

MARCH 2023

NATIVE HAWAIIAN ROAD MAP

NAVIGATING IMPACTS OF NĀ MA'I POINA:
ALZHEIMER'S DISEASE AND RELATED
DEMENTIAS AMONG NATIVE HAWAIIANS

Second Edition



Prepared for: Hawai'i's Executive Office on Aging

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PAPA OLA LŌKAHI BACKGROUND

Papa Ola Lōkahi (POL) is uniquely qualified in its organizational capacity to engage with community leaders, community-based organizations, and government agencies and offices to develop culturally appropriate initiatives to improve Native Hawaiian health and wellbeing, our focal point since inception in 1988. Throughout our 35-year history, POL has utilized advisory councils made up of community leaders, stakeholders, elders, content experts, Native Hawaiian physicians, and public health professionals to guide the development and evaluation of our work. Our long list of practices includes the Pacific Diabetes Education Program, 16 years of administering a National Cancer Institute-funded Special Populations Network, convening six task forces engaged in updating the E Ola Mau a Mau Hawaiian Health Needs Assessment in 2019 and 2023, and convening Statewide traditional Hawaiian healers. POL recently completed a statewide community health scoping process and is now conducting a similar process on the topic of tobacco use and prevention. The process that POL uses in community engagement and public communications is based on sound science and an informed understanding of the communities we serve. In collaboration with the Hawai'i Department of Health's Executive Office on Aging, the University of Hawai'i Center on Aging, and by virtue of statutory roles with our board of directors, POL is uniquely qualified to access relationships to inform program development and implementation with empirical health information.

MAHALO

Though POL's work in the area of kūpuna health [elders, grandparents, adults 65 and older] and Alzheimer's Disease and Related Dementias (ADRD) is recent, POL has been working to improve the health and wellbeing of Native Hawaiians with the help of our Statewide Native Hawaiian Health Care Systems and community partners for over 30 years. We acknowledge that there are many in Hawai'i who committed their lives to studying and resolving concerns about ADRD. We are grateful to those who allowed POL the opportunity to meet and collaborate with them for this project so that we can share their stories and recommendations with the Hawai'i Executive Office on Aging and the University of Hawai'i Center on Aging. It is their expertise, learned experiences, and guidance that we use to align our understanding about the impacts of ADRD with a culturally sensitive approach to engage communities, build relationships of trust, increase our understanding of concerns and needs, and document their recommendations. It is POL's sincere aim to share their mana'o (thoughts, advice) within this Road Map in a way that is respectful to the Hawaiian people while we celebrate our resilience from cultural genocide and the prior threat of extinction.

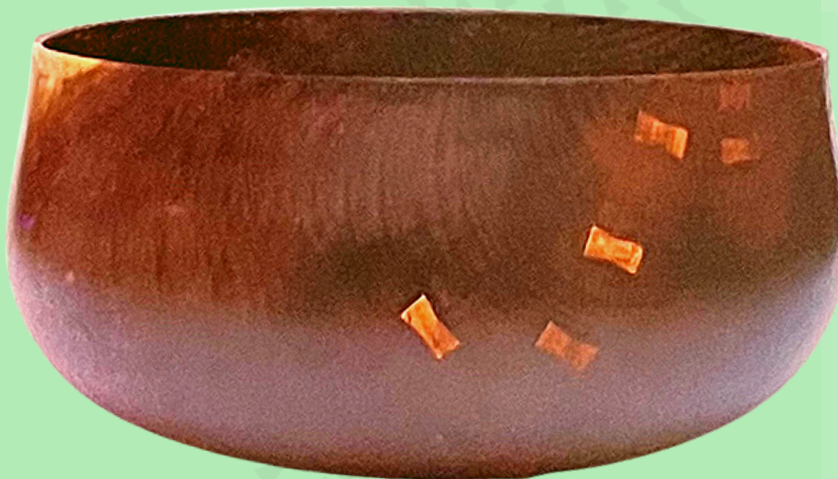
DISCLAIMER

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This living document, as written, is expected to evolve and grow as new information about ADRD, understandings from a Hawaiian perspective, and perceived needs are updated. Due to time and funding restrictions, POL acknowledges that this Edition of the Road Map is merely the beginning of a long-term process and commitment to continue much-needed conversations about Native Hawaiians impacted by ADRD. After having a successful engagement process, we are obligated to discern next steps to plan, align recommendations, and implement action items that honor the time and mana'o of statewide community members who met with us.

PEWA

The pewa, which looks similar to a fishtail, is a skillful repair found in traditional Hawaiian woodwork. It is used to prevent the wood from splitting or to patch broken calabashes. A calabash represents harmony within a family as it contained poi (pounded taro, Hawai'i's traditional staple food), which family members shared and ate from. Symbolically, the pewa represents the healing of families and the mending of wounds within the mind and spirit. The pewa is also a visual metaphor for the passage of time, where growth and understanding can lead to wisdom. It is used throughout this document to honor nā kūpuna Hawai'i, their wisdom, and the memories that they dearly hold on to.



Kauai Koa bowl with pewa
Photo Credit & Artist: Michael Ilipukea Dunn

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OVERVIEW OF NATIVE HAWAIIAN HEALTH

I ulu no ka lālā i ke kumu.
The branches grow because of the trunk.
Without our ancestors we would not be here.
(‘Ōlelo No’eau, #1261)

Native Hawaiians are descendants of seafaring voyagers who sailed across the Pacific around 100 A.D. It is estimated that somewhere between 800,000 to a million Native Hawaiians lived in Hawai‘i at the time of Captain James Cook’s arrival in 1778. They were a self-sufficient and self-governed population with a social structure and lifestyle grounded in aloha and a strong connection to their environment, also known as "lōkahi". However, by 1890, the increasing arrival of foreigners and exposure to disease lead to a devastating 90% population decline. After the death of Kamehameha I in 1819 and the first arrival of Christian missionaries in 1820, the Hawaiian way of life experienced major shifts, and their worldview was in disarray with a loss of identity and rapid decline in health and well-being.

The population collapse and dispossession of Native Hawaiians in the 1800s resulted in diminished support systems and elevated economic challenges for their families and communities. These historical realities persist into the present day and form the backdrop of Native Hawaiian material and economic well-being (Kana’iaupuni et al., 2021, p.10). Despite the loss of land, identity, and reduced health, Native Hawaiians have shown great resilience in the preservation and revival of their language and cultural practices, and statistics are now showing that Native Hawaiian kūpuna (grandparents, elders) are actually living longer compared to prior generations.



