts with the VA to provide services to a dozen veterans in the area. The agency provides personal care, skilled nursing, and home health aides. Cherokee has a case-management service in which the case manager develops a plan of care. The case manager includes community care into its calculations. Cherokee has come to learn that it needs another level of service that is not exactly reimbursed. Cherokee hired Licensed Practical Nurses (LPNs) from the communities and is teaching these navigators about the various resources both inside and outside the

community. The LPN navigators assist the family and patients by coordinating a patchwork of services to better meet the needs of the patient and family.

Peg Blakely, Director, Leech Lake Band of Ojibwe Elders Program

Notes from the Presentation

These are notes taken by a professional note-taker at the conference and are not a text of the speaker's comments. They do not represent an official statement of the presenter.

Ms. Blakely shared her knowledge of providing home- and community-based care through the Leech Lake Band of Ojibwe Elders Program, which is in Northern Minnesota about 100 miles south of the Canadian border. There are approximately 9,000 people enrolled in the Leech Lake Tribe, approximately half of which live on the reservation. The Tribe started administering long term care services for the elderly in September 2007. In 2009, they started to provide three of the disability waivers.

Below are some of the lessons Leech Lake learned in starting their Elders Program.

- When creating a new program, the Tribes should plan for 1 to 2 years of work on the ground before implementation.
- There has to be buy-in from the Tribal Council and organizational leadership.
- A multidisciplinary team of nurses, social workers, grants/contract staff, etc., should be formed to get the program off the ground.
- Network with other Tribes who are doing similar work.
- In forming the Leech Lake Elders Program, they sought out allies at the state and federal levels. They also formed a partnership with counties and Managed Care Organizations in the area.
- Meet with partners on a regular basis.
- Establish government-to-government relationships, as Leech did with the state of Minnesota.
- Assert Tribal rights to determine the target population and service delivery area. The Leech Lake Tribe serves Native Americans and all the members of any household that includes Native Americans. They also work in the four-county area in which the reservation is located.
- Maintain a positive outlook despite opposition and have patience with bureaucracy and partners.
- Empathy goes a long way.
- Provide feedback, over and over again, if necessary.
- First and foremost, be persistent. "Ask until you get an answer!"

- Expect surprises.

Lee Olitzky, Administrator, Tohono O'odham Nursing Care Authority (TONCA)

Note: Lee Olitzky was standing in for Frances Stout, Chairwoman of TONCA. Below is the prepared statement provided by Ms. Stout.

Good morning. My name is Frances Stout. I am a member of the Tohono O'odham Nation and Chairperson of the Tohono O'odham Nursing Care Authority (TONCA). TONCA is the governing body of the Archie Hendricks, Sr. Skilled Nursing Facility and the Tohono O'odham Hospice. Both of these health services programs are located within the Tohono O'odham Nation.

Our perspective is first and foremost the facility; second, it is flexible to meet our people's needs; and lastly, it has exceeded our expectations.

Briefly, I want to give you some information about our location. The nation is located within the Sonoran Desert in south central Arizona. We are about the size of the state of Connecticut with a land base of 2.8million acres. It is the second-largest Tribe in Arizona, as measured by its population of enrolled members and its geographic size. Enrolled members number 29,000 with approximately 13,500 living on the reservation. Our nation is divided into 11 governmental subdivisions called "districts," and within these districts are villages, which are scattered throughout the nation. At the end of 2009, there were 2,261 (17% of the reservation population) Tohono O'odham elders living within the boundaries of the nation. Growth of the elder population on the reservation has been significant: in 2007, the number of elders was 1,745 for a gain of 22% between 2007 and 2010.

In addition, there were more than 1,800 elders living off the reservation in 2009. I include both numbers, as TONCA has learned that many times when an elder residing off the reservation requires health care services, they often choose to return "home."

My view of facility-based care is what is needed by most Native American nations. However, I also know that many nations do not have the numbers of tribal members or funds to support a skilled-care facility. We, the Tohono O'odham Nation, are blessed with a committed and supportive Tribal government and gaming revenues. TONCA, this past month, was awarded by the nation a subsidy for the next 5 years.

Because we are a skilled-nursing facility, we not only provide long term care, but we also provide a significant amount of post-hospital care, wound care, short-term rehabilitation, and IV antibiotics.

Providing these kinds of additional services really means that we developed a health care facility that responds to a broader number of health care needs than only long term care.

I know the trend is toward community-based care, and yes, this is what should take place; one size does not fit all. However, when you take into consideration other nation's needs, geographic size, location, resources (which include money), and manpower, it may be very difficult for other Tribes to develop and operate long term care or skilled-nursing facilities. We know at this time there are only 14 nursing facilities in Indian Country.

We opened our doors to the facility on November 17, 2003. It had taken almost 20 years to get to that day. We did not respond to an outside agenda but to our own immediate need and agenda. This required strategic planning, passion, and commitment – a commitment to "Bring Our Elders Home."

During the long planning process for the facility, there was an emphasis on future health care needs of the nation. Not only was there no place for care of the elders, but short term care was also missing.

We saw the new nursing home as much more than offering a single, limited service; it was to be and is a health resource and community gathering place and space for our nation's people. While honoring our elders, we are able to provide complex health care to many young elders. Importantly, we envisioned a location where elder care would be provided and, potentially, other services.

