

# “Live and Die with Dignity”

Alaska Native Perspectives and Experiences on  
Dementia Caregiving and Family Stigma

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*University of Alaska, Anchorage*

*Aging Summit*

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**Caregivers**

# Acknowledgement



**Alzheimer's Resource of Alaska**

WORKING TOGETHER FOR HEALTH EQUITY



**IREACH**

INSTITUTE FOR RESEARCH AND EDUCATION  
TO ADVANCE COMMUNITY HEALTH



**AN  
CARE**

# AGENDA

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Introduction

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Family Stigma

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Study & Findings

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Future Directions

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Q & A



# Introductions



Steffi Kim, PhD



Hannah Rebadulla, MS



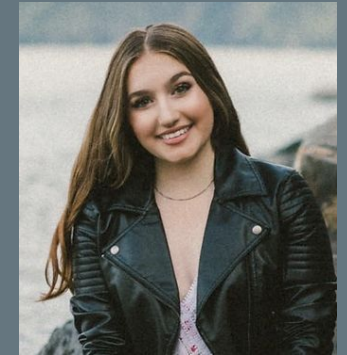
Jordan Lewis, PhD



Prince Alejo



Murat Demir



Zoey Hilderbrand



# BACKGROUND

Limited data on ADRD in Alaska

- *Estimated 11,000 people with ADRD*
- *6<sup>th</sup> leading cause of death (State of Alaska Division of Public Health, 2020)*

Alaska Native Population

- *Estimated higher incidence rate 22.1/1,000 instead of 19.3/1,000 person-year (Mayeda, et al., 2016)*
- *Alaska Native understanding of dementia not acknowledged (Crouch et al., 2023)*
- *Caregiver experience is under investigated (Lewis et al., 2022)*
  - Isolation
  - Access to fewer resources

# Stigma Impact

- Alaska's 10-year map to address ADRD identified stigma as a major issue impeding on:



What is Stigma?



# Stigma

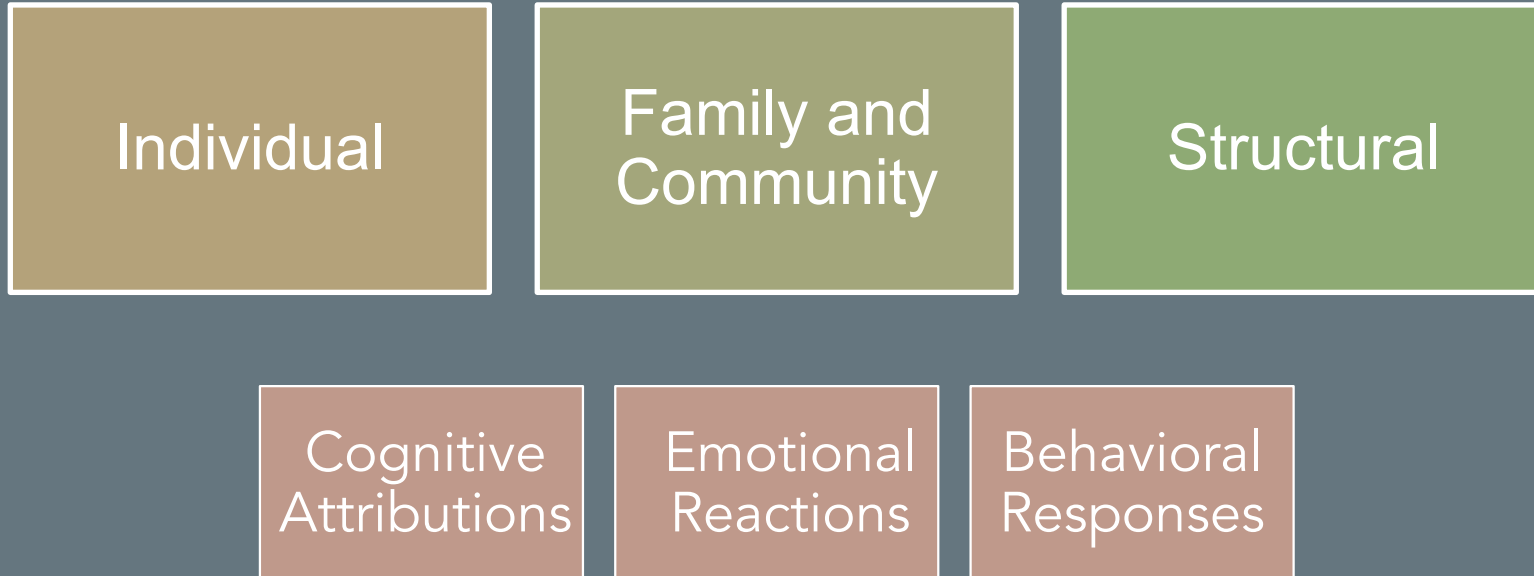
Stigma: defined as pervasive and a global devaluation of certain individuals on the basis of some characteristic they possess, related to membership of a group that is disfavored, devalued, or disgraced by the general society (Hinshaw, 2007, p. 23)

- Involves:
  - Negative attitudes
  - Biases
  - Stereotypes
- Results in:
  - Isolation
  - Depression
  - Shame
  - Non treatment seeking behaviors



# Family Stigma

Family Stigma: is related to experiences of having a relative with a stigmatizing condition such as a mental illness or neurocognitive disorders leading to social exclusion and shame, resulting in concealment