Traditional Hawaiian surfboards with pewa. Photo Credit & Artist: Kūnane Wooton

LITERATURE REVIEW

RISK FACTORS & HEALTH DISPARITIES

The history of Native Hawaiian health is not a simple account of illness and mortality; rather, it is a complex reaction to the obliteration of cultural and medicinal practices, land occupation, spiritual devastation, introduced infections, and decline in social status. Despite these adversities, research from Dr. Kana'iaupuni et al. says, "Hawaiians have tremendous resilience in the face of foreign-imposed political, economic, and educational structures. It is through these multiple lenses that we understand the challenges, disparities, and evolution of Native Hawaiian health" (Kana'iaupuni et al., 2021, p.15). In the next edition of this Road Map, POL will have information from additional community meetings about protective factors that continue to make Native Hawaiian kūpuna and their families resilient, especially from the impacts of ADRD.

Hawaiian elders are treasured for their wisdom, knowledge, and many contributions to strengthening the family and perpetuating Hawaiian culture and language. As of this report, they are burdened by a multitude of risk factors and significant health disparities. Health disparities are defined as: "preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations" (Centers for Disease Control and Prevention, 2020). Additionally, in comparison to elders of Hawai'i's other major ethnic groups, Hawaiian elders have a shorter life expectancy and a widening gap in longevity. In other words, Native Hawaiians appear to be living slightly longer compared to prior generations, but the numbers for other ethnic groups living longer continue to rise and exceed those of Hawaiians.

According to Hā Kūpuna: National Resource Center for Native Hawaiian Elders, "Life Expectancy is a measure of population health." Utilizing death records and population data made available through the Hawai'i State Department of Health, Hā Kūpuna found that "life expectancy of Native Hawaiians increased by 14 years, from 63 years in 1950 to 77 years in 2010. At the same time, the life-expectancy gap decreased between Native Hawaiians and Caucasians and increased between Native Hawaiians, Japanese, and Chinese" (Hā Kūpuna, Research). Meanwhile, Hā Kūpuna and other organizations continue to analyze the data to anticipate needs and prepare for the future. One consideration is how one's quality of life can increase their life span.

Between 2020 to 2030, the growth in the number of older adults 60 years of age and older in the State of Hawai'i is expected to increase by 17% and represent 28% of the State's total population. In addition, there will be a 31.7% increase in older adults 85 years of age and older over the next 10 years between 2020 to 2030 (State Plan On Aging 2019-2023). The Alzheimer's Association reports that the number of adults age 65 and older with Alzheimer's Disease will increase 20.7% between 2020 to 2025. Therefore, as Hawai'i's aging population increases, the need for a comprehensive and coordinated system of long-term, home and community-based services and supports to address current and anticipated needs will continue to rise (See Figure-1, 2022 Alzheimer's Disease Facts and Figures).

Lastly, while age, family history, and heredity are overlapping risk factors for chronic diseases, research from the Alzheimer's Association shows that Alzheimer's Disease or vascular dementia can be exacerbated by health conditions that damage the heart and blood vessels. That includes heart disease, diabetes, stroke, hypertension, and high cholesterol.

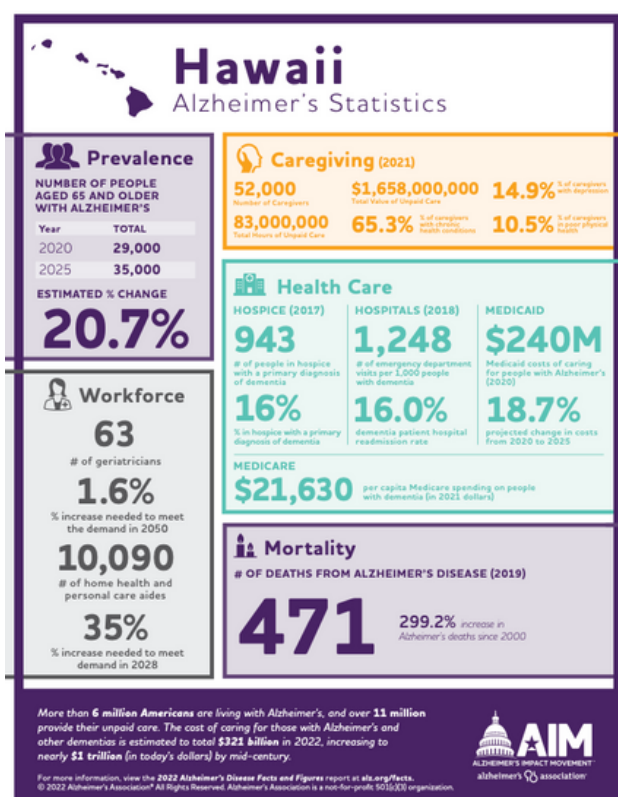
According to the U.S. Department of Health and Human Services, Office of Minority Health (OMH), “In comparison to other ethnic groups, Native Hawaiians/Pacific Islanders (NHPI) have higher rates of smoking, alcohol consumption, and obesity” than the national average (U.S. Department of Health and Human Services). Interestingly, from an oral health perspective, the mouth is the main entrance to the body.

Dr. Lauren Bundschuh, Dental Director of Kaua’i island Native Hawaiian Health Care System Ho’ōla Lāhui, emphasizes that physical health and brain health is affected by dental and oral health; she notes that her patients react with concern when she tells them that oral inflammation affects brain health and increases the risk of ADRD (“personal communication”, 2022, June 1). And, if not cared for properly, it can impact other bodily functions.

When brain health is compromised, so is its ability to cope with stress from environmental and social alterations. According to Bud Cook et al., “Native Hawaiians exhibit the most devastating health statistics and social indicators in the United States, and it may be attributed to cultural changes since the arrival of Captain Cook in 1778. These incidents of cultural trauma are postulated to achieve a level of potency that may affect the health status of post-modern individuals and communities” (B.P. Cook et al. 2003). In a report from the Office of Hawaiian Affairs, the state of kūpuna mental health is a concern, with “nearly 1 in 10 Native Hawaiian kūpuna have a depressive disorder” (OHA Women’s Health Report, Book 1, p. 11).

In summary, as research continues to demonstrate how mental health is a risk factor for dementia, years of data proves that Native Hawaiians have the highest prevalence of physical health disparities to put them at the highest risk for ADRD, more than any other ethnic groups in Hawaii. Therefore, it is absolutely necessary to keep Native Hawaiians in the forefront of conversations about health equity and public health policies. Continual use of data, specifically disaggregated data for Native Hawaiians, will be critically essential to inform such processes.

