American Indian and Alaska Native
Health Research Advisory Council (HRAC)
Annual Meeting
June 9-10, 2016
Arlington, VA

HRAC Tribal Delegates and Alternates
Tom Anderson—Oklahoma Area Delegate
Stacy Bohlen—National At-Large Member Alternate
Daniel Calac, MD—California Area Delegate
Simental Francisco—Navajo Area Delegate
Larry Jacques—Bemidji Area Alternate
Charlene Jones—Nashville Area Delegate
Aaron Payment—Bemidji Area Delegate
Michael Peercy—National At-Large Member
Ilene Sylvester—Alaska Area Delegate
Dawnette Weaver—National At-Large Member Delegate (proxy for Jefferson Keel)

HRAC Federal Partners
J. Nadine Gracia, MD, MSCE, Alexis Bakos, PhD, Marilyn Cabrera, Lena Marceno—Office of Minority Health (OMH)
Kishena C. Wadhwani, PhD—Agency for Healthcare Research and Quality (AHRQ)
CAPT Carmen Clelland, PharmD, and Delight Satter—Centers for Disease Control and Prevention (CDC)
Mose Herne—Indian Health Service (IHS)
James Anderson, MD, PhD—National Institutes of Health (NIH)
Sheila Cooper and David Dean Jr., PhD—Substance Abuse and Mental Health Services Administration (SAMHSA)

Invited Speakers
Tamara Henry, PhD, Elton Naswood, and Faye Williams—OMH Resource Center (OMHRC)
Kenneth Johnson, JD—HHS Office for Civil Rights (OCR)
Lynn Morin—National Institute on Alcohol Abuse and Alcoholism (NIAAA)

Other Attendees
Kendra King Bowes—Native American Management Services, Inc. (NAMS)
Jessica Escobedo, PhD—National Institute on Minority Health and Health Disparities (NIMHD)

Robert Henrichs—Native Village of Eyak
Erika Noyes, Christine Segal, and Deborah Thornton—Professional and Scientific Associates (PSA)

DAY ONE – Thursday, June 9, 2016

Invocation
Daniel Calac, MD, California Area Delegate

Dr. Calac opened the meeting with a traditional invocation.

Welcome and Introductions
Aaron Payment, HRAC Co-Chair and Bemidji Area Delegate

Chairperson Payment welcomed HRAC members and staff, and invited meeting participants to introduce themselves.

Following the introductions, Chairperson Payment noted that the HRAC was exempt from the Federal Advisory Committee Act (FACA) rules. The protocol for the meeting was set forth in the document outlining the exemption.

Opening Remarks
J. Nadine Gracia, MD, MSCE, Deputy Assistant Secretary for Minority Health and Director, OMH

Dr. Gracia welcomed continuing and new HRAC members and other attendees. She noted that Rick Haverkate had taken a position as Deputy Director of the Office of Clinical and Preventive Services at the Indian Health Service (IHS). Dr. Gracia's Senior Advisor, Alexis Bakos, who serves as Acting Director of the OMH Division of Policy and Data, is overseeing the AI/AN health policy portfolio until Mr. Haverkate's position is filled.

Dr. Gracia provided updates on the work of OMH. Highlights were as follows:

- Transition to a new administration: The work of the HRAC will remain a priority of HHS, and OMH will communicate the council's history and priorities to the new leadership.
- National Partnership for Action to End Health Disparities (NPA): The NPA is a national, community-driven initiative that utilizes a social determinants of health (SDoH) approach to address health disparities. The NPA implementation structure includes a Federal Interagency Health Equity Team (FIHET), 10 Regional Health Equity Councils (RHECs), and national and state-level partners. A new partnership with the National Indian Health Board (NIHB) will support the integration of SDoH into strategic planning and public health accreditation activities of tribal public health departments. A cross-RHEC AI/AN Caucus is working to address health disparities and SDoH among Native populations, with a focus on the Affordable Care Act, diabetes, oral health, and public health accreditation. The caucus is seeking new members, and OMH welcomes nominations from HRAC members.

- Hepatitis B and C viral infection: Hepatitis is known as the silent epidemic, and there are growing disparities of Hepatitis C virus infection among AI/AN populations. (a) OMH partnered with CDC to co-sponsor the National Academies of Sciences, Engineering, and Medicine to conduct a study to determine the feasibility of setting national goals for the elimination of Hepatitis B and C in the United States. The first phase of the study determined that setting elimination goals would be feasible; the second phase will set specific goals and targets. (b) OMHRC is conducting training on hepatitis, including a webinar on June 22 that will focus on hepatitis among AI/AN populations.
- Culturally and linguistically appropriate services (CLAS): Chairperson Payment has been a strong advocate of cultural and linguistic competency on the Secretary's Tribal Advisory Committee (STAC), and it is a priority for OMH. Think Cultural Health is a national clearinghouse for curricula and training materials for health professionals (www.thinkculturalhealth.hhs.gov). A new Tracking CLAS feature on the website shows states that have enacted or introduced legislation on cultural competency training for health professionals and/or have expressed support for the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (National CLAS Standards). A new compendium tracks state-sponsored activities related to the implementation of the National CLAS Standards. OMH receives numerous inquiries regarding culturally appropriate approaches for Indian Country and would value input from the HRAC on existing training materials, modules, and best practices.
- HRAC charter: Charter revisions approved at the 2015 annual meeting included terms of service for council members. Half of the current members have terms that will expire this month; the rotation was determined by lottery. Members can serve unlimited consecutive terms, but they must be renominated. Nomination materials were included in the meeting packet.