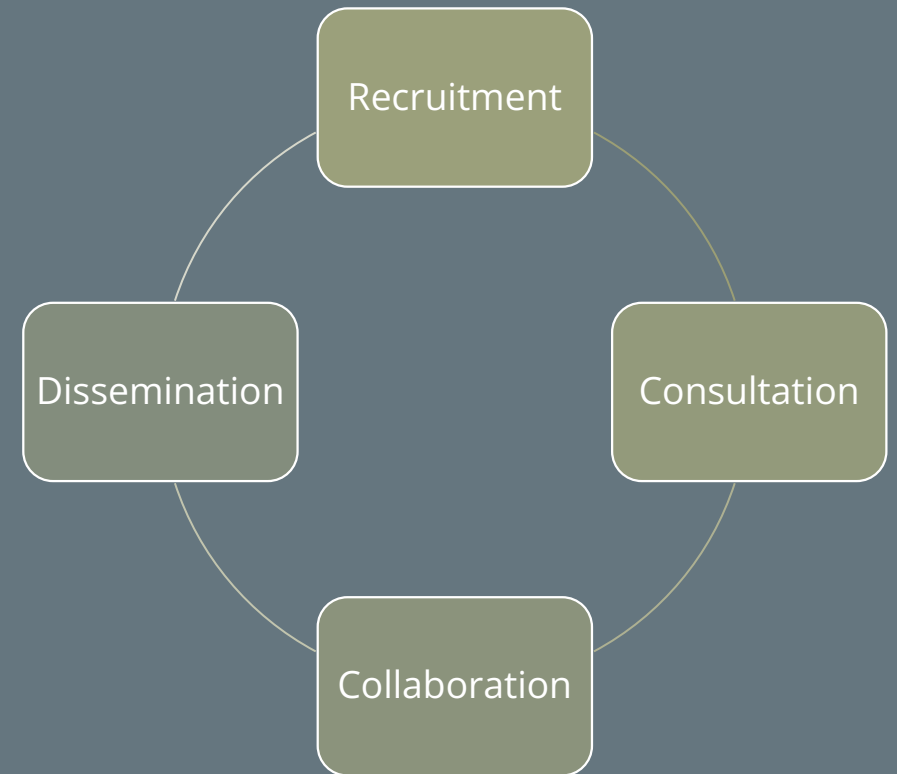


# OBJECTIVE, AIMS & PROCEDURE

- Objective
  - The goal is to understand Alaska Native caregiving stigma experiences better
  - Impact on caregiver's quality of life
- Aims
  - 1: Identify and discuss sources and levels of family stigma in rural and urban Alaska Native communities
  - 2: Describe how ADRD-related stigma impacts caregivers' quality of life
- Procedure
  - Recruitment (ARA, social media, snowball system)

# RESEARCH DESIGN AND METHODOLOGY

- Community-based participatory research (CBPR) approach
- Community partners
  - Alzheimer's Resource of Alaska (ARA)
  - Consultant with a diagnosis of ADRD
  - Alaska Native caregivers
- Collaborate
- Support
- Guidance