We have completed the design and plans for assisted-living residences on the same campus as the skilled-nursing facility. This level of care is for those elders who truly are not able to remain in their own home after everything has been tried, but they do not need the level of care provided in our nursing home. In our part of the country, assisted living is considered community-based care.

The TONCA board learned, as it evolved, that the elders both in the nursing home and in the community needed what the non-Indian community has called hospice services. There had been an outside hospice providing some services to the nursing home residents (very little to Tribal members in their own homes), but they were not sensitive to our culture, language, or practices. So working with our staff, we formed the Tohono O'odham Hospice. It became Medicare-certified after approximately 1 year of operation. You could say that we are also providing community-based hospice care as more of the hospice patients receive care in their homes than at the nursing facility. In order to operate a Medicare-certified hospice, you need to have an agreement with either a nursing home or hospital, so that when

the hospice patient needs more intensive support, one of those types of settings are available for care.

We learned from our hospice program that there was a significant need for other services. When elders and other adults were faced with a serious illness, they needed relief. This was relief from pain, fatigue, nausea, loss of appetite, shortness of breath, and stress.

With that as our understanding, we formed Desert Pathways – a program dedicated to providing palliative care to our Tribal members.

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

So as you can see, we have truly grown and matured in our approach to providing elder care.

We would like to take the opportunity to share with you what we are doing. We have been true to our mission of taking a leadership role in providing a continuum of care designed to meet the changing needs of our aging population. Our programs are based on strategic direction. We utilized surveys, worked with our districts, and used information from earlier focus groups in order to create an environment in which our facility will last.

Each of our three current programs has strong linkages to the IHS and Tribal government. This takes place at the planning level, the clinical level, and at the program development level. This has made for a very successful partnership. This should also enhance our ability to work with the changes that will take place as a result of the new mandates within the IHCIA.

I also want to share with you one other effort we have been working on for several years. It is one of my passions, and it is the Elder Care Consortium, or the ECC. The ECC is comprised of four primary partners at this point: the TONCA, the Tohono O'odham Community College, the Tohono O'odham Department of Health and Human Services, and the Tucson Area IHS, Sells Unit.

The ECC was formed to be a voice and advocate for our elders. It was formed to improve elder health care and social services by identifying needs, reducing fragmentation, and filling gaps in care.

It has taken a great deal of time and energy from all partners to establish the needed trust and support to get to the point where we can take the next steps. Addressing those areas, as you can easily see, is a very big challenge. The partners are not funded for this effort and must rely on agency and program board members and staff. We have been successful in receiving some small grants, but we are now seeking additional funding so the ECC can become more organized and formalized. This will permit the ECC to begin to address its mission for the elders. We are all of the belief that the ECC is and will be of great value to our elders and Tribe overall.

Vickie Bradley and David Hunt, Tsali Care Center

Notes from the Presentation

These are notes taken by a professional note-taker at the conference and are not a text of the speaker's comments. They do not represent an official statement of the presenter.

Ms. Bradley

The Tsali Care Center in Cherokee, NC, is a 60-bed facility that opened in 1996. Tsali was originally operated by a management company and was later converted to a Tribal program. The facility is now Tribally owned and gives the community a sense of ownership over the program and ownership in the community. Tsali has huge legislative and executive support for changes that need to be made within the facility. Care at the facility is culturebased, and Tsali is able to modify programming quickly for traditional patient needs. At least 50% of the staff is Tribal members.

The facility is dated, but there is a lack of funding to update it at this time. Approximately 53% of Tribal membership has no payer source.

The facility also has a number of atypical, non-elder patients with chronic diseases, such as diabetes, cardiovascular disease, alcoholism, depression, and traumatic brain injury.

They have huge successes, and there has been a major turnaround since David Hunt became administrator. However, there are challenges from being Tribally owned.

The facility was granted a state waiver. It also provides short-term rehab and therapy, and it is able to care for many different needs.

Mr. Hunt
Nobody wants to go to a nursing home. If you start a facility, understand that concept, and take care of the residents and the staff, you will be successful. Key elements of starting a nursing facility include knowing the system and knowing it extremely well.

Billing is also important. The Tsali staff is dealing with one of the most major changes in Medicare that they have seen in a long time. These changes can threaten reimbursement if staff does not know what they are doing. Last year, Tsali received a 19% supplement from the Eastern Band of Cherokee Indians. Tsali successfully billed $3.6 million, and the Tribe gave them $855,000.

Tsali's average census is 56.5 people per day, and they served 119 residents last year. The facility provides short-term rehab, does IV therapy, offers wound therapy, and offers a diabetes clinic, among others. Tsali is able to care for a lot of different needs. They send many people home after they receive care, a fact Mr. Hunt is proud of. It gives folks an opportunity to go back to their community, he said. Some do come to live at the Tsali facility for the rest of their life.

Tsali Care Center offers cafeteria-style dining, which gives residents flexibility. And they incorporate traditional foods as much as possible.

Tsali also offers three handicapped-accessible vans to take people into the community and help them feel connected. There are large outdoor spaces for cookouts in the summer. Tsali has raised gardens for their residents, but they cannot use that food in cooking. It has to be U.S. Department of Agriculture (USDA) inspected. Residents also have access to flat screen TVs, Wii games, wireless Internet, computers in day rooms, and aquariums.