Figure 1



DATA/RESEARCH GAPS

There are a limited number of comprehensive studies that focus on Native Hawaiian Health and fewer that look specifically at kūpuna impacted by dementia. It is a primary data gap when many projects in Hawai'i use national survey templates that do not disaggregate Native Hawaiians from other ethnic groups. Because this creates a barrier to conducting a targeted analysis, we do not have proper data to tell us how many Hawaiians have ADRD. Until data collection methods and tools are modified and consistently used, perhaps culturally-relevant methods to collect qualitative data, such as oral histories from the kūpuna and their 'ohana (families), can give personal insight into dementia and its effects on loved ones. Below are examples of gaps because of aggregated data collection:

- In December 2013, *Hawaii 2025: State Plan on Alzheimer's Disease & Related Dementias* was released in response to the National Plan to Address Alzheimer's Disease, and significant data was collected from surveys conducted at that time. However, the data for the Native Hawaiian and other ethnic communities were not represented individually. The need for accurate, disaggregated data has been an argument to better understand Native Hawaiian health disparities and address health equity on a systemic level.
- The Alzheimer's Association released their *2021 Alzheimer's Disease Facts and Figures*, accompanied by their *Race, Ethnicity and Alzheimer's in America* special report, which "examines perspectives and experiences of Asian, Black, Hispanic, Native and White Americans in regard to Alzheimer's and dementia care." However, the Native Hawaiian/Pacific Islander (NHPI) demographic was notably absent.
- The 2021 Kamehameha Schools *Ka Huaka'i Native Hawaiian Educational Assessment* reported that compared to other ethnic groups in Hawai'i, Native Hawaiians have the highest percentage of adults with cognitive disability. Cognitive disability refers to limitations in areas such as mental functioning, communication, self-care, and social interaction. This report also noted low income and low education attainment as possible associations. Here are other relevant data gaps noted in the report:
 - Despite the increased promotion of emotional and spiritual well-being, the availability of data for Native Hawaiians is severely limited.
 - Current literature about cognition, mental health, and spiritual beliefs and practices, mostly focus on individuals rather than families and communities.
 - Though current research is limited, Native Hawaiians are generally over-represented in indicators of poor mental health, such as depression and suicide.

SERVICE/PROGRAM GAPS

According to Hā Kūpuna, "Native Hawaiian health service providers believe that kūpuna care is rooted in Native Hawaiian or 'local' values. They also feel that most kūpuna hope to age in place with help from 'ohana" (Hā Kūpuna Mixed Methods Research Fact Sheet). In doing so, the practice of such values, along with compassion and understanding among service providers and families, will make a significant difference to maintain familial relationships and encourage the highest quality of life possible for an aging family member with dementia.

In a conversation with Brigham Young University–Hawaii President Dr. Keoni Kauwe, he emphasized the importance helping people understand that when seeking services, "there are not effective treatments for some causes of ADRD, and as such, strategies for reducing risk, preventing disease, and working to maintain high quality of life for those suffering from ADRD and their loved ones are paramount" ("personal communication", 2022, September 21). As some Hawaiian families rely on cultural beliefs and spirituality to overcome health adversities, here is a statement from POL's Kūpuna Council of Traditional Healer's: "Traditional Healing and Cultural practitioners [trained by Hawaiian master healers] recognize the importance of pule and compassion for a person and their 'ohana to strengthen their faith and hope when faced with traumatic and shattering changes in health and well-being." Hawaiian culture and values can be a pathway to improve services for kūpuna affected by dementia for example:

"Expand services/resources to meet the needs of multi-generational 'ohana in understanding and coping with an aging adult with Alzheimer's or other forms of dementia; increase access to resources that are culturally relevant, based on traditional practices, and offered in Hawai'i's official state language 'Ōlelo Hawai'i" (Hā Kūpuna, MMR Fact Sheet According to B.P. et al. "Providers serving Hawaiian populations must recognize the impact of cultural wounding and historical trauma, and aid patients by assisting them with the process of understanding and growing from knowledge of cultural identity" (B.P. et al., 2003).

Papa Ola Lokahi's 2020 Wili I Lei Lanakila Report says, "many kūpuna are not getting the help they need when they are home-bound [aging in place]. Many are also taking care of their grandchildren and not seeking assistance" (2020 Wili I Lei Lanakila Report). The report also shares the importance of 1. *Social interaction*: Kūpuna benefit from generativity and the social aspects of programs like talking story, going on outings, and socializing with friends, 'ohana, and others. Kūpuna also appreciate the sense of giving back – not just being a recipient of care. This aligns with a Native philosophy of giving and keeps kūpuna engaged with different services and people. Native Hawaiian-led Adult Day Care programs can be highly beneficial, as well as programs that focus on addressing barriers by providing transportation, social interaction, and introductory support for use of technology. 2. *Service information*: General information about local support services should be readily available for the kūpuna. They need to know what is available and how to access the support. Some kūpuna rely on Community Health Workers (CHWs) to navigate the system and provide information on how to access different supports or services. Those who are not connected with these supports may struggle to access necessary services. 3. *Administrative support*: Assistance with administrative-focused tasks is required for kūpuna. Access to benefits could be increased with support to complete service applications or to understand insurance coverage. The Covid-19 pandemic highlighted the need for kūpuna to develop a better understanding of technology to better engage with services like telehealth. Providing basic technology and administrative support will increase the number of kūpuna engaging in necessary health services (2020 Wili I Lei Lanakila Report).

RECOMMENDATIONS

Continual funding to sustain caregiver support programs.

The Hawai'i Kūpuna Caregiver's Program was launched in 2018. Also known as the Kūpuna Caregiver Law, it is managed through the Hawai'i State Executive Office on Aging. Continual funding for this program and others like it is critically essential as it provides compensation to family member caregivers. Additionally, caregiver support programs is a valuable response to the increasing number of kūpuna aging in place with the help of a family member/caregiver. In 2020, there were 51,000 caregivers in Hawai'i, logging in a staggering 81,000,000 total hours of unpaid care. The total value of that unpaid care was \$1,621,000,000. (Alzheimer's Association, 2019).

Develop culturally sensitive research methods to create programs based on Native Hawaiian values, such as the importance of 'ohana and kuleana (familial responsibilities) and integration of traditional medical practices.