Discussion

- Chairperson Payment stated that cultural competency is critical for program evaluators and grant reviewers. There are more than 500 individual tribal nations and more than 300 languages. General training is a good start, but it is important to work individually with tribal nations to understand cultural nuances. The Head Start classroom assessment is not culturally competent; supplemental training would be helpful. Chairperson Payment noted that the tribal advisory process was relatively new, and he expressed appreciation for the support provided by the current administration. He urged the council to look at where it has been, where it is going, where it wants to be, and what it wants to see in the next administration.
- Stacy Bohlen noted that the Great Plains tribes are experiencing a crisis in quality of care, which is probably not isolated. The NIHB created a task force to look at these issues. They conducted site visits and talking circles with the tribes in question and heard many heartbreaking stories. In one example, an elderly Lakota man at Pine Ridge did not understand why he could not speak his language in the IHS hospital, which reflected his experience in a boarding school. NIHB contacted Mary Smith at IHS regarding this issue and will continue to find ways to ensure that Native languages are

spoken at IHS hospitals and facilities. HHS recently issued a regulation that stressed the sacred nature of the ability to use one's primary language or language of choice in a healthcare setting.

  - Dr. Gracia replied that OMH defines CLAS as services that are 1) respectful of the cultural health beliefs, practices, health literacy levels, preferred languages, and communication needs of the individuals that are being served, and 2) implemented by every individual at every point of contact at a health or healthcare organization. The National CLAS Standards should be seen as a blueprint and a framework to raise awareness and promote the implementation of culturally and linguistically appropriate services; they are not intended to generalize stereotypes, perpetuate myths, or institutionalize specific behaviors.

- Ilene Sylvester noted that the core cultural values of the Native community in Alaska are the foundation for health services provided by her organization. The organization treats people as customers rather than patients; they emphasize relationships between customers and providers; they understand that everyone has a story; and they train providers to look into a person's eyes to see their heart. Fifty-five percent of the staff and 65 percent of management are AI/AN people, which further contributes to cultural competency.

HRAC History, Purpose, Accomplishments, and Member Roles/Responsibilities
Michael Peercy, HRAC National At-Large Delegate

Mr. Peercy provided an overview of the HRAC's history and accomplishments since its inception in 2005 and reviewed the council's purpose, structure, participating HHS components, meetings, and member responsibilities. Key points were as follows:

HRAC history:

- 2005: A formal process was launched to discuss health research issues and priorities and to solicit nominations for members. The process was driven by tribal leaders and HHS, with leadership from IHS.
- 2006: The first meeting was held in May with Cara Cowan Watts (Oklahoma Area) and Cecilia Fire Thunder (Aberdeen Area) as co-chairs. The FACA exemption was instituted at that time.
- 2007: A contractor was secured to support the HRAC. The federal working group met in September and October, and the HRAC met in December.
- 2008: Councilwoman Cowan Watts and Sally Smith (National At-Large Member) were elected co-chairs. The charter was ratified in June, and town hall meetings were held at the annual Native Health Research conference and the NIHB conference. The HRAC developed a discussion guide to ascertain health research priorities in Indian Country and sent the guide to tribal leaders for responses. Top concerns were cancer, diabetes, obesity, cardiovascular disease, and behavioral health and substance abuse.
- 2009: The HRAC held a face-to-face meeting in Washington, DC.
- 2010: The HRAC submitted recommendations to HHS Secretary Kathleen Sebelius in July and November. The first HRAC Research Roundtable was held, and the council

conducted outreach at the NIHB and Native Health Research conferences and the HHS Tribal Budget Consultation.

- 2011: The HRAC held a face-to-face meeting in June and approved the revised charter. The HRAC Research Roundtable was held in November.
- 2012: The HRAC held a face-to-face meeting in Denver, where Councilwoman Cowan Watts and Stephen Kutz (Portland Area) were elected as co-chairs. The HRAC Research Roundtable was held in November.
- 2013: The HRAC submitted recommendations by testimony and submitted a letter of request to the HHS Data Council in July regarding the sharing of tribal health data and requesting a tribal consultation.
- 2014: The HRAC held a face-to-face meeting in June and elected Councilman Kutz and Chairperson Payment as co-chairs. The Research Roundtable was held the following day.
- 2015: The HRAC held a face-to-face meeting in June, where it approved charter revisions and developed a list of priority issues.