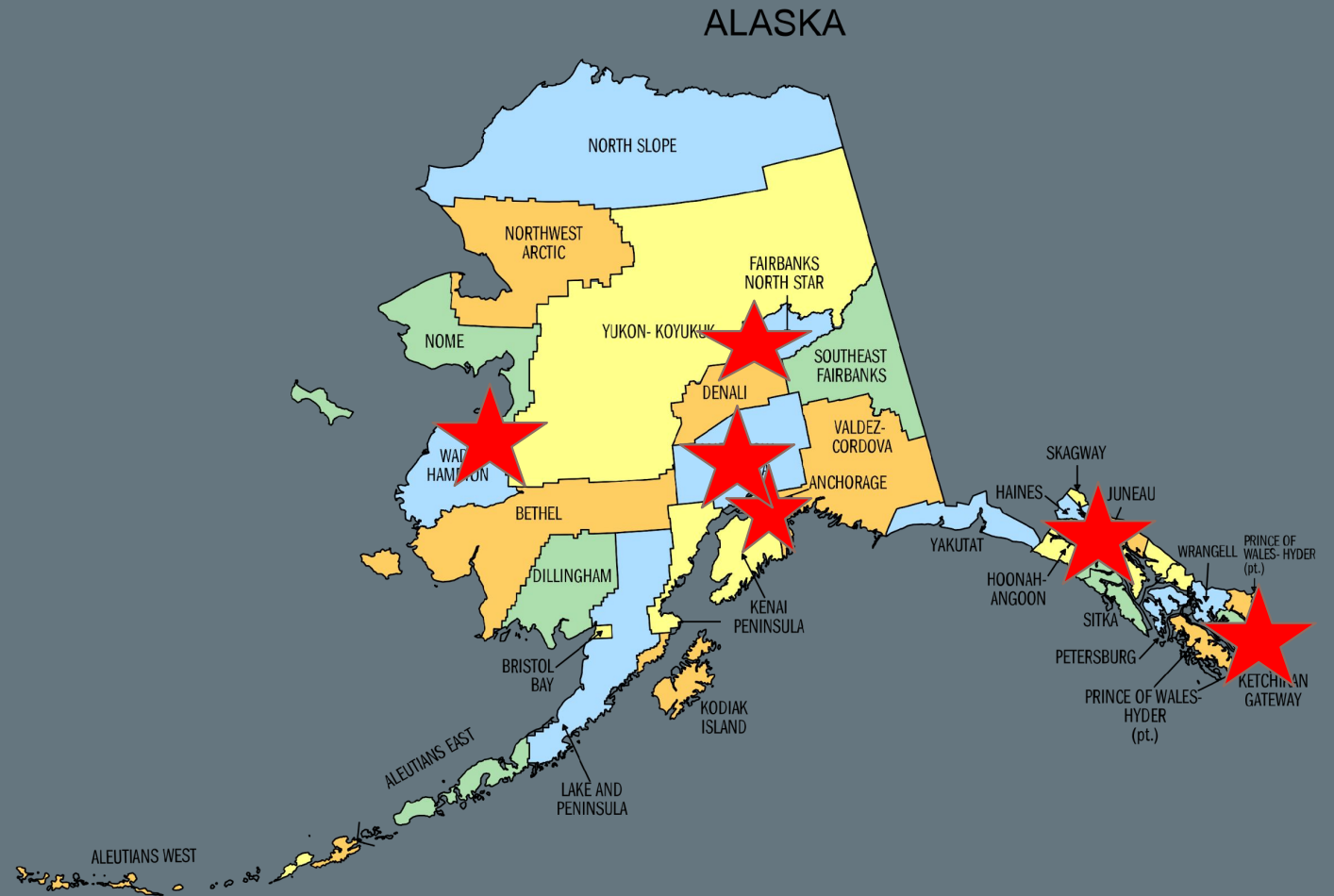


# RESEARCH DESIGN & METHODOLOGY

- 1 hour – 1.5. hour interviews
- Demographic questionnaire (age, location, services used)
- Administer questionnaire
  - *Adapted FS-ADS Scale: 62 items (5-point Likert scale)*
    - Subscales: caregiver stigma, layperson stigma, structural stigma
  - *GLEAN Scale: 18 items (5-point Likert scale)*
    - Subscales: Acts of self, traditional values, subsistence, family, providing
  - *Follow-up questions for contextual data*

# PARTICIPANT DEMOGRAPHICS

	N = 13	%
Gender		
Female	13	100
Average age	66	
Age range	(45 – 85)	
Education		
High School/equivalent	4	30
College	9	70
Location		
Urban	10	77
Rural	3	23
Geographically isolated	3	
Alaska Native identity		
Athabaskan	5	38
Yupik	3	23
Inupiaq	2	15
Tsimshian	1	12
Tlingit	1	12



# PARTICIPANT DEMOGRAPHICS

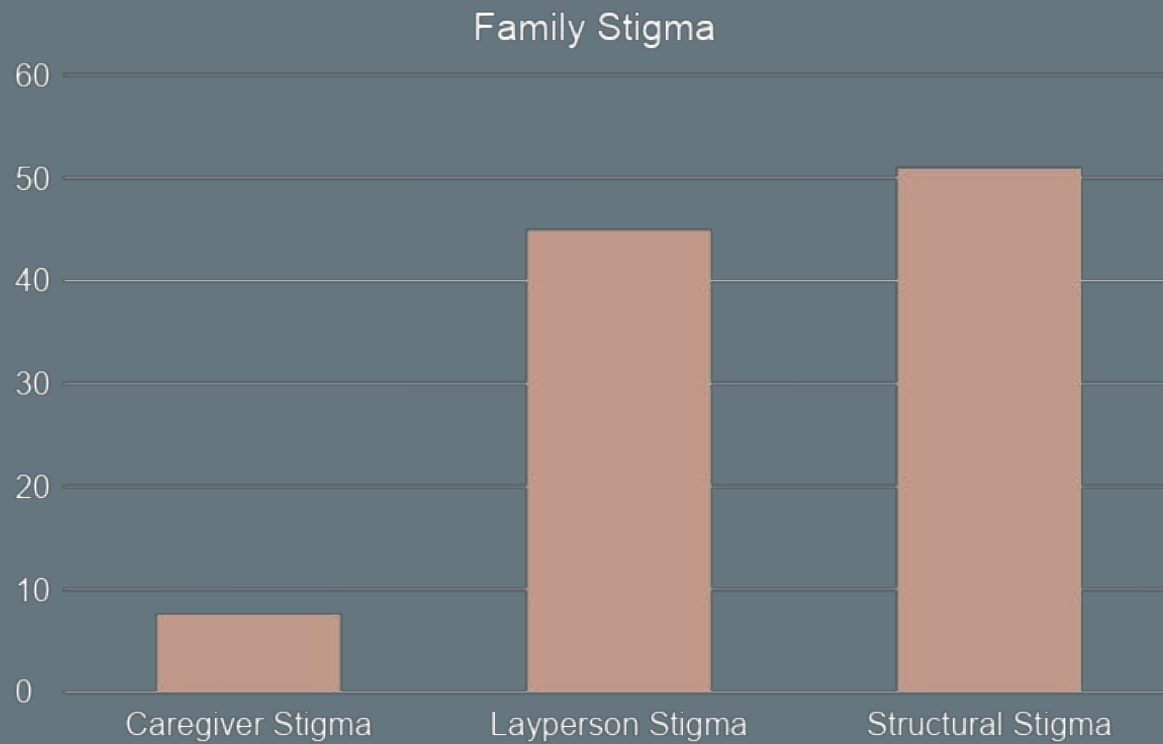
## Caregiving

- Despite low male participation, partners and siblings were highly involved in caring tasks (4 husbands and 1 brother)
- The average number of caring: intensified in the later stages, often alleviated when hospice started, or respite was arranged
- Services: none (2), VA (5), ARA (5), home health (4), tribal clinic (1)