Though there is no data about Hawaiians with Dementia, reports about other health concerns and the impacts on a family are similar to what was shared during POL's community meetings about impacts from dementia - it affects not only the individual but the entire family. According to Braun, Mokuau and Tsark, "Increasing the cultural competency of health care providers requires an understanding of the cultural group being served. In this study [about family support for Native Hawaiian women with breast cancer], focus groups were conducted in which Native Hawaiian and non-Hawaiian rehabilitation professionals were asked to interpret utilization data and offer their perceptions of the rehabilitation experience of Native Hawaiians. Consistently noted were cultural values and traditions reflecting the importance of 'āina (environment), 'ohana, kuleana, and kōkua (mutual support and interdependence). Findings demonstrate the link between cultural values and health behaviors and provide guidelines that inform practice, policy, and research" (Braun et al., 1997). Assisting healthcare providers to respect the wisdom and traditions of our elders can empower them by allowing them to maintain their dignity and sense of identity.

Expand/increase collaborations among organizations who provided community resources and conducted relevant studies focused on Native Hawaiian communities and their elders.

As collaborations among Hawaiian-serving organizations that focus on kūpuna with dementia increases, data collection about impacts and needs can also increase, advocacy will improve, and resources can be appropriately allocated. Papakōlea's Kūpuna Care Center Network (KCCN, under non-profit Kula No Nā Po'e Hawai'i) is a stellar kūpuna and caregiver support program that services the Papakōlea homestead through various programs, workshops, health services, and social activities. They also have a reputable relationship with other homestead communities across the State of Hawai'i. Additionally, Kula is contracted by POL to conduct a statewide Native Hawaiian Health Survey. This survey, which includes questions about memory and dementia, is expected to close in 2023. Another program, which is referenced throughout this document, is Hā Kūpuna: National Resource Center for Native Hawaiian Elders. Their research and the resources they produce within the University of Hawai'i at Mānoa has been and will continue to be informative as a stakeholder for future collaborations with other government agencies and Hawai'i non-profits.

Use traditional wisdom about food and diet to maintain good health.

Since Native Hawaiians have a high risk for chronic disease (heart disease, obesity, diabetes) and dementia, a traditional diet can be a solution for improved health outcomes. Here is what Dr. Claire Hughes shared in Ka Wai Ola, The Living Water of OHA, about food and the traditional Hawaiian Diet:

"A few changes in food choices, cooking methods, and physical activity can make a huge difference in health for our entire family. Our ancestors had a healthy diet: they knew it, practiced it, and gained mana (spiritual power) from it. Making personal changes that bring us closer to our diet can correct many illnesses. And, while it would be better if we ate this way from birth, it is never too late to get great benefit from a diet that mirrors our ancestors' diet. The traditional Hawaiian diet was nearly 80% plant in origin, mainly taro [kalo], sweet potatoes ['uala], many greens, limu [seaweed], breadfruit ['ulu] and a few fruits. Fish was the most important protein food, and fat consumption was very low... about 10% of total calories each day. We average about 40% now. Foods were steamed (imu), eaten raw, or cooked over an open fire, but never fried. The diet, known by the acronym THD, conveys an important cultural secret, lōkahi... that practice of maintaining personal balance and discipline. Reclaiming traditional practices and beliefs is a rewarding and healthful experience" (Claire Hughes, 2013).



'Ulu (breadfruit) and kalo (taro) are indigenous canoe plants that are staple crops in the traditional Hawaiian diet.
Photo Credit: Napua Casson-Fisher & Kia'i Lee

Develop Adequate housing and family support.

In POL's *Wili I Lei Lanakila* 2020 report, it was noted that the needs of kūpuna grow as they age, care for grandchildren, provide support for families and manage their own health and well-being. The statewide increase in kūpuna population over the next 10-20 years is going to increase the demand for home health care and require planning for possible Foster Care, Long Term Care, Residential Elderly Care Homes, and Assisted Living facilities. Home healthcare-related themes will include:

- *Good community services:* Overall, positive feedback was received regarding services provided by local Home Health Agencies. Palliative Care and Hospice services across all islands and communities were commended and described as respectful and caring. Although it was difficult to attract and maintain a stable workforce in this area, all services were acknowledged as being positive supports. The challenge for many kūpuna though is access.
- *Access barriers:* Home health care supports are expensive, not sufficiently covered by insurance plans and are limited for rural communities. Transportation for kūpuna is a challenge in general. Insurance coverage is also limited with some kūpuna unfamiliar with what is provided by their own insurance plans. Native Hawaiian kūpuna often choose not to seek these services due to pride or hilahila (shame) about their own state of health or housing. Humility also plays a role when these same kūpuna would prefer to let people who need the services more access the services first. Overall, access to home health is limited.
- *'Ohana training and support:* More family caregivers need training to care for aging relatives. Younger generations need to be involved to learn the skills and kuleana (responsibility of looking after kūpuna and the 'ohana. Many kūpuna prefer to age at home, so support should be explored for both 'ohana and kūpuna to help balance cost and effort. Respite support for 'ohana providing care should be available from local services. Additionally, according to the 2020 POL Alzheimer's and Dementia community survey, 35% of respondents are Alzheimer's/Dementia caregivers; 65% of caregivers are being most impacted financially, 28% are impacted physically, and 7% are impacted emotionally. Family caregivers need the proper support and tools to provide proper care and avoid burnout.
- *Services maintaining connection:* Meeting participants talked about how kūpuna highly regarded relationships and interactions with people. It was important for service providers to build relationships based on trust and explore opportunities to increase the provision of services, particularly in rural areas including those on neighboring islands. A high level of concern for kūpuna living alone and isolated during the COVID-19 pandemic was raised. Some CHWs described how it was important to check on kūpuna, provide supplies if possible, and visit in order to maintain social interaction.

NATIVE HAWAIIAN PERSPECTIVES

“Within the ‘ohana, elders taught youngsters to fish, raise taro, weave and build. Here proper behavior was taught, and rituals and kapus (taboos) memorized.”

- Mary Kawena Puku‘i

MEMORY

The role of kūpuna in a Hawaiian family is very important. Therefore, to discuss the importance of kūpuna, it helps to first understand the importance of roles within a Hawaiian family system and how memory was used across generations to learn and transfer information. In a traditional Hawaiian society, while the younger and capable men and women of ‘ōpio (young adult) and mākua (older adults/parents) status were hunting, gathering from the land and sea, building, or protecting their village, kūpuna would mālama (care, nurture, teach) and teach the keiki (children). Mary Kawena Puku‘i gives examples while she describes hiapo and punahele in Nānā I Ke Kumu, Vol. 1:

“The system of giving the hiapo (first born child) to senior relatives filled many of the needs of the society it existed in. Hawaiians placed great value on traditional ways and in knowing family genealogy and the family ancestor gods (‘aumakua). Yet there was no written language to record this history. The hiapo was the “living history book.” While other children of the ‘ohana learned to fish and tend taro, the hiapo memorized the family genealogical chants, social and religious customs, kapus (taboos) and specialized skills and knowledge. To do this, he became the constant companion of the grandparents, listening, learning, rehearsing, so the even tempo and cadence of each pule (prayer) and oli (chant) would be traditionally correct” (Nānā I Ke Kumu, Vol. 1, pg 52).