Purpose of the HRAC:

- Obtain input from tribal leaders
- Provide a forum to communicate and coordinate AI/AN health research activities
- Provide a conduit for dissemination of research information to tribes

Structure of the HRAC:

- Federally recognized tribal delegates
- Elected and/or appointed tribal officials representing the 12 IHS areas, plus four National At-Large members
- Participating HHS components: Administration for Children and Families, AHRQ, Office of the Assistant Secretary for Planning and Evaluation, CDC, Health Resources and Services Administration, IHS, NIH, OMH, Intergovernmental and External Affairs, and SAMHSA

Meetings:

- Quarterly conference calls and one in-person meeting per fiscal year
- Voting is by consensus

HRAC member responsibilities:

- Participate in calls, meetings, and other communications
- Provide feedback and recommendations on health research issues to their community and area tribes
- Share information and resources with tribes in their areas

<u>Discussion</u>

- Chairperson Payment noted that the council would develop a logic model during the course of this meeting. He reminded members that prior HRAC chair Ms. Cowan Watts emphasized the importance of defining who is an American Indian. The small population

size presents a challenge for researchers, with AI/AN populations often classified as "Other." The definition is also important to confirm the identity of researchers who purport to be AI/AN.

Business Items

Chairperson Payment called for a motion to approve the minutes of the March 11 quarterly meeting. The motion was made by Tom Anderson, seconded by Dr. Calac, and carried by unanimous voice vote.

Introduction to Workgroup Logic Model Development Session
Tamara Henry, PhD, and Elton Naswood, OMHRC

Mr. Naswood and Dr. Henry described how a logic model is structured and how it is used for planning and evaluation. Key points were as follows:

- A logic model illustrates what a program is trying to achieve; clarifies the underlying strategy; builds common understanding about the relationships between actions and results; communicates what the program is (and is not) about; and forms a basis for evaluation.
- A logic model is a graphic representation of the overall program goal or intended impact, the resources and activities to achieve that goal, and anticipated outputs and outcomes. Goals are usually broad; resources, activities, outputs, and outcomes are specific.
- Outputs generally include numbers, so they are measurable (e.g., number of trainings held, number of medical providers trained, number of parents and children receiving information packets).
- Outcomes include three time frames (i.e., short-term, mid-term, and long-term).
- A logic model is a series of "if-then" statements: If the resources you need for the program are available, you can accomplish activities; if you accomplish the activities, you will deliver services (outputs); if you deliver services, there will be benefits for clients, communities, systems, or organizations.

Council members made the following observations:

- A logic model helps to clarify what a program is about and provides a framework for evaluation.
- A key question in Indian Country is, "Why should I care?"
- Stakeholders who have resources should be included when developing activities so they will be invested in the program.
- Long-term outcomes will support the sustainability of the program.
- Unanticipated events can impact long-term outcomes. It is important to build checkpoints into the model and be prepared to modify it if outputs and short-term outcomes are not as expected.

Workgroup Logic Model Development
Working in groups, council members developed logic models for the top two priority issues for the coming year:

- Priority 1: Development of an HHS-wide umbrella policy on AI/AN research
- Priority 2: AI/AN culture-specific modes of intervention

HRAC Workgroup Reports
Council members presented the draft logic models developed by the breakout groups as follows:

Priority 1: Development of an HHS-wide umbrella policy on AI/AN research

Initial goal

- HHS-wide policy on data collection in AI/AN populations

Activities

- Conduct a scan to identify existing policies on data collection and human subject protections with indigenous communities (federal agencies, universities, tribal governments, foreign governments)
- Identify existing data sources (e.g., electronic databases, morbidity and mortality data, state data)

Outputs

- Number of tribes that review the proposed umbrella policy
- Number of federal agencies that review the proposed policy
- Number of stakeholders that review the proposed policy
- Number of comments received from policy reviews

Outcomes

- Short-term
    - Baseline understanding of existing policies for data collection and human subject protection with AI/AN populations
    - Understanding of gaps in existing policies
- Mid-term
    - Proposed HHS-wide umbrella policy on data collection with AI/AN populations
- Long-term
    - HHS-wide umbrella policy on data collection with AI/AN populations
    - Individual agencies adopt the policy

Discussion

- Chairperson Payment stated that this activity helped to clarify the concepts involved in this priority. The breakout group determined that two separate logic models should be developed: one for data collection and handling, and a separate logic model for data use and accountability. Additional work would be required to fully develop those models.

- Dr. Calac noted that it would be a major undertaking to address the significant knowledge gaps, especially in the area of genomic research.
    - Chairperson Payment stated that this would require convincing people in Indian Country of the value of genomic research.
    - Kishena C. Wadhwani, PhD, noted that AHRQ and IHS were cofunding a grant to support research in genetics and biomedicine in Olympia, WA.
- Sheila Cooper suggested that an approved HHS-wide policy would be an output rather than an outcome; the outcome would be a policy that is institutionalized across the Department through funding opportunities.
- Dr. Wadhwani noted that it would be important to consider what resources are available.
    - Chairperson Payment suggested that it would be useful to develop an overall logic model for implementation of all HRAC priorities so the council could align its resources and activities.
    - A council member stated that an overall logic model would help to determine what resources are needed.
    - Chairperson Payment suggested that the National Congress of American Indians (NCAI) and NIHB could identify additional resources to support agency-level implementation.

