

# Seasons of Care: Assisting American Indian Elders with Health Care Access



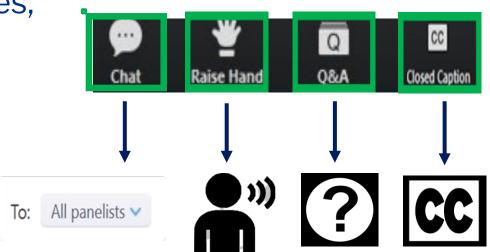


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### **Webinar Objectives**

- Identify historical and systemic conditions that influence access to health care for American Indian elders
- Describe American Indian elders' perspectives on health, wellness, and accessing health care
- Name at least two feasible and culturally congruent approaches for aiding American Indian elders when addressing barriers to health care



### **Today's Presenters**



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# Seasons of Care: Assisting American Indian Elders with Health Care Access

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### What We'll Talk About Today

- Historical and systemic conditions that influence access to health care for American Indian Elders
- Elders' perspectives on health, wellness, and accessing health care
- Culturally congruent approaches to aid Elders in addressing health care barriers



# Historical and Systemic Conditions Influencing Health Care

# **Policies Shaping American Indian Health**

 Pre-Contact
 Removal
 Assimilation
 Termination
 Self-Determination

# **Policies Shaping American Indian Health**

#### **Pre-Contact**

 Local policies based on traditional laws and beliefs

#### Removal

- Doctrine of discovery—
   "colonization and conquest"
- Manifest destiny
- Treaties

#### **Assimilation**

- Dawes Act (1887)
- Snyder Act (1921)

#### **Termination**

- Sales of tribal land
- De-recognition of some tribes
- Public Law 280 (1953)
- Transfer Act (1955)

#### Self-Determination

- Indian
   Education Act
   (1972) and
   Indian Health
   Care
   Improvement
   Act (1976)
- Patient
   Protection and Affordable
   Care Act
   (2010)

## **The Federal Trust Obligation**

# Legal right to health care

- Commonly included in treaties
- Snyder Act of 1921
- Transfer Act of 1955

Provided through the Indian Health Service (IHS)

- Hospitals, tribally run programs, and urban health clinics
- Purchased/referred care (PRC)

# **The Federal Trust Obligation**

- IHS funding is discretionary
- Less health care spending for IHS users
- Limited resources for health care and ancillary services for Elders



## Consequences of Underfunding

**Outdated facilities** 

Truncated service hours

Insufficient staff

Lack of comprehensive services

Shortage of PRC funds



# Overview of Seasons of Care Study

"Improving Native American Elders' Access to and Use of Health Care and Health Insurance"

### **Key Research Questions**

- What are American Indian Elders' experiences with health care?
- What are Elders' experiences with health insurance?
- How do health professionals and tribal leaders understand factors affecting insurance and health care for American Indian Elders?
- How do national/state policies impact care for American Indian Elders?



## Research Study

#### Setting

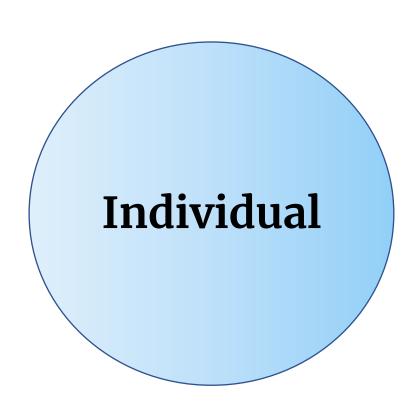
- 8 tribal communities participated
  - Some relied on IHS
  - Others exerted control over health care
- Non-reservation urban communities

#### Methods

- Mixed methods: Surveys, semi-structured interviews, concept mapping
- Development of an online navigation tool
- Community Action Board + Elder consultants

# Elders' Perspectives on Health, Wellness, and Accessing Health Care

### Health, Wellness, and Accessing Health Care



### What Does Wellness Mean to You?

#### Physical health

• "Wellness is just being able to get up in the morning and just do stuff and be active." (Male, age 55–64, Western region)

#### Mental and emotional health

- "I would call wellness ... a mental acceptance of your life and to be happy." (Female, age 65+, Metro region)
- "[Wellness] is being with a clear mind, and you have all your faculties." (Female, age 55–64, Metro region)

### What Does Wellness Mean to You?

#### "Balance"

• "Wellness takes physical, mental, emotional, and spiritual health. They all have to be kind of in balance." (Male, age 65+, Metro region)