The punahele was not just the “favorite child” as we know favoritism today. The punahele as the “spring or source that continues” was destined to learn the family traditions, genealogy and general lore-of-living so he could in turn pass them on to the future generations. He would hold in trust and strengthen the “sense of family” that binds Hawaiian relatives so closely. As an adult he would be the senior member who would guide, counsel and make decisions that would affect family welfare. It was a responsible role. To prepare for it, the punahele would memorize the family chants, listen to and absorb the advice of elders, and spend most of his time in a sort of “apprentice for seniority” training course (Nānā I Ke Kumu, Vol. 1, pg 190). Today, some elders call this process “kupuna-in-training.”

In Nānā I Ke Kumu Volume 2, Mary Kawena Puku‘i recalls her own account of being a punahele: *“The grandparents went out of their way for the punahele. Teaching, teaching, teaching, all the time. I know because I was a punahele. Every day, Grandmother would quiz me: ‘Do you remember the place we went yesterday and the ‘aumakua (ancestral family guardian in the form of an animal) who guards it?’ And then, three days later, ‘Now, tell me again. What was the name of the ‘aumakua? How far does his kuleana extend?’ I had to memorize all the family ‘aumakua by name. We had 50. I had to know which ones would help in a certain problem; which ones to call on in another kind of trouble. I memorized our family history. I learned what to do when a family member died, how to talk to quarreling members, and how ho‘oponopono helped keep family in harmony” (Nānā I Ke Kumu, Vol. 2, pg 55).* Yet, in modern society, technology is now the preferred “source” of information, so it strips away the social context of the traditional Hawaiian family system. With each passing generation, children are further disconnected from their aging kūpuna.

“Aging in place is multi-generational relations.” – Ke’ala Kwan

AGING

As Hawaiian kūpuna with dementia prefer to age in place among family members, their health will directly impact multi-generations within the home. Hā Kūpuna research tells us that 12% of Native Hawaiian grandparents live with grandchildren (prior to western contact it was closer to 100%), compared to 7% of grandparents in all races combined in the state, and to 3.6% of grandparents in the U.S. Although strong family-centric cultural values guide Native Hawaiian grandparents with caregiving, their declining and fragile health makes it challenging to provide care (Hā Kūpuna, Research). Meanwhile, how do we use a Hawaiian lens to recognize differences of normal aging from symptoms of dementia?

In an email with Hā Kūpuna, they shared the following about their research to find Hawaiian words and stories about aging kūpuna and dementia:

“Hua ‘ōlelo Hawai‘i (Hawaiian terms) for dementia have been elusive. We found some words that would describe symptoms (for example: forgetfulness, dizziness, confusion) (see figure 2) but we cannot assume attribution (or even the existence) of dementia. We have not yet found words for senility or dementia. Although, we have found multiple accounts of very old people (like 110 and older), but they haven’t made mention of dementia symptoms in them.”

After further exploration, there is no information about dementia, forgetfulness, or memory loss in Nānā I Ke Kumu Vols 1 & 2, only examples of memory use (mentioned in section “Memory” above). Additionally, there is no account of brain disease in Hawaiian literature, only examples of treatment for “sickness” by kāhuna (master healers). According to Puku’i, the focus for healing was not only on the physical symptoms. Impacts on health were also determined by assessing the psyche [soul, mind, spirit].

Puku’i further explains that prayers and rituals would accompany medical treatment. The interaction of the psyche and some mind-emotions and body was recognized, though the recognition came in a spiritual-supernatural context (Nānā I Ke Kumu Vol. 2, pg 154 & 155). Still, when information cannot be found in literature, one can turn to kūpuna who still remember the stories and values they were taught.

During a 2022 all-state Traditional Healer’s Kūpuna Council gathering on Kaua’i, educator and ho’oponopono practitioner Ke’ala Kwan referred to Dementia as “ma’i poina”, the forgetting sickness (ma’i and poina are defined in the Glossary, figure 2). He also shared his mana’o about aging and the importance of pule:

“There’s power in pule. Why pule? Our kūpuna did it. It provides tools for living. And, what’s good about pilikia (trouble)... it reminds you you’re still alive. The basis for healing is pule and spirituality. It’s the power of giving hope to people. We then get into the ways of dying with dignity. Not just for the one who dies, but for the family. It’s a life event that stays with us. How was it? Positive or a negative haunting? My puna [affectionate term he used for his great-grandmother] is a strong figure who made me who I am. I get emotional when I think of her.... Pule when you scared, when there’s pilikia, but pule all the time. The idea of life and death was a constant” (“personal communication”, 2022, Oct. 14).

GLOSSARY

Hawaiian family systems thrive in aloha and lōkahi (love and harmony). The terms in figure 2 is not a complete list, but it gives insight for possible terms to describe dementia and to recognize and understand conditions relevant to aging Hawaiians, memory loss, and cognitive function. Hawaiians believed that the spoken word had power over life and death, and therefore negative/negated terms were used with utmost caution, if at all. According to kūpuna, Hawaiian words have several meanings to include things that are literal, metaphoric, and aesoteric. The summaries below are mostly limited to literal meanings and are sourced from Puke Wehewehe, The Hawaiian Dictionary (Pukui & Elbert, 1986).