Priority 2: Recommend that HHS agencies include AI/AN culture-specific modes of intervention in funding proposal requests

Activities

- Identify existing survey efforts for data, resources, and gaps
- Identify literature and scholars
- Identify specifics to request in report
- Request representation on study sections and funding for a nationwide search
- Engage agency tribal liaisons
- Draft a letter or recommendation to HHS

Outputs

- More funding for AI/AN graduates (two percent set-aside of budget)
- Measurable report
- How-to guide for tribes

Outcomes

- Short-term
    - 100 percent increase in AI/AN representation in study sections
    - Training for tribal liaisons for special study section placement
- Mid-term
    - Increased grant awards
    - Interval report and plan update

Resources

- HHS agencies
- Intradepartmental Council on Native American Affairs
- STAC
- Indian Alcohol and Substance Abuse (IASA) report with behavioral health data and recommendations, including data from Tribal Epidemiology Centers (TECs)

Discussion

- David Dean, PhD, noted that the IASA report would include data on behavioral health issues from HHS agencies, the Department of the Interior (DOI), and the Department of Justice (DOJ). The report will include a description of each dataset, estimates of behavioral health issues, a discussion of the limitations of federal datasets, and recommendations.
- Alexis Bakos, PhD, suggested that the next HRAC meeting should include a presentation on the National CLAS Standards. She noted that SAMHSA incorporated the National CLAS Standards into all of its funding announcements. Evaluation criteria for grant applications include points for meeting those requirements.
- CAPT Clelland observed that the logic plan did not include activities related to "culture-specific modes of interventions" and did not define that term. He noted that CDC was using its tribal convening process to identify culturally specific aspects that could be incorporated into its grant programs. Tribal traditional practitioners developed a list of 10 components to include in funding opportunity announcements (FOAs). A work group would meet in August to determine next steps.
    - Ms. Sylvester said it would be helpful for the HRAC to have a copy of that list.
- Chairperson Payment noted that Dr. Bauer of the National Center for Chronic Disease Prevention and Health Promotion visited the Sault Ste. Marie Tribe and participated in a traditional healing activity. He stated that if cultural practices are built into funding requirements, there must be adaptations for individual tribes, and reviewers need to understand what is being proposed.
- Ms. Cooper added that project officers should understand the nature of the interventions they are responsible for monitoring.
- Chairperson Payment commented that the logic model has an inherent cultural bias toward a linear, Western perspective.
    - Ms. Cooper noted that the Lummi tribe felt the traditional logic model was too siloed. They developed a logic model for their SAMHSA Systems of Care grant that reflects a Native perspective.
    - Chairperson Payment stated that it would be helpful if the FOAs indicated that alternate formats are acceptable. He noted that some tribes use the Spirit Wheel as a holistic way to illustrate their programs.

Council members agreed that formalized logic models for Priorities 1 and 2 should be developed for discussion at the next quarterly meeting.

Council members agreed to develop logic models for the four remaining priorities, as follows:

- Priority 3: Ilene Sylvester, Tom Anderson, Charlene Jones, Kishena Wadhwani, Carmen Clelland
- Priority 4: Michael Peercy, Kishena Wadhwani, Carmen Clelland, James Anderson, Aaron Payment
- Priority 5: Michael Peercy, Tom Anderson, Simental Francisco, James Anderson
- Priority 6: Ilene Sylvester, Charlene Jones, Simental Francisco, Aaron Payment

Federal Partner Updates

AHRQ
Kishena C. Wadhwani, PhD

AHRQ is funding three projects relevant to AI/AN populations:

- Biobanking in Native Communities: Culturally Driven Deliberations and Consensus
- University of Washington Patient-Centered Outcomes Research Partnership
- Results of Baseline American Indian CAHPS® Survey Lead to Implementation of Customer Service Quality Improvement Initiatives

Detailed descriptions of these projects were provided in the written briefing report. Dr. Wadhwani encouraged council members to contact AHRQ, CDC, or NIH if they knew of a research project for which they would like to request federal funding.

Dr. Bakos noted that OMH also has funds to support research.

NIH
James Anderson, MD, PhD

NIH is creating a new Tribal Health Research Office within the Office of the Director. The new office will place a high priority on conducting more research related to AI/AN communities and ensuring more equitable geographic distribution of NIH studies.

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) is developing a new study to evaluate the current state of preventive and treatment interventions for American Indian, Alaska Native, and Native Hawaiian communities. A presentation on this project was scheduled for the second day of this meeting.

The written briefing report included information on NIH activities related to suicide prevention in AI/AN populations, activities to engage AI/AN researchers, NIH leadership visits to Indian Country, upcoming tribal advisory meetings, and top issues for HRAC input.

Chairperson Payment asked Dr. Anderson to provide an update on the Precision Medicine Initiative. Dr. Anderson noted that the president announced the initiative during the 2015 State of the Union address. The initiative has strong bipartisan support in Congress, and the first set

of awards has been announced for outreach activities and enrollment of volunteers. Precision medicine enables treatments to be tailored to the individual, rather than the statistical average. It takes into consideration the physical and social environment as well as genomics. There are various levels of participation in the initiative.