Moving Beyond Paradigm Paralysis: Care at End of Life

Dave Baldridge, Director, National Indian Project Center

Notes from the Presentation

These are notes taken by a professional note-taker at the conference and are not a text of the speaker's comments. They do not represent an official statement of the presenter.

Dave Baldridge said it is important to acknowledge that Indian issues are more complicated than usually acknowledged and that national research has not considered the Native perspective in palliative care and end-of-life care. He asked people to challenge their assumptions about what Native elders want or do not want and what they are willing to talk about with regard to these issues.

Mr. Baldridge discussed various facilities that have been successful in providing end-of-life care and ones that should be looked to as models for others.

- The first facility is the Fort Defiance's Home-based Care Program, which Baldridge calls the cultural team model. This program began when Fort Defiance was an IHS hospital and is continuing now that the program is Tribally operated. In 1999, their completion rate for advanced directives was 1% and 4% for Designated Medical Power of Attorney (DMPOA). The team created a plan to address the issue, and it worked. In 2010, their completion rate for advanced directives for patients enrolled with their program was 85% and nearly 80% for DMPOAs. Fort Defiance uses the Medicare hospice benefit and an interdisciplinary team model. Fort Defiance focuses on reducing hospital re-admission. Their staff is embedded in the community; they know patients personally; they are fluent in Navajo; and they are empathetic. Fort Defiance involves end-of-life in the continuum of care. They have elevated cultural sensitivity and that has made all the difference. He stressed that it is important that how, where, when, and why questions are asked.
- The Cherokee Nation uses a client-directed model. They have a PACE program, home health program, and a hospice program. The Cherokee Nation focuses on personal care, homemaker chore services, and respite care. The key here is they threw all the models out and began asking the question, "what do you need?" Cherokee cut out the non-essentials and got to the heart of the needs.
- The Zuni Home Health Care Agency has 1,350 Zuni and Navajo elders within 5 miles of the facility. The Zuni model uses their Medicare- and Medicaid-certified home health agency and the Medicaid personal-care program embedded in an interdisciplinary team to provide end-of-life care. The key to Zuni's success has been the respect and consistency with cultural beliefs. They let the patient and the family lead. Zuni is incorporating end-of-life care into the long term care continuum. In 9 years, Zuni has served 76 patients in that small community. Working in partnership, the Zuni Home Health Care Agency and the IHS hospital have built a level of trust in the community over the years, and it is working superbly at Zuni to increase access to end-of-life care.
- The University of New Mexico Palliative Care Program is an urban model in Albuquerque, which includes New Mexico's 23 Tribes and an Urban Indian population representing more than 100 Tribes from throughout the country. The hospital is the only Level 1 Trauma Center in the state. They have the highest percentage (10.3%) of AI/AN admissions of any academic hospital in the U.S. It is a 2-year-old program with a small team and most of the time they meet their patients for the first time when they need palliative or end-of-life care. Most patients come to them in crisis. There is no chance for this team to build years and years of trust with patients. The program offers high levels of expertise, both medical and cultural.

During the past 2 years, the preference of Native patients is for comfort and symptom management rather than aggressive interventions. AI/AN preference for "do not resuscitate" (DNR) orders at the end of life has increased from 22% to 62%, and family end-of-life meetings increased from 30% to 70%. They let the patients and families lead all discussions.

Section 5: ATTENDEE LIST AND PRESENTER BIOS

Attendee List

First and Last name, Organization, City, State
This list is alphabetical by last name and includes only as much information as attendees chose to share.

Cecelia Aldridge, AOA/OAIANNHP, Washington, DC
Nadine Aleman, Pascua Yaqui Senior Center, Tucson, AZ
Elaine Alexander, Indian Health Service, Albuquerque, NM
Pearl Alonzo, Pine Hill Health Center, Pine Hill, NM
Frank B. Andrews Jr., Colville Confederated Tribes, Coulee Dam, WA
Deanna Aquiar, Fort Defiance Indian Hospital Board, Inc., Albuquerque, NM
CharleeArchambault, Rosebud Sioux Tribe, Rosebud, SD
Tyra Baer, National Indian Health Board, Washington, DC
Dave Baldridge, National Indian Project Center, Albuquerque, NM
Marjorie Bear Don't Walk, Indian Health Board of Billings, Billings, MT
Peggy Becker, VHA Central Office, Washington, DC
Lee Begay, Inter Tribal Council of Arizona, Inc., Phoenix, AZ
Winona Begay, ShiprockIndian Health Service, Cortez, CO
Josephine Binford, Taos-Picuris Health Center, Taos, NM
John Bioff, Norton Sound Health, Nome, AK
Peg Blakely, Leech Lake Health Division, Cass Lake, MN
Roxane Spruce Bly, Laguna Rainbow Corporation, Albuquerque, NM
Vickie Bradley, Health and Medical Division, Cherokee, NC
Kay Branch, AK Native Tribal Health Consortium, Anchorage, AK
Terra Branson, National Congress of American Indians, Washington, DC
Mariel Braun, Kauffman & Associates, Inc., Silver Spring, MD
Rozan Brown, Lake County Tribal Health, Lakeport, CA
Marjorie Buckskin, Yurok Tribe, Klamath, CA
Wendy Burdette, Muckleshoot Indian Tribe, Auburn, WA
Pat Butler, White Earth Home Health Agency, White Earth, MN
Shapiro Cambridge, National Council of Urban Indian Health, Washington, DC
Amy Cesspooch, Ute Indian Tribe, Ft. Duchesne, UT
Randal Chevalier, Menominee Indian Tribe of Wisconsin, Keshena, WI
Sue Clain, HHS/Planning & Evaluation, Washington, DC
Tamara Clay, Indian Health Service, Shepherdstown, WV
Henry Claypool, Office on Disability/HHS, Washington, DC
Robin Clemons, Pueblo of Acoma Elderly Program, Pueblo of Acoma, NM