	N = 13	%
Cared for		
mother	4	31
father	3	23
father and mother	2	15
husband	3	23
grandfather	1	8
Average # years	6.8	
Range	(1.5 – 25)	
Average hours of care per week	66.2	
Diagnosis		
Alzheimer's Disease	5	34
Vascular Dementia	1	6
Dementia	8	53
Undiagnosed	1	6

# RESULTS

Stigma as it is experienced by AN ADRD caregivers



# CAREGIVER VS LAYERSON STIGMA

Caregivers

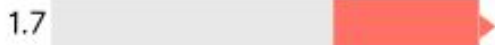
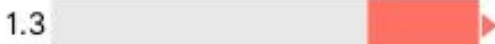
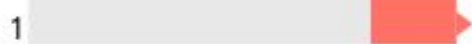
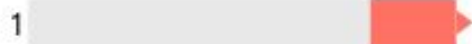
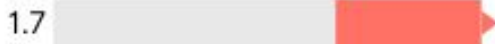
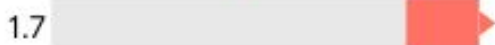


VS



Layperson

Average Score 1-5



## Cognitive Attributions

Dangerousness

## Emotional Attributions

High

Help, Assistance,  
Support,  
Compassion,  
Sympathy,  
Sadness

Compassion,  
Sympathy

Moderate

Grief, Sorrow,  
Concern

Help, Assistance,  
Support, Grief,  
Sorrow, Concern,  
Sadness

Low

Shame, Embarrassment, Putt off, Fear, Loss  
of Respect, Uneasiness, Dread, Dislike, Guilt

## Behavioral Reactions

Concealment

Limit Social  
Relationships

Hiding

Avoid

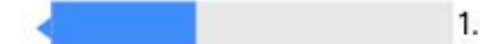
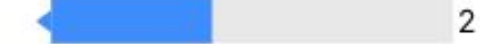
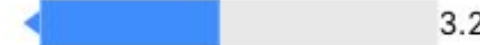
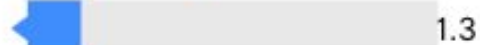
Distancing

Stay Away

Decreased  
Caregiving

Ignore

Average Score 1-5





# CAREGIVERS - Emotions

## Guilt

*"Maybe about ten percent of the time. I felt like why did she have this. Maybe did I do something wrong? Did I cook wrong or...? Periodically, those emotions would show up." (11)*

## Shame in social interactions

*"Because I was not educated about the disease and the progression and the behavior, when we would be out in public, and he would display behavior that would be inappropriate -- I would say not forcing himself in a conversation at a next table but just talking to strangers in a manner like they were very familiar. and I was ashamed because that generally was not the kind of person he was before." (4)*

# CAREGIVERS - Emotions

## Shame related to personal reactions

*"When I lose my temper and I don't, I'm not patient with her and I know she can't help it but I do feel shame. Like why did I do that?" (7)*

## Respect

*"I knew they had a disease, and I always told myself they can't help it. I'd mutter that to myself. So, no, I always had respect for my folks as I was taught in the Native culture." (9)*

## Gratitude

*"It's just how it is. That's always on my mind. I just have to say a blessing and be thankful." (6); "Because I appreciate being able to take care of my family that I can still do this or what I can do for them. And that they are still here to do this for." (9)*

# COMMUNITY & FAMILY - Emotional Response

## Social Isolation

*"I think that's the part that hurts the most is not seeing them. It's a very complicated situation we're in, but part of it is that family and friends are very uncomfortable. It's just like with everything else that we don't know about, we're uncomfortable. And I just don't blame them, but I do miss it. I miss them. We had a lot of gatherings in our home. And it's not that I don't-- I could continue but the awkwardness is felt so deeply, I don't want to put people in that same situation." (6)*

## Embarrassment

*"My relatives, I think they never were around very much. And they never really understood why he did what he did. And they were more likely to be embarrassed." (6)*

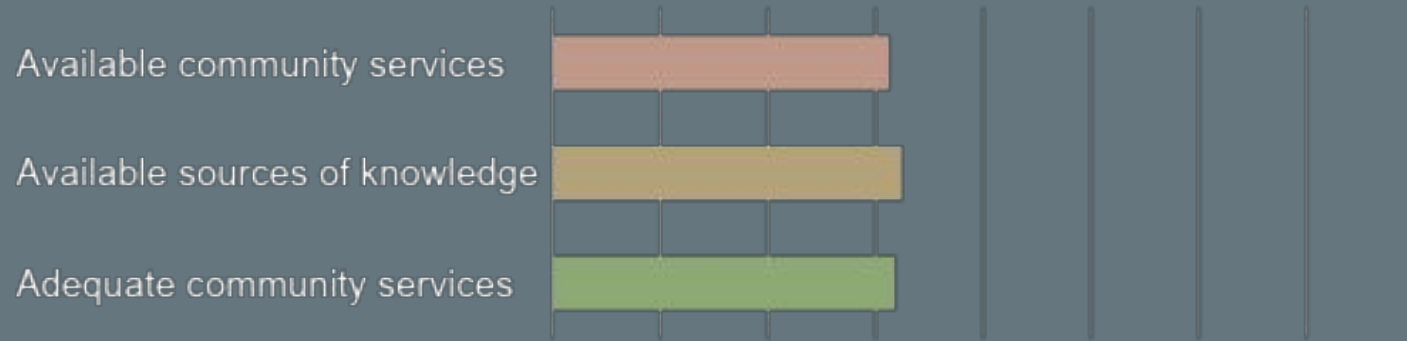
# COMMUNITY & FAMILY - Community Engagement