Chairperson Payment stated that precision medicine is based on the understanding that health is individual, especially when it comes to race. He asked if the potential outcomes of the science would outweigh concerns about protections, and he noted that communication and dialogue regarding this initiative would be important in Indian Country.

Dr. Anderson asked who NIH should contact to discuss the initiative with tribes. Chairperson Payment stated that NCAI and NIHB could convene focus groups. Ms. Cooper noted that the STAC could be a vehicle for communicating concerns.

CAPT Clelland indicated that half of Native Americans do not live on reservations. Ms. Cooper suggested that the Urban Indian Health Institute could help NIH contact Native Americans who do not live on reservations.

Ms. Sylvester said she would not want NIH to solicit individual tribal members to participate in the initiative.

CDC

CAPT Carmen Clelland, PharmD

CAPT Clelland highlighted CDC activities that were described in detail in the written briefing:

- Yakama Reservation Exposure Investigation: The Agency for Toxic Substances and Disease Registry (ATSDR) conducted an investigation to address community concerns about air quality issues near animal feeding operations located on the Yakama Indian Reservation. Information collected through the investigation will be used to determine human exposures to airborne concentrations of ammonia, hydrogen sulfide, and particulate matter.
- Prospective Birth Cohort Study Involving Exposure in the Navajo Nation: The study looks at the relationship between uranium exposures and birth outcomes and early developmental delays in the Navajo Nation. Preliminary findings will be released in the near future.
- Arctic Investigations Program: The program aims to prevent infectious disease in people of the Arctic and Subarctic, with particular emphasis on indigenous people's health. The program includes seven separate studies in Alaska.
- Tribal Public Health Capacity Building and Quality Improvement Program Cooperative Agreement: CDC established a five-year cooperative agreement, with input from the CDC/ATSDR Tribal Advisory Committee, to strengthen and improve the infrastructure and performance of tribal public health agencies and tribal health systems through capacity building and quality improvement.

- Good Health and Wellness in Indian Country: CDC launched a five-year, $13 million cooperative agreement in 2014 to re-establish a culture of health by building communities and environments that empower Native Americans to take charge of their health. CDC is working with the Urban Indian Health Institute to coordinate program evaluations. Preliminary results will be available in the near future.

CDC leadership made numerous visits to Indian Country to gain an understanding of tribal culture and public and environmental health issues. Chairperson Payment said the visit by Dr. Bauer was extremely important for his tribe and noted that the traditional medicine program is part of their annual funding agreement. CAPT Clelland noted that the tribe's traditional leader provided input at the CDC tribal convening.

SAMHSA
Sheila Cooper and David Dean Jr., PhD

Ms. Cooper and Dr. Dean highlighted SAMHSA activities that were described in detail in the written briefing:

- SAMHSA's Principal Deputy Administrator, Kana Enomoto, is leading the agency following the departure of SAMHSA Administrator Pam Hyde in August 2015.
- The Suicide Prevention Branch of the Center for Mental Health Services developed two reports on preventing and responding to AI/AN suicide. The documents will be published in the near future; a report on suicide, substance abuse, and intimate partner violence in tribal communities is in progress.
- IASA is finalizing a comprehensive report on Indian alcohol and substance abuse problems based on datasets from SAMHSA, IHS, DOJ, DOI, CDC, and NIH. The report provides the background of the IASA Data Workgroup, describes each of the datasets, discusses methodological issues, and describes what is known in a variety of topic areas, broken out by adult and youth measures. SAMHSA plans to modify the report for submission to a peer-reviewed publication so it can be disseminated as widely as possible.

Chairperson Payment stated that the data report would provide a clear picture of the outcomes of historical trauma and the interagency nature of the datasets would be extremely helpful. He suggested that SAMHSA should make a presentation on key findings from the datasets at the next annual meeting.

Dr. Anderson suggested that project officers (POs) and directors should be required to visit Indian Country. Ms. Cooper replied that SAMHSA would require all POs and directors to participate in a training, since travel funds are limited. They are also requiring project evaluators to have training in cultural competence, especially for projects that involve children in traumatic situations.

Ms. Sylvester noted that her organization decided to change community norms regarding alcohol and tobacco without waiting for research results. They partnered with foundations

to create video vignettes highlighting respected community leaders and developed a sobriety pledge for annual Native functions.

DAY TWO – Friday, June 10, 2016

Invocation
Ilene Sylvester, Alaska Area Delegate

Ms. Sylvester offered an invocation to open the second day of the meeting.

Welcome and Introduction

Chairperson Payment welcomed council members and staff and provided a summary of the first day of the meeting.

Introduction to the National CLAS Standards

Dr. Gracia provided an overview of the National CLAS Standards, including a fact sheet describing resources available from Think Cultural Health (www.ThinkCulturalHealth.hhs.gov). She highlighted the *Blueprint for Advancing and Sustaining CLAS Policy and Practice* and noted that the National CLAS Standards provide guidance without prescribing specific actions. OMH would be pleased to provide a more in-depth presentation at a future meeting.