Jennifer Cooper, National Indian Health Board, Washington, DC
Bonnie Culfa, Sault Tribe of Chippewa Indians, Sault St. Maine, MI
Sharon Curley, Muckleshoot Indian Tribe, Auburn, WA
Elaine Dado, Northwest Portland Area Indian Health Board, Portland, OR
Liam Devlin, Eastern Aleutian Tribes, Anchorage, AK
David Dietz, Office of Minority Health, Rockville, MD
Joan Domnick Johnson, Norton Sound Health Corporation, Eagle River, AK
Leslie Dye, Portland Area Indian Health Service, Portland, OR
Barbara Edwards, Centers for Medicare & Medicaid Services, Baltimore, MD
Elizabeth Egan, Squaxin Island Tribe, Shelton, WA
Carmen Estrella, Tucson, AZ
Sylvia Etsitty, Navajo Nation Division of Health, Window Rock, AZ
Jay Farmwald, Dowl HKM, Anchorage, AK
Cindy Ferguson, Snoqualmie Tribe, Snoqualmie, WA
Joe Finkbonner, Northwest Portland Area Indian Health Board, Portland, OR
Reis Fisher, Blackfeet Tribe, Browning, MT
Terry Flamand, Blackfeet Personal Care Program, Browning, MT
Paul Fowler, Indian Health Service, Rockville, MD
Theresa Gardner, Hogansburg, NY
Gary Hartz, Indian Health Service, Rockville, MD
R. Turner Goins, West Virginia University, Morgantown, WV
Angela Gorn, Norton Sound Health Corporation, Nome, AK
Meg Graves, Administration on Aging, Washington, DC
Leslie Green, Administration on Aging, Washington, DC
Sandra Haldane, Indian Health Service, Rockville, MD
Paul Hansen, Maniilaq Health Center, Kotzebue, AK
Leonard M. Harjo, Seminole Nation of Oklahoma, Wewoka, OK
Hank Haskie, Navajo Area Agency on Aging, Window Rock, AZ
Margaret Hemnes, Native Village of Unalakleet, Unalakleet, AK
K.J. Hertz, National Association of Area Agencies on Aging, Washington, DC
Bonnie Hillsberg, Centers for Medicare & Medicaid Services, Baltimore, MD
Sandy Horton, OCC/HHS, Dallas, TX
Kevin Howlett, Confederated Salish and Kootenai Tribe, Ignatius, MT
Sara Hubbard, Native Health, Phoenix, AZ
Kathy Hughes, Oneida Tribe, Oneida, WI
David Hunt, Tsali Care Center, Cherokee, NC
Sally Hutton, Colville Tribal Convalescent Center, Nespelem, WA
Michael Icay, Lake County Tribal Health, Lakeport, CA
Jessica Imotichey, Chickasaw Nation, Washington, DC
Sandra Irwin, Hualapai Tribe, Peach Springs, AZ

Danette Ives, Port Gamble S'Klallam Tribe, Kingston, WA
Lee Ivinson, Little River Band of Ottawa Indians, Manistee, MI
Yvonne Jackson, Administration on Aging, Washington, DC
John Johns, Centers for Medicare & Medicaid Services, Baltimore, MD
Johnny Johnson, Navajo Area Agency on Aging, Window Rock, AZ
MechelleJohnson-Webb, Esq., MPH,HHS, Rockville, MD
Miranda Jones, HHS OGC, Chicago, IL
Shoshannah Jordan, Colville Tribal Convalescent Center, Nespelem, WA
Andy Joseph, Northwest Portland Area Indian Health Board, Portland, OR
Susan Karol, Indian Health Service, Rockville, MD
Julie Kauppila, LTBB, Harbor Springs, MI
Frank Kearns, Tuolumne MeWuk Indian Health Center, Tuolumne, CA
Hilary Keeley, Office of General Counsel-Indian Health Service Branch, Rockville, MD
Alice Koskela, Office of the Reservation Attorney, Nespelem, WA
Marilyn Lambert, Tsali Care Center, Cherokee, NC
Cheryl LaPlant, Sault St. Marie, MI
TenaLarney, Indian Health Service, Office of Tribal Self-Governance, Rockville, MD
Donna LeBeau, Cheyenne River Sioux Tribal Health, Eagle Butte, SD
Leland Leonard, Fort Defiance Indian Hospital Board, Inc., Fort Defiance, AZ
Jordan Lewis,University of Alaska Fairbanks,Fairbanks,AK
Mueller Liz,Jamestown S'Klallam Tribe,Sequim,WA
Kris Locke, Locke and Associates, Sequim,WA
Melanie Loveric,Oneida Indian Nation Health Center,Oneida,NY
Rebecca Loving,Oklahoma City Area Indian Health Service,Shawnee,OK
Christine Lowery,New Mexican Indian Council on Aging,Paguate,NM
Stefanie Luna,Chickasaw Nation Division of Health,Ada,OK
Michelle Manuel, Pascua Yaqui Tribe, Tucson, AZ
Sandy Markwood,National Association of Area Agencies on Aging,Washington,DC
Margaret Marsh,Fort Peck Tribes,Poplar,MT
Debra Martin,St. Regis Mohawk Tribe,Hogansburg,NY
Kitty Marx,Centers for Medicare & Medicaid Services,Baltimore,MD
Victor Hugo,Marx III, U.S. Health & Housing Foundation,Birmingham,AL
Elmer Milford,Fort Defiance Indian Hospital Board, Inc.,Fort Defiance,AZ
KayciMiller,AST Health Authority, Inc.,Shawnee,OK
Marie Miller,Little Traverse Bay Bands of Odawa Indians,Harbor Springs,MI
ArnoldoMoore,Social Security Administration,Baltimore,MD
SherriahnMoore, Indian Health Service Headquarters - ORAP,Rockville,MD
Christina Morrow, HHS/OGC/Indian Health Service,Rockville,MD
Gerald Moses,Alaska Native Tribal Health Consortium,Washington,DC
Margaret Moss,Yale School of Nursing,New Haven,CT