- Barriers
  - *Disease awareness*
    - Social distancing
    - Missing socialization skills
  - *Accessibility*
    - Bathrooms
    - Wheelchair access
  - *COVID*



# STRUCTURAL CHALLENGES

## Availability of Services for Person with Memory Loss



## Professionals



*"They gave no information to me... They just told me, this is what's going to happen—when and how it happens, and different things, and so on. And for specific questions, I had to go back online." (2)*

# STRUCTURAL CHALLENGES

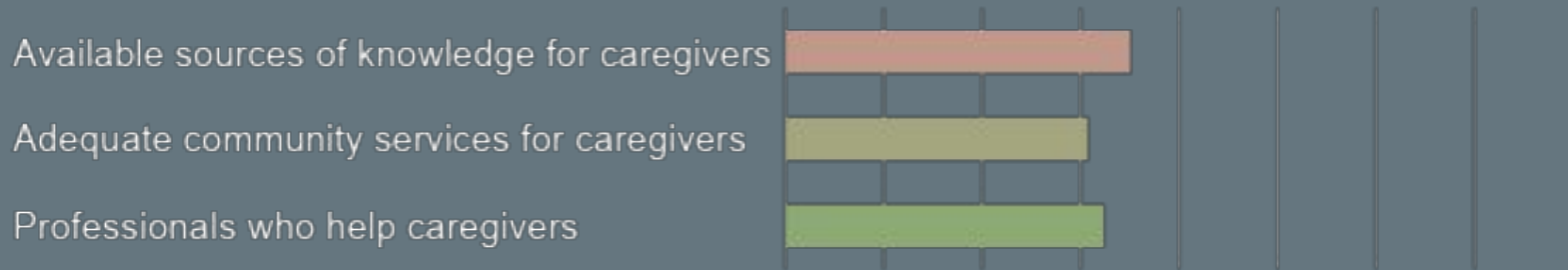
## Medical Professionals

*"You've got Alzheimer's and the guy did a test and when he did the test, [...] then he did ask him were you a drinker? And he said oh yes. He said, "How old were you when you started drinking?" He said I'd say 15. He said, "What did you drink?" Johnny Walker Deluxe. And he said, "That could be why you got Alzheimer's." Is what he said. And that was it. That was the end of our visit." (1)*

*"I said I already have a wheelchair I bought, a \$300, but we need one that [the sides] come off. And I said: what if I can't find one here because this is a little town. They don't have a medical store here. And [the doctor] said: 'That's what you get for living here'." (1)*

# STRUCTURAL CHALLENGES

## Caregiver support



## Caregiver resources



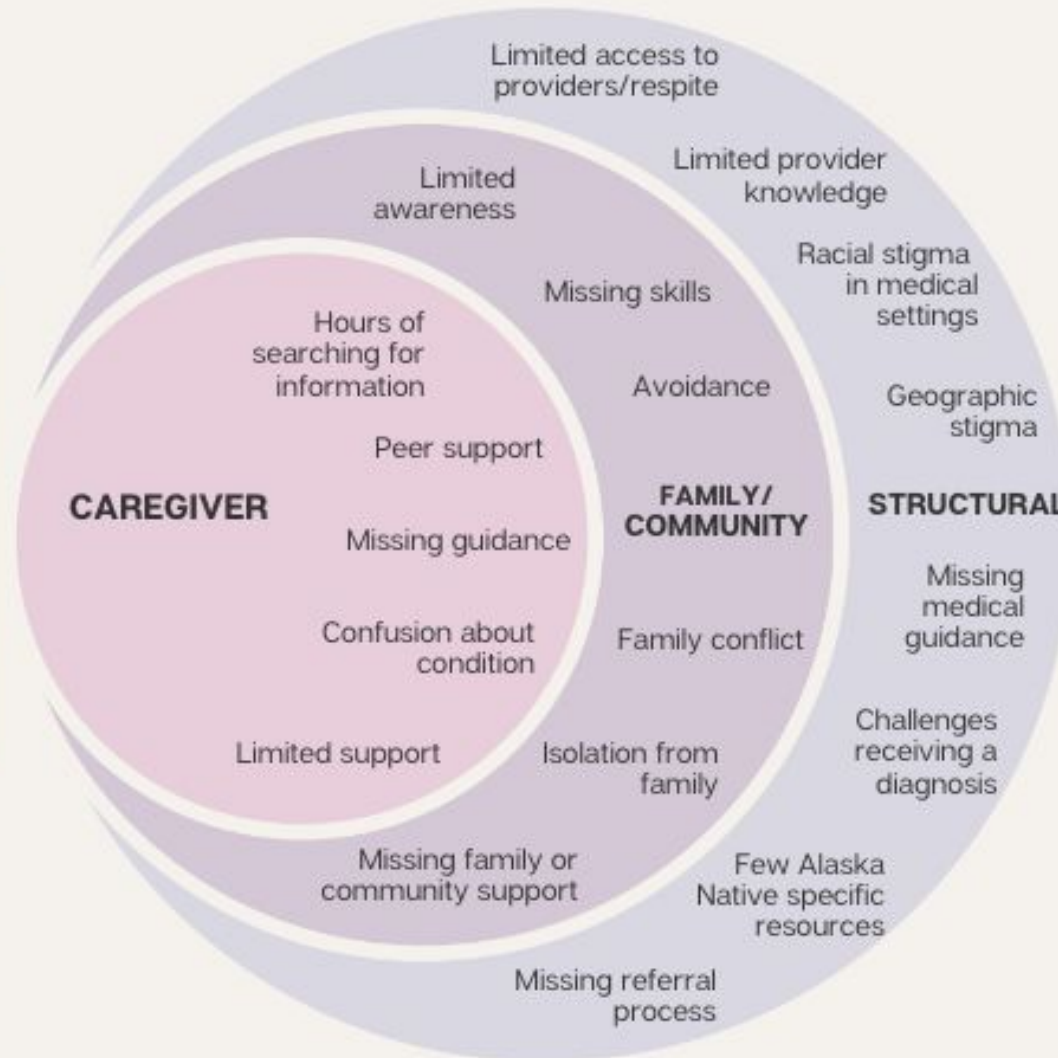
*"I think there should be more. If there were public service announcements about watching for symptoms of cognitive decline." (4)*