Discussion

- Chairperson Payment commended the principal standard of the National CLAS Standards, noting that the principal standard is to provide care and services that are "effective, equitable, understandable, and respectful." He emphasized that "equitable" care is not the same as "equal" care—it requires an additional step to meet people where they are, with an understanding of disparities and inequities.
- Dr. Calac asked how the standards were developed.
    - Dr. Gracia replied that the first iteration was developed in 2000, and the enhanced standards were issued in 2013. The enhancement process conducted from 2010 to 2013 included a literature review, public comments, an advisory committee (including a HRAC member), and listening sessions around the country.
- Dr. Calac asked if OMH had received any feedback from those who participated in the listening sessions.
    - Dr. Gracia replied that the enhanced National CLAS Standards have been used by a variety of institutions and individuals, including hospitals and state and local health departments. She noted that OMH would host a webinar on June 30 with presentations on how the standards have been implemented in the healthcare delivery system, public health organizations, and academic medical settings. OMH is currently evaluating a subset of organizations that have implemented the National CLAS Standards and plans to release a manual based on the findings.

- Dr. Calac asked if the standards address special needs populations.
    - Dr. Gracia stated that the definition of "culture" in the first iteration of the National CLAS Standards focused on race, ethnicity, and primary language. The enhancement initiative broadened the definition to include additional elements such as sexual orientation and gender identity, disability status, socioeconomic status, and spirituality, and it acknowledges that an individual's culture can evolve over time, based on life experiences. OMH promotes a framework that looks at how to provide services that are respectful of and responsive to the key elements of culture that may influence an individual's healthcare experience. More details are provided in the Blueprint document.

Office for Civil Rights Section 1557 Final Rule
Kenneth Johnson, JD, Section Chief, Office for Civil Rights, HHS

Mr. Johnson provided an overview of the final rule of Section 1557 of the Affordable Care Act, which is the nondiscrimination provision of the law. Key points were as follows:

- The process of developing the rule began in 2010. The final rule was issued in May 2016.
- Section 1557 prohibits discrimination based on race, color, national origin, sex, age, or disability in certain health programs and activities. It has been in effect since the Affordable Care Act was signed into law in March 2010. The final rule aims to educate consumers about their rights and help covered entities understand their obligations.
- Section 1557 builds on prior federal civil rights laws, including Title VI of the Civil Rights Act of 1964; Title IX of the Education Amendments of 1972; Section 504 of the Rehabilitation Act of 1973; and the Age Discrimination Act of 1975.
- Section 1557 extends protection to populations that have been most vulnerable to discrimination in health care and health coverage including women, members of the lesbian/gay/bisexual/transgender (LGBT) community, individuals with disabilities, and individuals with limited English proficiency (LEP). It is the first federal civil rights law to broadly prohibit sex discrimination in health programs and activities.
- Section 1557 applies to all health programs and activities that receive federal financial assistance from HHS; all health programs and activities administered by state-based and federally facilitated health insurance marketplaces; and all health programs and activities administered by HHS.
- The final rule clearly specifies what a covered entity may not do, and what it must do, in order to comply with all aspects of the law. For example, Section 1557:
    - Strengthens long-standing provisions to ensure language access for individuals with LEP.
    - Extends protections to ensure access for individuals with disabilities, including communication assistance.
    - Requires equal access to health care and insurance coverage regardless of an individual's sex, including gender identity and sex stereotypes, and it prohibits exclusions or limitations in coverage for all healthcare services related to gender transition.
- More information, including a link to the final rule, is available at www.hhs.gov/ocr.

Discussion

- Chairperson Payment noted that some issues in the implementation of the Affordable Care Act limited access for American Indians. For example, a survey conducted by NIHB found that call centers were not prepared to serve Indian Country. Enrollment cannot be increased without baseline information. Chairperson Payment is working through the STAC to call these disparities to the attention of the Secretary, because it is important to ensure that the Affordable Care Act is implemented equitably.
    - Mr. Johnson encouraged council members to write directly to OCR. He noted that OCR sits on the HHS Data Council, and he stated that the letter-writing process had been effective for a number of stakeholder groups.
- Dr. Calac asked if protections for same-sex marriage would extend to a marriage between an Indian and a non-Indian, for purposes of services provided at IHS.
    - Mr. Johnson stated that the rule extends to healthcare services provided by HHS, including IHS. OCR will address inquiries on a case-by-case basis.