Stephanie Moss,Tribal Health,Fort Hall,ID
Cyndi Nation,Tanana Chiefs Conference,Fairbanks,AK
Stella Nullake,Sac and Fox Nation,Stroud,OK
Clayton Old Elk, Indian Health Service, Rockville, MD
Lee Olitzky,Tohono O'odham Nursing Care Authority,Tucson,AZ
Richard Olson,Indian Health Service,Rockville,MD
Peggy O'Neill,Yurok Tribe,Klamath,CA
Lisa Palucci,Indian Health Service,Rockville,MD
DevenParlikar, HHS
Andrea Patton, Indian Health Service, OTSG,Rockville,MD
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Denise Pommer,Menominee Indian Tribe of Wisconsin,Keshena,WI
George Provencher,Pinoleville Pomo Nation,Ukiah,CA
Steven Raynor, Indian Health Service,Rockville,MD
Rebecca Renolds,U.S. Government,Arlington,VA
Rick Richards,Cherokee Nation Home Health Services,Tahlequah,OK
Caleb Roanhorse,Fort Defiance Indian Hospital Board, Inc.,Fort Defiance,AZ
Jim Roberts,NW Portland Area Indian Health Board,Portland,OR
Lee Robinson, Indian Health Service/OEHE,Rockville,MD
Jane Rooney,Oneida Indian Nation,Oneida,NY
Geoffrey Roth, Indian Health Service
Gayle Ruhl,Saginaw Chippewa Indian Tribe,Mt. Pleasant,MI
Lisa Schwartz,South East Regional Health Consortium,Haines,AK
David Segura,Kenaitze Indian Tribe,Kenai,AK
Al Sherman,Indian Health Service Aberdeen Area,Aberdeen,SD
Josephine Shije, Laguna Rainbow Center, Espanola, NM
Bernadine Shriver,Confederated Tribes of Grand Ronde Oregon,Gresham,OR
Carissa Siebeneck,Navajo Nation Washington Office,Washington,DC
Randall Simmons,Navajo Nation Washington Office,Washington,DC
Margaret Simons,Qutekcak Native Tribe,Seward,AK
Gregory Smith,Smith & Brown-Yazzie LLP,Washington,DC
Jane Smith,Oneida Community Health Center,Oneida,WI
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CelissaStephens, Indian Health Service,Edmond,OK

Cathy Stueckemann,Indian Health Service,Rockville,MD
Lane Terwilliger,CMS,Baltimore,MD
Andrew Teuber,Kodiak Area Native Association,Kodiak,AK
Leonard Thomas,Indian Health Service,Albuquerque,NM
LeoraTreppa-Diego,Lake County Tribal Health,Lakeport,CA
Patsy Triana, Tucson,AZ
Roselyn Tso, Indian Health Service,Rockville,MD
YeshimebetTulu, San Carlos Apache Tribe, San Carlos,AZ
Ashley Tuomi,Lake County Tribal Health,Lakeport,CA
Robert Two Bears,Ho-Chunk Nation,Black River Falls,WI
Lorraine Van Brunt
Norma Wadsworth,Tribal Health & Human Services,Fort Hall,ID
Wilson Wewa,Confederated Tribes of Warm Springs,Warm Springs,OR
Glenda Whitelaw,Colville Tribal Convalescent Center,Nespelem,WA
Jessica Wiles,Hobbs Straus Dean and Walker, LLP,Portland,OR
Joe Willey,JBS International Inc.,North Bethesda,MD
JacklynWilliams,Sac and Fox Nation,Stroud,OK
Phyllis Wolfe,Indian Health Service,Rockville,MD
Dennis Worden,National Indian Health Board,Washington,DC
Lenard Wright,Rosebud Sioux Tribe,Rosebud,SD
PengWu,Sonosky, Chambers, Sachse, Endreson& Perry,Washington, DC
Jeannette Yazzie,Indian Health Service - Navajo Area,Window Rock,AZ
Kim Yost,Yurok Tribal Court,Klamath,CA
Anita Yuskauskas, PhD, Centers for Medicare & Medicaid Services, Baltimore, MD

Presenter Bios

Dave Baldridge currently serves as the Director of the Albuquerque, NM-based National Indian Project Center. He served as executive director of the National Indian Council on Aging (NICOA) from 1991-2003 as the nation's foremost non-profit advocate for older Indians and Alaska Natives. Under his leadership, NICOA tripled in size while significantly influencing legislation and federal policies affecting American Indian and Alaska Native elders. Mr. Baldridge has been actively involved in public policy and research efforts on federal, state, and local levels. His publications on a wide variety of Indian aging issues have been widely distributed and cited.