#### Spirituality and tradition

- "I do a lot of praying and [being] thankful ... praying good, thinking good thoughts." (Female, age 65+, Metro region)
- "I do a lot of our tradition ... because that's important, that's part of how you keep your health." (Female, age 55–64, Metro region)

#### Positive attitude; staying free from worry and stress

• "I try to look for the positive in everything in life." (Female, age 65+, Southern region)

### What Does Wellness Mean to You?

#### Independence

- "Being able to do what I want to do and not worry about elevating my feet or having to stop." (Female, age 65+, Southern region)
- "To be able to function like I did ten years ago without outside help .... Sometimes I get my clothes, I fill the bathtub with water, and I wash them by hand .... A long time ago I used to do that, and that just makes me feel my worth." (Male, age 55–64, Metro region)

### Speaking out

• "Wellness is speaking out; it's your duty. My first obligation to myself and to my people is to speak your mind and heart in the Indian way." (Female, age 65+, Western region)

# **How Do You Stay Well?**

#### Diet, exercise, and staying active

- "All day long I'm going here, there. Sometimes [my husband] will tell me, 'Sit down, will you? You make me dizzy,' because I don't stop all day. If I feel good, I don't stop." (Female, age 65+, Southern region)
- "That's hard. [I] have to measure food, read labels, get schooling for diabetes." (Female, age 65+, Southern region)

#### Going to the doctor and following medical advice

• "If something happens to you like you get ill, go to the doctor right now, don't want like tomorrow or the next day." (Female, age 65+, Northern region)

# **How Do You Stay Well?**

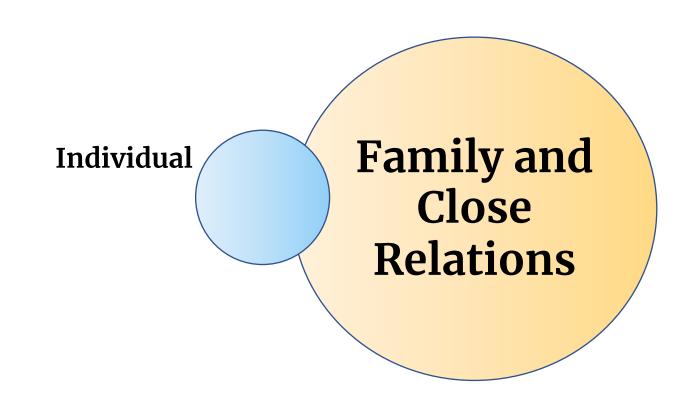
- All these ways of staying well are connected
  - "I walk all the time. Walk and pray. Walk and pray. My doctors agreed that the best thing is just that time to yourself and you're praying, and I just burn my sweetgrass and do my prayers and walk and I'm here." (Female, age 55–64, Metro region)



### **Obstacles to Wellness**

- Uncertainty about what health care services and medications are available or covered by insurance
  - "Knowing that you have this process to contend with, with insurance coverage and knowing who is paying for what and what they're billing for and what is covered and what is not covered and buying additional benefits to cover gas and services ... sometimes it can be very overwhelming." (Female, national administrator)
- Unease communicating with providers and insurers, and not knowing how to advocate for yourself
  - "Health care providers always ask, 'Do you have any questions?' Then I said, 'I don't know this enough to ask any questions." (Female, age 55–64, Metro region)

### Health, Wellness, and Accessing Health Care



# **How Do You Stay Well?**

#### Encouragement and support

• "Me and my daughter and my grandson go to the gym every morning because I didn't notice myself but ... my daughter looked at me and she says, 'You need to get yourself into the gym." (Female, age 55–64, Metro region)

#### Caring for others

• "I exercise by holding my granddaughter – I use her as exercise." (Female, age 65+, Northern region)

# **How Do You Stay Well?**

#### Sources of knowledge

- "We were very fortunate in being around our Elders and our older people and they raised us and taught us different things. One of the things they taught us how to cope with stress and anxiety and health issues and it's the way we were raised." (Female, age 65+, Western region)
- "She's teaching them [young people] about right from wrong, having respect for people, having to help other people out. She's teaching them the customs and traditions of the tribe. She's teaching them how to speak in Indian." (Male, age 65+, Southern region)