Federal Partner Updates

National Institute on Alcohol Abuse and Alcoholism (NIAAA)

Ms. Morin noted that NIAAA is a NIH institute that facilitates collaboration with other entities. They are extremely interested in research with tribal communities. She provided an overview of the NIAAA's American Indian, Alaska Native, and Native Hawaiian Alcohol Intervention Review, as follows:

- The study is looking at the state of preventive and treatment interventions for AI/AN and Native Hawaiian populations. The first goal is to develop a dissemination approach for preventing fetal alcohol spectrum disorders in Native communities.
- Future goals are to collaborate with AI/AN and Native Hawaiian public health and research professionals to review prevention and treatment strategies to address other alcohol harms within Native communities.
- NIAAA is conducting a pilot to replicate a successful intervention for colleges. They are also collaborating with the National Institute on Drug Abuse, and they hope to collaborate with the National Institute of Mental Health.
- NIAAA is conducting focus groups to learn about prevention and treatment needs in Native communities. The findings will inform FOAs that will drive research.

Ms. Morin encouraged council members to contact NIAAA director Dr. Judith Arroyo for additional information.

Discussion

- Dr. Calac noted that Dr. Arroyo had supported research conducted at his clinic, including multiple focus groups regarding the use of alcohol within the community.
- Ms. Sylvester described a pilot program that her organization was conducting for youth ages 14-18 that includes activities to simulate the effects of alcohol and marijuana. They also conduct a treatment program that places a priority on pregnant women.

- Ms. Morin stated that NIAAA was planning to create a website with examples of successful programs that are being implemented in Native communities, with a goal of creating a network to develop culturally sensitive approaches.

SAMHSA Tribal Behavioral Health Agenda
Sheila Cooper, SAMHSA

Ms. Cooper described the Tribal Behavioral Health Agenda, which is a tribally driven document that will serve as a blueprint for use by federal agencies, state authorities, tribes, and nonprofit organizations. The initiative grew out of a discussion at the SAMHSA Tribal Technical Advisory Committee; the issue was further discussed at the STAC and at the first mental health session at the White House Conference.

SAMHSA is taking the lead in developing the document, based on information provided by tribal leaders and community members during 23 listening sessions conducted in partnership with IHS and NIHB. Five foundational elements emerged through those conversations:

- Historical and intergenerational trauma
- Social ecological approaches
- Prevention and recovery support
- Behavioral health systems and support
- National awareness and visibility

Ms. Cooper noted that an executive summary would be distributed to HRAC members. The full draft document would be sent to tribal leaders, the STAC, and HRAC members by the end of June, with a 30-day comment period.

Significant efforts were made to ensure that the agenda reflects the Native voice. The document emphasizes tribes' ability to address their own needs, with support from federal agencies. Interagency collaboration is a high priority. Seventeen federal agencies met in December 2015 to discuss how existing strategies and initiatives could be leveraged to support a tribal behavioral health agenda.

SAMHSA envisions a six-month to one-year period to roll out the agenda, beginning in early August. The rollout would include further discussions regarding how tribes, regional organizations, and federal agencies could implement the agenda.

The behavioral health agenda will help to inform the new administration regarding needs and concerns across Indian Country, including crosscutting issues related to youth, identity, culture, individual self-sufficiency, and tribal leadership.

SAMHSA is proposing that the White House Council on Native American Affairs advise federal agencies on conducting behavioral health assessments.

Tribal Advisory Committees

STAC
Aaron Payment, HRAC Co-Chair and Bemidji Area Delegate

Chairperson Payment outlined the rational for a heightened approach for Indian Country. He noted that AI/AN communities have the greatest health disparities. The problem is extensive and systemic.

Federal Indian policies—including forced assimilation and boarding schools that stripped away cultural identity—led to historical trauma and the erosion of social norms across Native communities that resulted in outcomes such as the highest rates of suicide and alcoholism and the lowest education attainment rates. There has been growing recognition that the federal government has a responsibility to undo the impact of those policies. The behavioral health agenda legitimizes the issues that need to be addressed in a variety of sectors, including education.

The STAC has discussed how to maintain the progress that has been made during the current administration. One approach would be to develop an interagency tribal action plan to address the symptoms and outcomes of historical trauma. Secretary Burwell has said she would communicate the urgency of the STAC's request to the White House Council on Native American Affairs.

The STAC also discussed the HHS quality of care committee that was formed to address the situation of the Great Plains tribes, which includes a high-level commitment from HHS and IHS. Chairperson Payment stated that the problems experienced in the Great Plains could be seen across Indian Country. He noted that when his tribe switched from IHS to a tribal health system, they created a culture of quality improvement that led to improved services and improved performance by providers, and he proposed that IHS adopt a similar approach.

OMH Resource Center (OMHRC) Knowledge Center
Faye Williams, Knowledge Center Manager, OMHRC

Ms. Williams provided an overview of the services and resources available from the OMHRC Knowledge Center. Key points were as follows:

- OMHRC was established in 1987, one year after the formation of OMH. Components include the Knowledge Center, Information Services, Communications, and Capacity Building.
- The Resource Center and database have materials in more than 40 languages as well as statistical profiles on 13 health conditions and chronic diseases.
- Knowledge Center services include document retrieval, literature searches, organization searches, statistics and data, and legislative tracking.