# ALASKA NATIVE ADRD FAMILY STIGMA

## Precursors

- Limited Disease Awareness
- Missing Disease Knowledge
- Limited Access to Resources

## Experience



## Outcomes

- Depression
- Isolation
- Loneliness
- Shame & guilt
- Distress



## Community support

Tight-knit communities

## Cultural understandings

Natural progression  
Second childhood  
Communicating with spirits  
Traditional ceremonies

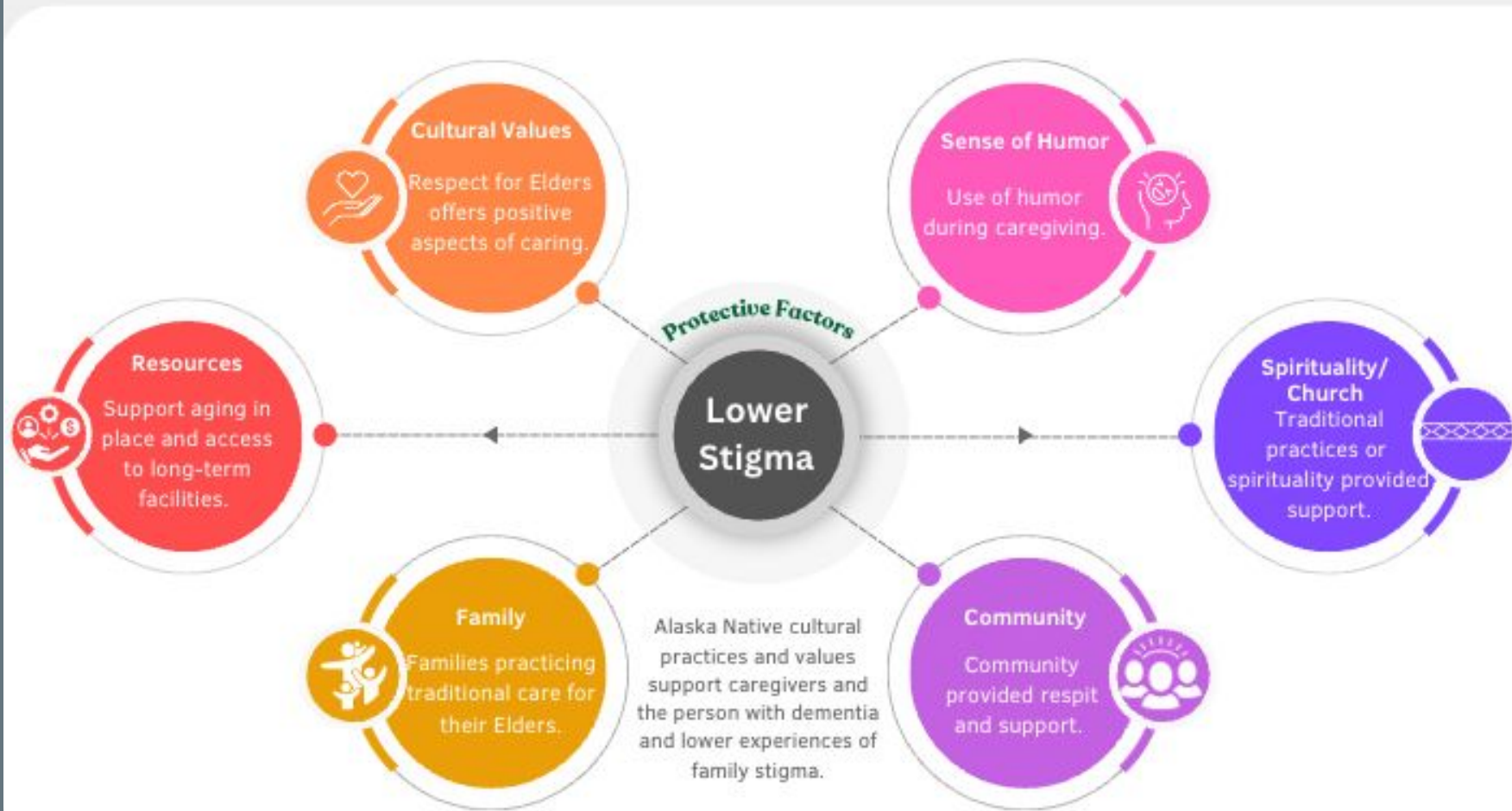
## Traditional values

Pride  
Respect  
Choice  
Preparation  
Caring  
Dignity

## Traditional activities

Self-care  
Gathering & Hunting  
Family & Community gatherings  
Spending time on land