### **Obstacles to Wellness**

#### Sometimes a source of stress

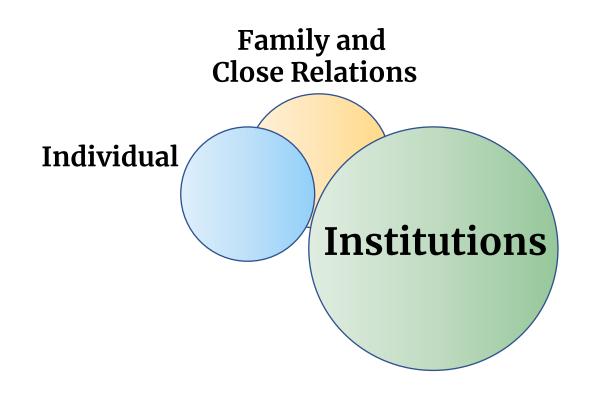
• "I'm going to take care of my kids and my grandkids, [but] that's my worry at times." (Female, age 65+, Western region)

#### Concern about burdening families

• "How comfortable are [Elders] in talking to other people about their health issues? A lot of them will just say, 'No, I'm okay, I'm alright,' or they don't want to be a burden to their families, so they won't say exactly what has been ailing them for a while." (Female, age 65+, Northern region)



### Health, Wellness, and Accessing Health Care



# **Navigating IHS**

#### Waiting

• "If you have to reschedule an appointment, then maybe you're pushed back another month. Maybe you're pushed back a couple of weeks. You're back down to the bottom and then try to climb your way back up to the top." (Male, age 55–64, Western region)

#### Disrupted relationships with providers due to turnover

• "We have no choice; they're going to be changing. That's why I always ask them, 'How long are you going to be here? Tell me the truth now." (Female, 65+, Metro region)

## **Accessing Specialty Care**

#### Difficulty getting services covered

• "I have to wait to first get rejected by PRC and then Medicare picks it up. For some reason, I don't know, but they run it through PRC, and they should just automatically know they are going to reject me ... or maybe that's the way they go about pursuing other avenues." (Male, age 55–64, Metro region)

#### Difficulty getting referrals

• "You have to come get it and take it over. And then the lady at the spine place, she says, 'How come they won't fax it?' She said every time they fax it, it gets lost. That's why she wanted me to come to [the city] to get it and take it .... I'm going to burn gas going up and down." (Male, age 65+, Northern region)

### Understanding and Using Health Insurance

#### Reliance on technology

• "I'm one that will not listen to the recording. I press the zero for operator and I said, "I want to talk to a human.' I don't want to talk to no recorders, so even if I have to wait for five minutes or whatever it takes, I will talk to a human, not a recorder." (Female, age 55–64, Northern region)

#### Complexities of enrolling in, keeping, and using plans

• "Many of us have been brought up on IHS and we've not had a structure like that [with health insurance] .... Indian people are used to Indian Health Service. I think knowing that you have this other process to contend with, with insurance coverage and knowing who is paying for what and what they're billing for and what is covered and what is not covered ... sometimes it can be very overwhelming." (Female, national administrator)

#### Lack of trustworthy outreach

• "... insurance companies come in and talk to [Elders] about their own plans, trying to sell it to them without proper interpretation .... To me it's just a total loss of respect for them." (Female, Benefits coordinator, Southern region)

# Challenges for Professionals Working with Elders

- Health professionals must rely on relationships and staff knowledge to help Elders
  - "Among our staff we ask each other as coworkers how we dealt with certain situations and then maybe go from there. Sometimes we share numbers, we share names to call a certain individual to get that information so that we can get the assistance that this individual needs." (Female, tribal community health representative [CHR], Southern region)
  - "[Name] is a big help because she's worked in many different things ....
    She's worked for Medicare, she's worked for Medicaid, she's done a lot, so
    I'll go to her." (Female, benefits coordinator, Northern region)

# Challenges for Professionals Working with Elders

#### Knowledge comes mostly from personal experience

• "In any Native culture you respect your Elders, and you do anything you can to help them so .... I took care of my grandma for so long, dealing with the health care system, whether setting up her appointments, picking up her medications to actually going to her appointments .... But then again like that girl with the Social Security, she brought up fraud and I felt uncomfortable because I haven't experienced that personally." (Female, health insurance tribal liaison, Metro region)