Peg Blakely is a licensed social worker and is the Director of the Elders Department at the Leech Lake Reservation Health Division, where she has been employed for 6 years. She is a Long Term Care consultant and case manager for the department's Waiver Program. Ms. Blakely was part of a team that worked with the State of Minnesota and four local counties in which the reservation is located. She has also served as Coordinator of Anishinabeg Minosewag Behavioral Health Program. She has 15 years of experience working with the Native American population as an In-Home Family Social Worker, Children's Mental Health Case Manager, and Lead Case Manager in the Cass Lake area. She and her husband Phil – a Leech Lake enrollee – have lived on the reservation for 14 years.

Kay Branch is employed as the Elder/Rural Health Program Coordinator at the Alaska Native Tribal Health Consortium, focusing on the health status and long term care needs of Alaska Native Elders. She has over 15 years of experience working with Alaska Native elders, including Older Americans Act programs, personal care services, and assisted living and workforce development issues. Under agreement with the Indian Health Service (IHS), Ms. Branch provides technical assistance in long term care service development to IHS Elder Care Grantees. She received a bachelor's degree in anthropology from the University of Alaska Anchorage and a master's degree in applied anthropology from the University of South Florida, with a focus in gerontology specifically related to American Indian and Alaska Native elders.

Henry Claypool serves as the primary advisor to the Health and Human Services (HHS) Secretary on disability policy and oversees the implementation of all HHS programs and initiatives pertaining to Americans with disabilities. Mr. Claypool has 25 years of experience developing and implementing disability policy at the federal, state, and local levels, and he has personal experience with the nation's health care system from the perspective of an

individual with a disability. Mr. Claypool sustained a spinal injury more than 25 years ago. In the years following his injury, he relied on Medicare, Medicaid, Social Security Disability Insurance, and Supplemental Security Income, which enabled him to complete his bachelor's degree at the University of Colorado. After completing his degree, he spent 5 years working for a Center for Independent Living, after which he became the Director of the Disability Services Office at the University of Colorado-Boulder. Mr. Claypool served as the policy director at Independence Care System, a managed long term care provider in New York City. Mr. Claypool has advised the federal government on disability policy for several years. From 1998 to 2002, he held various advisory positions at HHS, including senior advisor for disability policy to the Administrator of the Centers for Medicare and Medicaid Services during the Clinton administration. From 2005 to 2006, he served as a senior advisor in the Social Security Administration's Office of Disability and Income Support Programs. Mr. Claypool was also appointed by Governor Tim Kaine of Virginia to serve on the Commonwealth's Health Reform Commission in 2007.

Commander David Dietz, U.S. Public Health Service, is a senior public health advisor at the Office of Minority Health, Department of Health and Human Services. He is the subject matter lead for issues relating to health information technology and gerontology. Commander Dietz has served as a senior advisor at the Centers for Medicare and Medicaid, Office of the National Coordinator for Health Information Technology, and the Administration on Aging. As an officer in the Public Health Service, he has deployed to several disasters, and he has spent time in Vietnam, Republic of the Philippines, and Singapore as a member of the Pacific Partnership Mission 2008. As a result of his achievements, Commander Dietz has been awarded four Commendation Medals, several Outstanding Unit Commendations, and the Hazardous Duty Service Award. Commander Dietz has earned a Bachelor of Arts from Brandeis University, Master of Social Work from Howard University, a Master of Health Services Administration from George Washington University, and he is currently completing a doctoral degree at Howard University.

Barbara Coulter Edwards currently serves as the Director of the Disabled and Elderly Health Programs Group in the Center for Medicaid, Children's Health Insurance Program, and Survey and Certification at Centers for Medicare and Medicaid Services. Ms. Edwards has almost 30 years of public and private sector experience in health care financing. She is a nationally recognized expert in Medicaid policy, including managed care, cost containment, long term care, and state and federal health care reform. She served for 8 years as the Ohio State Medicaid Director and has been a Principal with Health Management Associates, Inc. since December 2005. Ms. Edwards' work at Health Management Association has focused on Medicaid, national health reform, and service delivery for persons with chronic and

disabling conditions. She also spent 6 months as the Interim Director of the National Association of State Medicaid Directors.

Bruce Finke, MD, is a family physician and geriatrician and serves as the national lead in Elder Care and Palliative Care for the Indian Health Service (IHS). Since 1998, he has provided support to tribal, IHS, and urban programs in the development of improved clinical and preventive care for the elderly. He has had a leadership role in the development of long term care policy, in support of tribal long term care programs, and in the development of palliative care resources in Indian health. As a physician at the IHS Hospital in the Pueblo of Zuni from 1991 to 2003, he worked in an interdisciplinary team setting to develop innovative elder care programs and collaborated closely with Tribal programs in the development of services in the community, including a tribal hospice program. He now works with the Tribes of the Nashville Area and nationally in the development of health care services for elders.