- The Knowledge Center is the nation's largest dedicated repository of health disparities information, with a public catalog of more than 55,000 records. Sixty percent of the collection is available online.
- More than 600 documents have been added to the Library of Congress digital archives (http://archive.org/details/minorityhealth).
- The Knowledge Center's catalog search can be used to create customized bibliographies on any subject.
- The Knowledge Center has been involved in creating library networks such as:
    - Library of Congress Indigenous Law Portal: legal documents, tribal websites, regional and national advocacy organizations, and general resources (http://www.loc.gov/law/help/indigenous-law-guide)
    - Government Publishing Office Federal Depository Library Program (makes documents available to tribal college libraries)
    - Library of Congress FEDLINK, which formed an American Indian Libraries Working Group to share resources.
- Knowledge Center staff made presentations at the Association of Tribal Archives, Libraries, and Museums, the American Indian Library Association, the Medical Library Association, and the National Library of Medicine.
- The Knowledge Center can be accessed online (www.minorityhealth.hhs.gov/opac), by phone (800-444-6472), by email (KnowledgeCenter@minorityhealth.hhs.gov), and in person (by appointment).

Indian Health Service Update
Mose Herne, IHS

Mr. Herne highlighted IHS activities that were described in detail in the written briefing document, as follows:

- Native Research Network conference: In response to HRAC recommendations, IHS conducted a preconference institutional review board (IRB) training for Native researchers in collaboration with NIH, NCAI, and academic researchers. Topics included genetics, specimen research, and other issues. IHS is preparing a summary of the training. They plan to identify domains for additional training and may offer training via webinars to help tribes develop their own IRBs.
- Tribal Epidemiology Centers (TECs):
    - Nine TECs have signed data sharing agreements with IHS. An initial assessment of data sharing between states and TECs is available at: https://cste.confex.com/cste/2014/webprogram/Paper3879.html. Mr. Herne made a presentation on this topic for state epidemiologists.
    - A list of TEC publications was included in the briefing document.
    - TECs collaborated with the National Institute on Minority Health and Health Disparities to develop a series of community health profiles.
    - TECs were funded by CDC to evaluate grantees of the Good Health and Wellness in Indian Country program. CDC would like to expand the funding to include urban Indian programs in fiscal year 2017.

- Native American Research Centers for Health (NARCH): IHS administers the NARCH program in collaboration with NIH. More than $10 million in funding was awarded to 29 centers to support 80 tribal-driven research projects. IHS also supported more than 100 AI/AN students and junior faculty to attend the 2015 conference of the Society for the Advancement of Chicano and Native American Scientists (SACNAS) and the 2016 Native Research Network conference.
- Environmental Health and Justice: IHS collaborated with NIH to support a number of environmental health and justice research projects, including capacity-building projects with tribal colleges.
- Telehealth: Reimbursement for telebehavioral health will be determined on a state-by-state basis. Developments can be tracked at http://telehealth.org/reimbursement.
- Behavioral health integration: The IHS Division of Behavioral Health and the IHS Improving Patient Care Program are coordinating learning sessions for outpatient primary care teams working on quality improvement and patient-centered medical homes accreditation.

Discussion

- Dr. Calac asked if Mr. Herne had any information on the status of a tax exemption for IHS scholarships; whether the NARCH IX grants would be administered by IHS before the transition to NIH; and whether IHS would support students to attend the 2016 SACNAS conference.
    - Mr. Herne said he did not have any updates on tax exemptions. NARCH IX and NARCH X were announced simultaneously and will be administered by IHS. He will provide information regarding the availability of funds for conference support as soon as possible.
- Mr. Anderson asked if any funds were allocated for the Office of Indian Men's Health.
    - Mr. Herne stated that the Indian Health Care Improvement Act authorized the establishment of an Office of Indian Men's Health. However, no funds have been appropriated for that purpose.
    - Chairperson Payment stated that he would bring this up at the STAC.

Scheduling of 2017 Calls and Annual Meeting

Chairperson Payment announced that a draft schedule for the 2017 quarterly conference calls will be distributed to council members for discussion at the next quarterly conference call (August 26, 2016, at 2:00 p.m. ET). The face-to-face meeting in 2017 will be scheduled in conjunction with the STAC meeting, which is typically held during the first or second week of June.

Open Discussion

Ms. Morin announced that the National Institute of Mental Health would conduct a webinar on suicide prevention research in Arctic communities on June 17 at 2:00 p.m. She will provide a link to the webinar.

Dr. Calac asked if it would be possible to provide the written materials and presentation slides in PDF format for future meetings.

Chairperson Payment announced that a proposed bill would exempt tribal communities from the employer mandate of the Affordable Care Act. This would have a significant financial impact for tribal communities. The STAC requested a tribal consultation. Congressman Tom Cole was spearheading this effort. HRAC members were encouraged to contact Rep. Cole and their senators.

Dr. Anderson reported that he would provide Kendra King Bowes with contact information for the individual at NIH who is responsible for tribal participation in the Precision Medicine Initiative. He also noted that NIH was seeking a director for the new Tribal Health Research Office, and he encouraged council members to contact him if they wished to recommend a potential candidate. The ideal candidate would be a trained scientist who has experience working with tribal communities.

The meeting was adjourned at 11:28 a.m. ET.