Figure 2

| Term (English) | Term (Hawaiian) | Meaning (literal) |
|----------------|-------------------------|--|
| Age | kahiko | Old, ancient, antique, primitive, long ago, beforehand; to age; old person. |
| | ho'okahiko | To think, act, speak in the old way; to speak of old times; to cling to old ways; old-fashioned; maturity. |
| | kūnewa | To pass, of time; to age. |
| | mae | To fade, wilt, wither, droop; to fade away; to waste away, as with illness. |
| | ho'omae | To cause to wilt, fade; to fade. |
| Brain | lolo | Brain |
| | lolo po'o | Head brain. |
| | lolo 'eleu | Active mind or intelligence. |
| Blood | koko | Blood |
| | koko pi'i, koko lana he | High blood pressure. |
| | koko pi'i ko'u | My blood pressure is high. |
| Confusion | hili hewa ka no'ono'o | Mental confusion |
| | no'ono'o | Thought, reflection, thinking; to concentrate, to consider; intellectual process. |
| | no'ono'o mākua | To be thoughtful and considerate of parents and elders. |
| | no'ono'o hāiki | Narrow-minded; a narrow mind. |
| | no'ono'o laulā | Broad-minded. |
| | ho'ono'ono'o | To cause to think, reflect; reminiscent, recalling to mind, remembering. |

GLOSSARY (continued)

| | | |
|--------------|---|--|
| | hali'a | Sudden remembrance, memory, especially of a loved one; fond recollection; premonition; to recall, recollect fondly. |
| | ho'ohali'a | To evoke reminiscence or recollection; remembrance; to remind. |
| | hihia | Entangled, interwoven, involved, perplexed, obscure and difficult to understand; difficulty, problem, trouble. |
| | ho'ohihia | To get into difficulties, entangle, perplex, beset with trouble, complicate. |
| | Ka hihia pa'a o ka nahele. Ka ho'ohihia 'ana o kēia kanaka iā kākou. | The dense thicket of the forest. This man is a snare to us. |
| Cry | Uē, uwē | To cry, weep, lament, mourn; a cry, lamentation, weeping. |
| Crazy | lōlō | Feeble minded, crazy. |
| | pupule ho'opupule | Crazy, insane, reckless, wild. To make insane; to drive crazy; to act crazy. |
| Dizzy | niniu | Worried, sad; dizzy; dizziness, vertigo, unclear or blurred vision; blurred, indistinct. |
| Depressed | lu'ulu'u | Bent or bowed down, as with weight, sorrow, or trouble; painful, sorrowful, sad, wretched, woeful, bereaved, downcast, depressed, toilsome, overladen. |
| | loha | Drooping, wilting; hanging low, as a branch; beaten down, as by rain. <i>Fig.</i> , sullen, spiritless, depressed, unsociable. |
| Forget(ful) | poina Mai poina 'oe ia 'u. poina wale poina ka no'ono'o ho'opoina | To forget; forgotten. Don't forget me. Forgetful, absent-minded. Forgetful; amnesia, dim memory. To cause to forget. |
| Frail/feeble | kūmīmī | Lacking physical strength, especially as a result of age or illness. |
| Frustration | hoka | Disappointed, thwarted, baffled; disappointment, frustration |

GLOSSARY (continued)

| | | |
|--------------|--|---|
| Inflammation | hō'ā | To set on fire, burn, ignite. |
| | ula | A flame; to flame, blaze. |
| | wela | Hot, burned; heat, temperature. |
| Learn | 'imi na'auao waihona o ka na'auao ho'opa'a | To seek knowledge or education; ambitious to learn. Repository of learning [a learned person]. To learn, memorize, master, study, complete, fix. |
| Loss | emi Emi ke kino Emi mau nō ke olakono. | To diminish, reduce; to lose vigor, droop, lower; thin; loss. To lose weight. The health keeps failing. |
| | nalo / nalohia / nalowale 'A'ole au e nalo iā'oe. ho'onalo | Lost, vanished, concealed, hidden, forgotten, missing; to lose, pass away, disappear. You will not fail to recognize me. To cause to be lost; to conceal, secrete, put out of sight. |
| Memory | Ho'omana'o 'ana, waihona ho'omana'o | Memory |
| | hali'a hali'a aloha ho'ohali'a | Sudden remembrance, memory, especially of a loved one; fond recollection; premonition; to recall, recollect fondly. Cherished or loving memory; to remember fondly. To evoke reminiscence or recollection; remembrance; to remind. |
| | pōwehi / pōwehiwehi | Dim, obscure, indistinct, vague, faint, unclear. |
| | mana'o pōehiehi, mana'o pōwehiwehi, mana'o kāwelewele | Dim memory |
| Old | 'elemakule luahine | Old man; to become an old man; old (of males). Old woman, old lady; to be an old woman. |

GLOSSARY (continued)

| | | |
|------------------|---|--|
| Remember | hā'upu | To recollect, recall, remember. |
| Sadness | kaumaha | Heavy; weight, heaviness; sad, wretched, dismal, dreary, downcast, troubled, depressed; grief. |
| Sickness | ma'i ma'i make 'ōma'ima'i pāmake | Sickness, illness, disease, ailment, patient, sick person; sick, ill. Fatal or terminal disease or sickness. Chronic disease. Fatal, of disease; to be near death. <i>Lit.</i> , touch of death. |
| Thought/think | mana'o ho'omana'o | Thought, idea, belief, opinion, intention, meaning, suggestion, mind, desire, want; to think. To remember, recall, commemorate, reflect deeply on, in memory. |
| Unconscious | pau ka 'ike / pau ka lohe / pau ka ho'omaopopo 'ana. | To lose consciousness. |
| Unaware | 'ike 'ole | Without knowledge, awareness, understanding, recognition, comprehension. |
| | hihia | Obscure and difficult to understand; difficulty, problem, trouble. |
| Understand/aware | 'ike 'Ike aku, 'ike mai. kū'ike maopopo Maopopo ka 'ikena Maopopo 'ole Maopopo loa Maopopo maika'i, maopopo le'a. ho'omaopopo Ho'omaopopo 'ē Ho'omaopopo 'ole 'ia | To see, know, feel, greet, recognize, perceive, experience, be aware, understand. To recognize one another. To know by sight, to understand or know in advance or beforehand. To understand, recognize, realize; clear; plainly, clearly; understanding. Clearly seen or known. Unintelligible, unaware, unaccountable. To understand clearly, definite, certain. Obvious, evident, clearly understood. To understand, make plain or clear, tell clearly, cause to understand, pay attention in order to understand; to certify, inform, remember, recollect, recall, think about, remind, believe in, realize, ascertain, take care of, recognize, discover. To understand ahead, anticipate; inkling. Misunderstood, unintelligible, uncared for, unclear. |

INFORMATION GATHERING

In 2022, POL used grant funds from the EOA to contract Maka Casson-Fisher to facilitate community meetings, collect information, and prepare island-specific reports. An Advisory Board for the grant consisting of health practitioners, kūpuna caregivers, and kūpuna advocates, was assembled and convened in early May of 2022. Maka and POL Health Specialist Kia'i Lee presented the Road Map to POL's Traditional Healers Kūpuna Council and to the project's advisory council. Both groups cautioned that this topic is very deep and has many layers.