R. Turner Goins, PhD, is an Associate Professor in the Department of Community Medicine and in the Center on Aging at West Virginia University, Robert C. Byrd Health Sciences Center. Dr. Goins also works with the Native Elder Research Center at the University of Colorado-Denver. She received her Master of Science degree and doctorate in Gerontology from the University of Massachusetts-Boston and completed a National Institute on Aging Post-Doctoral Fellowship at Duke University's Center for the Study of Aging and Human Development. The focus of Dr. Goins' research is on Native American aging issues, including access to long term care services and family caregiving.

David Hunt has been a nursing home administrator since 1992. For the past 5 years, Mr. Hunt has served as the administrator of Tsali Care Center. Tsali Care is a 60-bed long term care facility owned and operated by the Eastern Band of Cherokee Indians. During his tenure at Tsali Care, the facility has enjoyed a steady growth in census and revenue. Currently, the facility is expanding to add a 12-bed memory care unit that is targeted to open in October 2011. In 2008, the Nashville Area Indian Health Service selected Mr. Hunt as an Employee of the Year in the Supervisory Staff Category. Mr. Hunt holds a Bachelor of Science degree in Economics and Business Administration from High Point University.

Susan Karol, MD, FACS, FAECP CMO, was selected in September 2008 as the Chief Medical Officer (CMO) of the Indian Health Service (IHS). She is a member of the Tuscarora Indian Nation. Dr. Karol served from 1988 through 1990 as a Lieutenant Commander in the U.S. Public Health Service while holding the position of Chief of Surgery

and Anesthesia at the Shiprock Indian Hospital, Shiprock, NM. Dr. Karol came to the IHS from the Essex Surgical Associates, PC, in Beverly, MA, where she worked since 2004. From 1991 to 2003, she worked at Beverly Surgical Associates, Inc. From 1991 to the present, Dr. Karol also has served as the Medical Director of The Hunt Breast Center, Hunt Hospital, Danvers, MA, and as an active staff member of the Beverly Hospital. From 1996 to the present, she has served as Chief of Surgery at the Beverly Hospital. Her other appointments include serving as an assistant Professor of Surgery at Tufts Medical School from 1994 to the present; Trustee of the Northeast Health Systems, Inc., Beverly Hospital; and as Assistant Medical Director of Specialty Care of the New England Community Medical Group. Dr. Karol graduated from Dartmouth College with an AB in biology and received her medicine degree from the Medical College of Wisconsin. Her post-doctoral training includes work as Clinical Fellow in Surgery at the Massachusetts General Hospital; Chief Resident and General Surgery Residency, University of Massachusetts Medical Center Coordinated Surgical Program; General Surgery Resident, St. Mary's Hospital and Medical Center; and Categorical Surgical Resident, University of Massachusetts Medical Center Coordinated Surgical Program. As the IHS CMO, Dr. Karol provides medical advice and guidance to the Office of the Director and staff on American Indian and Alaska Native health care policies and issues. She serves as the primary liaison and advocate for IHS field clinical programs and community-based health professionals. Dr. Karol also provides national and international health care leadership and representation for the agency. In addition, she ensures that patient care and medical standards and concerns are represented in the decision-making process of the agency. Dr. Karol is a fellow of the American College of Surgeons and a fellow of the American College of Physician Executives. She also is a member of the American Society of Breast Surgeons, Association of American Indian Physicians, Essex Surgical Society, and the Massachusetts Medical Society.

Dave Larson holds a master's degree and is a licensed Nursing Home Administrator at the Oneida Community Health Center. He has over 30 years of management experience, more than 18 of which is in healthcare. He is experienced in both long term and primary care settings, having held administrative positions in hospital, medical center, skilled nursing facilities as well as managing the Home- and Community-Based Waivers Program.

Cindy R. Padilla was appointed to the Principal Deputy Assistant Secretary on Aging in December 2009. Ms. Padilla most recently served as the Secretary of the New Mexico Aging & Long Term Services Department (ALTSD) under the administration of Bill Richardson. She holds a bachelor's degree in Social Work and studied Public Administration at the University of New Mexico Graduate School of Public Administration. As the Secretary of the New Mexico Aging and Long Term Services Department, Ms. Padilla managed many

programs that focused on Independence and Dignity for older New Mexicans and people living with disabilities. Ms. Padilla brings her New Mexico experience in elder justice (i.e., protection, intervention, and advocacy), Aging Network Services, Long Term Care Ombudsman, and consumer and elder rights as well as her work with New Mexico's Tribes, Pueblos, and the Navajo Nation to Washington, DC. She also brings a focus on people and the importance of building relationships with the people served through the Administration on Aging. Although her professional work in aging is a recent career change, she has a lifetime commitment to public service. Ms. Padilla has 23 years of experience in environmental regulation and operations and community advocacy and organizing.