# 6 ALASKA NATIVE CULTURAL ELEMENTS LOWERING FAMILY STIGMA

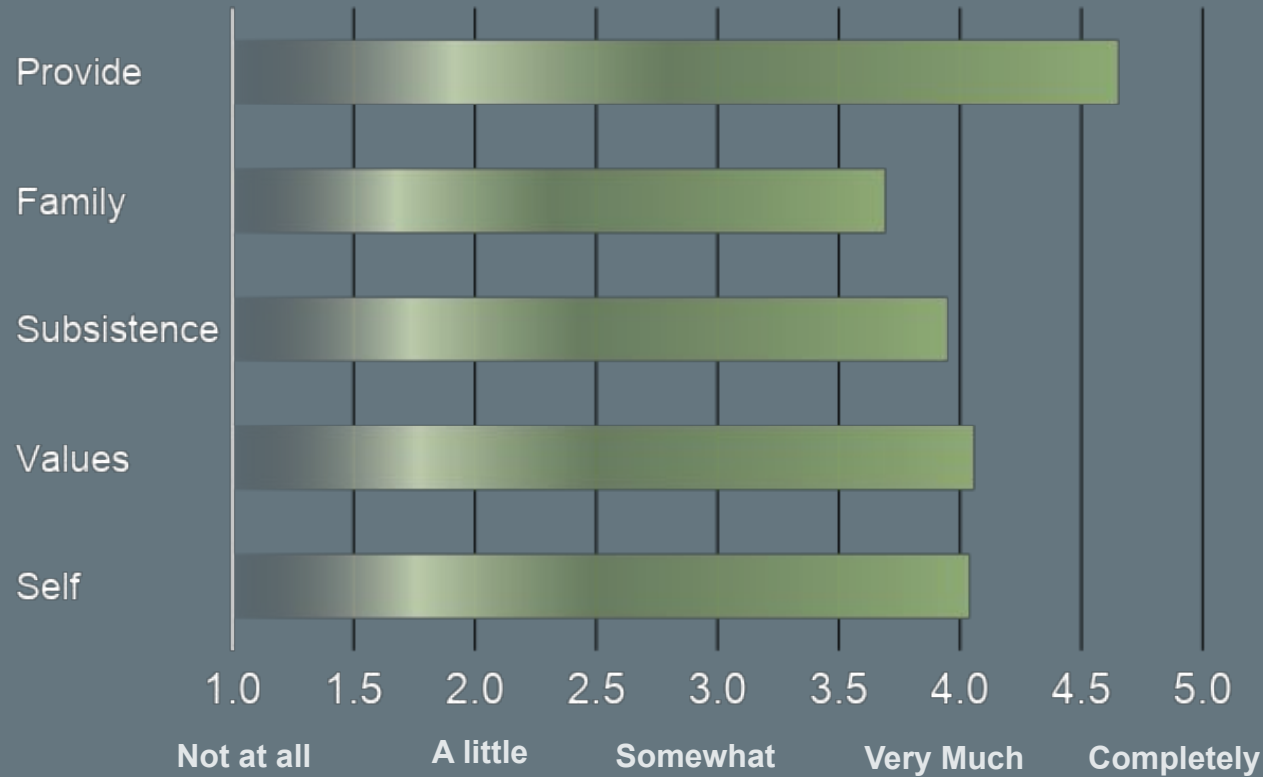


# RESULTS

## Cultural Strengths

- *“I think very important. I mean, caring for Elders that was very much imprinted in us growing up. Part of the Native culture and just respecting them.” (4)*

# RESULTS – Quality of Life



## Context

- Families continue to provide
  - Work, subsistence
- Mixed bag of family support
- Traditional activities
- Alaska Native values guide caregiving
- Taking care of oneself to be able to give care