The advisory council suggested using a few questions and themes for stories to naturally surface while meeting with statewide community members. These are the recommendations from both groups that guided foundational steps for the development of this Road Map :

1. Build a relationship of trust with the community of Hawaiian-serving organization leaders, kūpuna, and their families.
 - Focus on a process to collect information versus questions to collect information.
 - Use the process to build trust.
 - Identify stakeholders, and discuss how you can support each other.
2. Use themes to guide conversations with community members and families:
 - Provide foundational education about Alzheimer's and other Dementia using both western and Hawaiian understandings.
 - Collect information about western and Hawaiian approaches for prevention education to improve early detection and to delay the onset of ADRD.
 - Uplift current programs and services - find out who's doing the work and has a relationship with kūpuna and families across the State of Hawai'i.
 - Uplift families – be mindful and sensitive toward family members who provide care for kūpuna that age in place. Though it can be stressful and taxing, celebrate the ways that families rise to the occasion to surround, support, and show aloha for one another and their loved ones with ADRD.



Photos of POL's information gathering session on the island of Molokai.
Photo Credit: Maka Casson-Fisher

PRELIMINARY FINDINGS

*“In a society without a written language,
history was a matter of human memory and human voice.”
(Nānā I Ke Kumu, Vol. 1, pg 96)*

STATEWIDE MEETINGS

During the months of May and June in 2022, meetings were held via Zoom with Hawai'i island, Maui, O'ahu, and Kaua'i. To overcome a technology barrier, POL was invited to have an in-person meeting on Molokai, which occurred in July with over 50 people at the Molokai Community Health Center. The purpose of these meetings were:

- Build relationships with Native Hawaiian communities with guidance from the Advisory Council & Traditional Healer's Kūpuna Council.
- Discuss POL's involvement in developing a Native Hawaiian Road Map.
- Gauge what people know about ADRD and gain an understanding of how Native Hawaiians and their families are impacted.
- Develop public health strategies from a Hawaiian perspective.
- Provide recommendations to Hawai'i's EOA.

During our information gathering meetings, communities asked us to return to continue our conversations about ADRD. When we do re-engage with communities, POL will 1) identify Hawaiian-serving programs that focus on ADRD, and 2) develop specific action steps to address health inequities, shape public policies, and strengthen programs to improve the health and wellbeing of Native Hawaiians. These are the top recommendations expressed in the statewide community meetings, with additional recommendations in the island-specific reports:

1. Increase early detection and diagnosis; it is associated with a lower burden of disease and better care.
2. After diagnosis, prepare and equip families to help kūpuna live their best quality of life so that they can die with dignity.
3. Promote holistic lifestyle changes, such as healthy diet, minimize stress, consistent physical activity, and maintaining healthy relationships.
4. Develop a resource guide for Native Hawaiian families impacted by ADRD. Aside from the common legal processes surrounding death, it will be uniquely inclusive of physical, mental/emotional, and spiritual aspects of Hawaiian culture and a perspective about death that is circular, not linear.
5. Improve caregiver support to family members across generations with a focus on environment safety, finances/compensation, self-care, and education about caregiving.
6. Strengthen collaborations among stakeholders.
7. Implement culturally sensitive and relevant research methods.
8. Increase Hawaiian-specific disaggregated data.

Maka Casson-Fisher compiled the information from each meeting and developed island-specific reports with similar formats to highlight understandings of ADRD, personal experiences, community concerns, community strengths, communities in practice, and needs. The reports are included as attachments to this Road Map, all of which are available on Papa Ola Lōkahi's website.

STATEWIDE NHPI COMMUNITY HEALTH WORKER GATHERING

In May 2022, POL convened a Native Hawaiian and Pacific Islander Statewide Community Health Worker (NHPI CHW) Gathering in Hilo and conducted a focus group activity. With five groups of four (20 CHW participants total), each group discussed and agreed on a top concern for Native Hawaiians impacted by ADRD and recommendations/needs to address the concern(s). Below is what each group presented:

Group 1: Caregiving

Needs:

- Educate the family – gather family members to address the need of the kupuna/client
- Discuss availability of healthcare for dementia patients
- Discuss care options: age in place vs. care facility/program
- Discuss finances: resources, affordability, needs for financial help
- Tailor plans to family capability

Group 2: Caregiver Burnout

Needs:

- Policy Change – Bill SB3000
- Respite/Self Care
- Family Education
- Community Support
- Resources
- Goal: Stop Caregiver Burnout

Group 3: Planning

Needs:

- Safety
- 'Ohana Support
- Nutrition Planning
- Community Network – education
- Communication
- Resource allocation

Group 4: CHW Phone Call (intake)

- Identify kūpuna w/ potential ADRD (intake/assessment tool)
- Develop a "Kōkua Kūpuna Plan":

What Alz/Dem (ADRD) is ('ohana education & counseling)

What do we have?

- 'Ohana strengths & values (strengths-based approach)
- Roles & commitments

What do we need?

- Training
- Resources
- Community Support

Group 5: Safety

Needs:

- Safety around the home
- Access to resources
- Education for 'ohana caregivers & CHWs
- Community awareness about strangers and wandering of client/kūpuna



NHPI Community Health Worker Gathering on Hawai'i Island.
Photo Credit: Papa Ola Lōkahi

KŪPUNA HEALTH FAIR SURVEY

In June 2022, POL conducted 39 Interviews during a kūpuna health fair at KEY Project on the island of O‘ahu. 15 self-identified as Hawaiian; 24 non-Hawaiian.

- None disclosed having an ADRD Diagnosis.
- Four said that they have a family member with ADRD but did not live with them; all helped to provide care.

Below are the questions asked and responses from the Hawaiian participants. In bold are the most common answers:

How does local culture or being Hawaiian influence your caregiving?

“Diet”

“I’m not a licensed caregiver but I try to **mālama** papa because he is my kupuna.”

“I grew up with a giving ‘ohana.”

“**Kuleana** to care for those who cared for me.”

What is the most difficult challenge about being a caregiver for someone with ADRD?

Patience; trying to **understand** [the disease]; managing their behavior and how to support them; financial support; stress; watching them **forget**/becoming someone unrecognizable; episodes of frantic panic; keeping them safe; nutrition.

As a caregiver, what kinds of support do you need?

Updated methods of communication; **time for myself**; equitable pay; support services (educational and hands-on); love and aloha; knowledge about caregiving.



A traditional healing lā‘au lapa‘au presentation at KEY Project on O‘ahu island.