Rick Richards has served as the Chief Executive Officer for Cherokee Nation Home Health Services for 15 years. During that time, the agency has grown from 26 employees serving 60 clients to an agency with 220 employees serving over 600 clients. When Mr. Richards assumed duties at Cherokee Nation Home Health Services, the agency was offering Medicare home health services only. Under his leadership, Cherokee Nation Home Health Services expanded services by adding Cherokee Nation Home Health Outreach, a department that provides services under the Medicaid Advantage Program, and Hospice of the Cherokee, a department offering hospice services to eligible clients. Mr. Richards served on the PACE start-up team for the Cherokee Nation, which was responsible for opening the first PACE Center in Oklahoma and the first Tribal PACE center in the nation. Prior to his time at Cherokee Nation Home Health Services, Mr. Richards worked as a Nursing Home Administrator and a Medicare consultant assisting Skilled Nursing Facilities in securing their Medicare certification status.

Yvette Roubideaux, MD, MPH, is a member of the Rosebud Sioux Tribe, SD, and the Director of the Indian Health Service (IHS). The IHS is an agency within the U.S. Department of Health and Human Services that is responsible for providing preventive, curative, and community health care to approximately 1.9 million American Indians and Alaska Natives in hospitals, clinics, and other settings throughout the U.S. Her past experience has included conducting extensive research on American Indian health issues, with a focus on diabetes in American Indians/Alaska Natives and American Indian health policy. Dr. Roubideaux received her medical degree from Harvard Medical School in 1989 and completed a residency program in primary care internal medicine at Brigham and Women's Hospital in Boston in 1992. She completed her Master of Public Health degree at the Harvard School of Public Health in 1997. Dr. Roubideaux also completed the Commonwealth Fund/Harvard University Fellowship in Minority Health Policy before transitioning to a career in academic medicine and public health. Dr. Roubideaux is a past president of the Association of American Indian Physicians and co-editor of the American

Public Health Association's book *Promises to Keep: Public Health Policy for American Indians and Alaska Natives in the 21st Century*. She has authored several monographs and peer-reviewed publications on American Indian/Alaska Native health issues, research, and policy.

Jane Smith, BA, RN, NHA, has 30 years of professional experience in education, critical care, mental health, and long term care and has worked as a Nurse Manager, Director of Nursing, and Nursing Home Administrator. For over 10 years, she has been employed by the Oneida Comprehensive Health Division and is currently the Administrator of the Anna John Nursing Home. Under her administration, the nursing home became Medicare Certified, and in 2009, Anna John Nursing Home was one of only three facilities in the northeast region of Wisconsin to receive a 5-star ratting from the Wisconsin Division of Quality Assurance. She has served as the Oneida representative to the Wisconsin Council on Long Term Care Reform. Since 2009, she has been actively involved in the Oneida Nation's interface with the State of Wisconsin Department of Human Services on issues of state long term care redesign and its implications for Native people. She is an enrolled member of the Bay Mills Indian Community of Michigan.

Lillian Sparks, a Lakota woman of the Rosebud and Oglala Sioux Tribes, is the Commissioner of the Administration of Native Americans. Miss Sparks was confirmed by the U.S. Senate as the Commissioner on March 3, 2010, and was sworn in on March 5, 2010. She has devoted her career to supporting the educational pursuits of Native American students, protecting the rights of indigenous people, and empowering Tribal communities. Prior to her appointment, Ms. Sparks served as the Executive Director of the National Indian Education Association (NIEA), where she worked extensively on K-12 and early childhood education policy and appropriations affecting American Indian, Alaska Native, and Native Hawaiian students. Before joining NIEA, Ms. Sparks served as a staff attorney with the National Congress of American Indians where she worked on international indigenous rights, sacred sites and religious protection, and issues related to youth and healthcare. Ms. Sparks also previously worked in the legal department at the National Indian Gaming Commission at the Department of the Interior. Named one of seven young Native American Leaders by USA Today Magazine, Ms. Sparks received her Bachelor of Arts degree in political science from Morgan State University, located in her hometown of Baltimore, MD, and her Juris Doctor degree from Georgetown University Law Center in Washington, DC. Ms. Sparks is admitted to practice in Maryland.

Frances Stout, a retired registered nurse, is a member of the Tohono O'odham Nation. Her entire nursing career of 33 years was spent in the Indian Health Service in the area of nursing administration. Since retirement, she has continued to work in the area of health care. In 2009, she received the Community Health Leader Award from the Robert Wood Johnson Foundation. She has chaired the Tohono O'odham Nursing Care Authority Board for the past two terms.

Anita Yuskauskas, PhD, is currently the Technical Director for Quality in Home and Community Based Services with the Centers for Medicare and Medicaid Services (CMS). She was previously a Waiver Analyst at CMS and was involved with the Independence Plus Initiative and Tribal issues. Preceding her federal tenure, Dr. Yuskauskas served as a Division Chief in Hawaii's Department of Health, overseeing the developmental disabilities, Hansen's Disease, and brain injury programs. She also served as Chief Policy Analyst for the Center for Outcome Analysis in Rosemont, PA. Dr. Yuskauskas holds a doctorate in rehabilitation from Syracuse University. She conducted numerous program evaluations and qualitative research projects specializing in organizational change and taught undergraduate and graduate courses in human services and special education. Dr. Yuskauskas previously volunteered her time as an advisor for Speaking for Ourselves, a statewide self-advocacy organization in Pennsylvania, and she is a trained mediator.