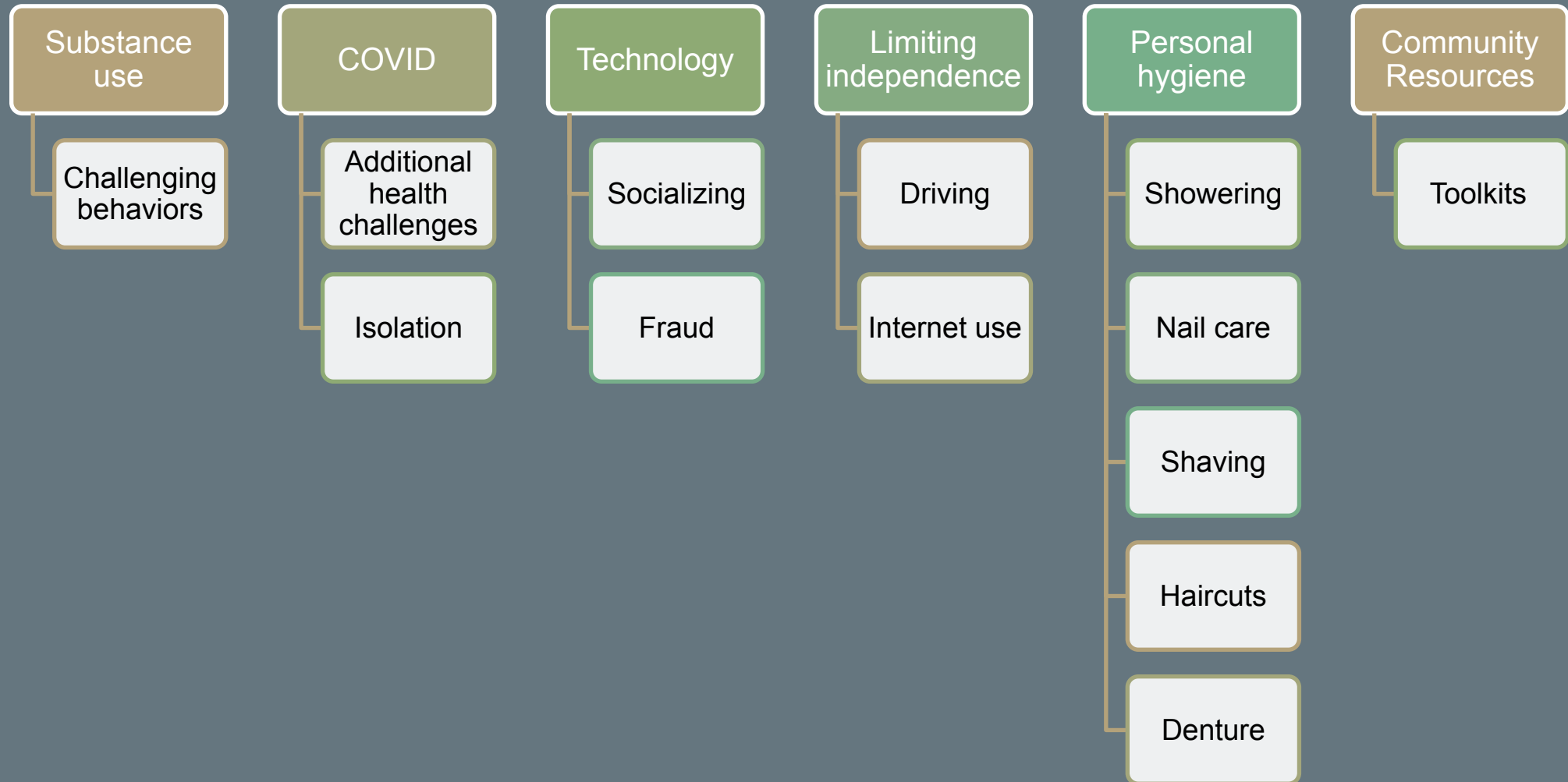
# CAREGIVER IDENTIFIED NEEDS

## Resources

- Increased access to caregiver resources
- Increased public awareness
  - *Educational materials that involve cultural considerations*
    - Traditional values & practices
- Implementation of supports that are community driven
  - *Improve access to public spaces*

# CAREGIVER IDENTIFIED EDUCATIONAL & SERVICE NEEDS

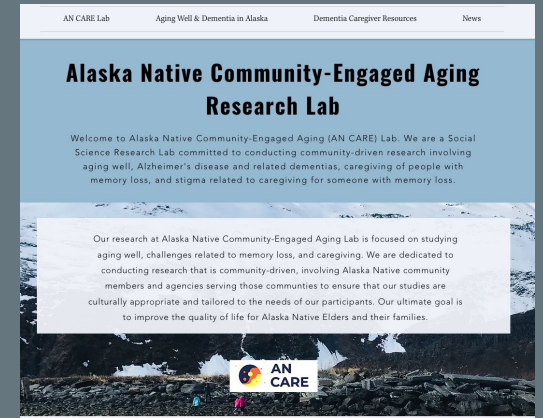
*At home care:*



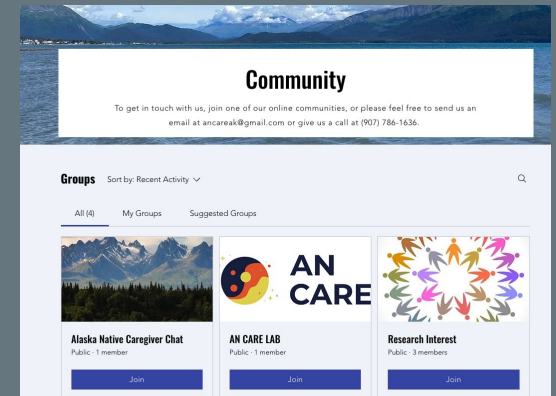
# FUTURE DIRECTIONS

Strengthen collaborations between statewide community partners to foster health equity

- 1) Create a collaborative of AN caregivers, community partners, and service providers to establish path forward that is community-driven and culturally sensitive
- 2) Create a measure that captures the stigma experienced by AN dementia caregivers for use within communities and agencies to inform materials, services, and policies reflecting the needs of caregivers within their unique context
- 3) Secure funding to develop strength-based culturally and community-driven stigma-reducing interventions for Alaska Native communities to improve caregiver health and wellbeing



[www.ancarelab.com](http://www.ancarelab.com)



# SOURCES

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Thank you for joining us  
today!

Questions?

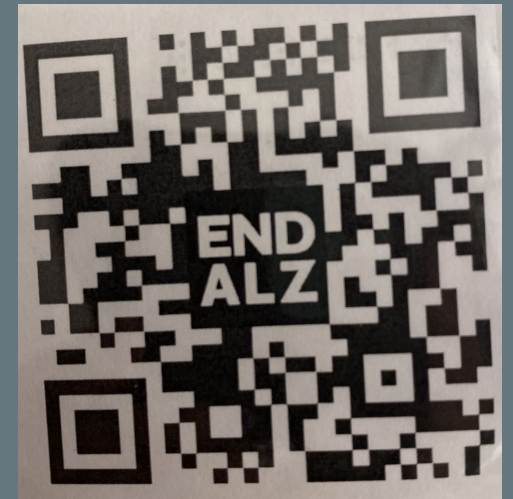
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you. Please share with  
us in our survey.



Advocate for policy  
changes with an email  
to support research.