# Challenges for Professionals Working with Elders

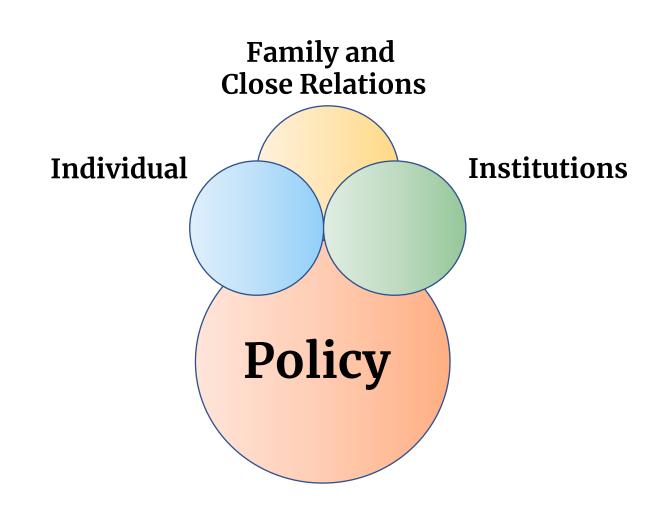
- Importance of communicating cultural knowledge
  - "The cultural part of it is .... 'We have to amputate your toe or something,' and then you're going to go and tell them [the doctor], 'Hey doc, you might want to be a little bit sensitive about how you tell them you're going to remove their toe and you're making sure you're telling them you're not just throwing it [out] or ask them what they want to do with it .... Like making sure they explain the best care for them but to be really sensitive with the culture." (Female, tribal CHR, Southern region)

### **Need for Information and Tools**

#### To help Elders:

- Learn about health care and insurance options
- Overcome barriers
- Manage their own decisions

# Health, Wellness, and Accessing Health Care



# **Elders in State and National Policy**

- Program and provider shortages
- Limited funding for IHS and tribal clinics
  - "Doctors and medication are needed in our Indian communities.
     When funds are allocated by the United States government to these medical clinics, we don't know how much or where the funding is being spent." (Male, age 65+, Southern region)
- Lots of priorities for tribal leaders
- Invisibility of Elders in health policy
  - "As Native people, we're ignored." (Male, age 65+, Western region)

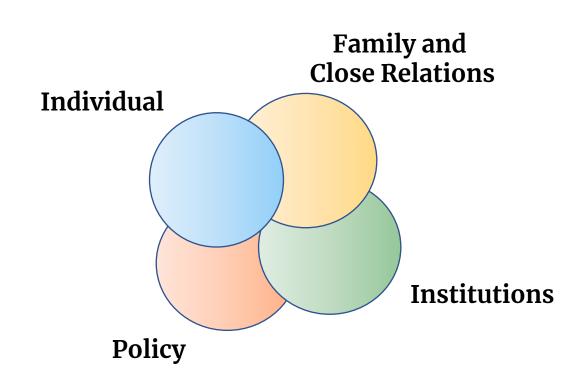
# **Elders in State and National Policy**

- Lack of funding + complexity of systems = "invisibility"
  - "Our leaders in Washington, D.C., have no idea that American Indians are even alive in this country, and they don't have any idea as to the vastness of our communities and the struggles and the trials of our communities as a whole or as separate tribes." (Female, national administrator)



### Conclusions

- Different levels interact—sometimes to benefit wellness ...
  - Being a caregiver (Family and Close Relations)
    contributes to feelings of independence and
    wellbeing among Elders (Individual)
  - Tribal leaders' awareness of Elder health issues (Policy) helps make Elder health a priority in local health systems (Institutions)
  - National policies (Policy) can increase resources for local health systems (Institutions) and access to care (Individual)



# Making American Indian Elders Visible

## What Can Elders and Families Do?

Learn advocacy skills Accompany Elders to their appointments Respect privacy and autonomy Encourage Elders to ask lots of questions Make it okay for Elders to ask for help Elders can educate their peers

### What Can Health Care Providers and Staff Do?

Take time to build trust and rapport

Long-term services in one community

Learn about local needs and resources

Elicit questions and take time to answer

Confirm Elders and their families understand questions

# What Can Health Administrators Do?

Invest in health workforce

Invest in services that Elders need

Invest in support for Elders

Change scheduling and provider assignment

Conduct outreach and community engagement

### What Can Tribal Leaders Do?

Educate themselves about health care and insurance Conduct needs assessments Carry our initiatives across administrations Deploy tribal resources to pay for support services Integrate clinical and community services Support community programs that engage Elders

# What Can Policymakers Do?

Get educated about American Indians and policy

Dedicate resources to patient and family navigation

Ensure line-item funding

Provide technical assistance to tribes



#### What Can Policymakers Do?

- Fund and support the Indian health system at 100% of need
- Simplify health care and insurance requirements
  - Automatic reenrollment
  - "Universal" networks
- Support efforts of Elders and their allies to win elected office

#### **Our Research Partners**

- Seasons of Care Community Action Board and Consultants
- REACH Committee
- Pacific Institute for Research and Evaluation–Southwest Center (E. Haozous, E. Jaramillo, and C. Willging)
- New Mexico Indian Council on Aging Health Committee
- Independent Consultants (E. Lujan and R. Bly)
- University of New Mexico (S. Verney)
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#### **Questions?**