Photo Credit: Kia'i Lee

COMMUNITIES IN ACTION

There are hundreds of organizations that offer education, assistance, care, or support for kūpuna and their families in Hawai'i. Additionally, there are State and County Kūpuna resource guides with these organizations listed in them. However, there are only a few that focus specifically on serving Native Hawaiians, and there are fewer who are adequately equipped to help Hawaiians impacted by ADRD. It is POL's aim to use this Road Map project to begin conversations, build relationships with stakeholders, and plan activities to narrow that gap. It will be a long-term endeavor to delineate recommendations in this Road Map and tailor them for various groups, such as individuals, caring family members, concerned community members, educators and researchers, medical providers, social service providers, and government agencies. For now, this document is primarily for, but not limited to, informing public health policies, developing long-term partnerships among stakeholders, and affecting systemic change for meaningful impacts to benefit Hawaiian families.

The following are programs and services that were shared and discussed with POL throughout this 2022 Road Map project. With additional time and funding, POL would like to re-engage communities to develop a thorough comprehensive list of the communities in action as this current list will have gaps.

State & County Affiliated Agencies and Institutions

- Hawai'i's Executive Office on Aging - Hawaii Kūpuna Caregiver's Program/Kūpuna Caregiver's Law; State Plan on Aging/BOLD Advisory Board and working groups/committees; Hawaii State Health Insurance Program (SHIP)
- Hawai'i's Department of Human Services, Adult Protection Services
- University of Hawai'i, Maui College Community Health Worker (CHW) Program
- University of Hawai'i, Maui College Certified Nursing Assistant (CNA) Program
- University of Hawai'i, Kapi'olani Community College CHW Program
- John A. Burns School of Medicine, Native Hawaiian Health Center of Excellence
- Project Lifesaver, Hawai'i Island Fire Department, Hilo
- Kaua'i Agency on Elder Affairs (KAEA)

Medical/Health Service Providers

- Statewide Native Hawaiian Health Care Systems:
 - Ho'ōla Lāhui, Kaua'i
 - Hui No Ke Ola Pono, Maui
 - Nā Pu'uwai, Molokai
 - Ke Ola Mamo, O'ahu
 - Hui Mālama Ola Nā 'Ōiwi, Hawai'i Island
- Wai'anae Comprehensive Health Center
- Waimānalo Community Health Center
- HMSA
- Hawai'i Pacific University School of Nursing
- 'Ahahui o Nā Kauka Association of Native Hawaiian Physicians



Kula Nō Nā Po'e Hawai'i, located at Papakōlea Homestead
Photo Credit: Kula No Nā Po'e Hawai'i

COMMUNITIES IN ACTION (CONTINUED)

Community Organizations

- Kula No Nā Po'e Hawai'i - SAVVY Caregiver Training Program; Papakōlea Kūpuna Care Center Network (KCCN)
- ALU LIKE, Inc.
- Lunalilo Home
- Alzheimer's Association, Aloha Chapter (AAA)
- Ma Ka Hana Ka 'Ike
- Our Kūpuna

Researchers

- University of Hawai'i, Hā Kūpuna: National Resource Center for Native Hawaiian Elders
- Brigham Young University, Hawai'i
- University of Hawai'i's Center on Aging
- University of Hawai'i, School of Social Work and Public Health
- Kamehameha Schools
- Office of Hawaiian Affairs



These photos show various Hawaiian cultural practices. They are a reminder that the Native Hawaiian nation is a "community in action" because such practices have been perpetuated for generations, and it encourages healthy diet, cognitive stimulation, physical activity and spiritual wellness. Photo Credit: Papa Ola Lōkahi

COMMUNITY-INFORMED RECOMMENDATIONS

The following recommendations are primarily for, but not limited to, the EOA State Plan on Aging. It is inclusive of themes from Statewide meetings, meetings with individual stakeholders, POL's CHW network, and POL's Traditional Healer's Kūpuna Council. It also absorbs all the recommendations mentioned earlier in this document before the community engagement process began.

Recommendation #1. Data

- 1.a. Have a Native Hawaiian organization, such as POL, on the Hawai'i research consortium to expand research and programs to benefit Hawaiian families.
- 1.b. Align assessment and data gathering tools used among Native Hawaiian health organizations, state agencies and Universities (EOA and UH COA).
- 1.c. CHWs to assist with developing, implementing and collecting surveys in isolated rural Hawaiian communities.
- 1.d. Use disaggregated data to better understand Native Hawaiian health disparities and to ensure their health equity on a systemic level.
- 1.e. Improve collaborations and utilize a process to share data among stakeholders
- 1.f. Support participatory and decolonizing approaches to research.
- 1.g. Grow more indigenous researchers who understand and respect Hawaiian culture.

Recommendation #2. Programs & Services

- 2.a. Define ADRD “testing” and “treatment” – locate ADRD specialists, educate families how to access them, and understand assessment tools that they use.
- 2.b. Strengthen collaborations among stakeholder to increase early detection and regular screening for dementia; continue to work with service agencies and community members to identify and outreach to potential Hawaiian-serving partners.
- 2.c. Ensure informed and coordinated care and services for persons with dementia.
 - i. Collaborate with Native Hawaiian doctors and the “Kauka Hui” to develop a list of ADRD specialists in Hawai'i.
 - ii. Promote and implement navigational support utilizing an interdisciplinary, team-based approach to enable a smooth transition from hospital to home and follow-up care.
- 2.d. Add culturally-tailored brain health messaging to existing health promotion programs.
- 2.e. Promote and increase access to the Traditional Hawaiian Diet and other culturally relevant diet and nutrition resources.
- 2.f. Provide adequate and timely support for caregivers of persons with dementia.
 - i. Identify opportunities to scale and sustain Recognise, Engage, Act, Call, Help is on its way (REACH) and Savvy Caregiver programs for Native Hawaiians.
 - ii. Provide comprehensive and culturally-tailored information and tools to help Hawaiians with dementia and their caregivers anticipate, avert, and respond to challenges that typically arise during the course of dementia, including wandering kūpuna.
 - iii. Promote and utilize support groups in to receive advice, relive stress, and share information and resources.
 - iv. Utilize volunteers to provide respite care and social support.

RECOMMENDATIONS (CONTINUED)

- 2.g. Better understand intergenerational caregiving relationships in local communities, and recognize potential caregiving barriers for youth caregivers and grandparents raising grandchildren.
- 2.h. Maintain the dignity and rights of people with dementia and their caregivers.
 - i. Partner with the Native Hawaiian Bar Association and their elder law attorneys to offer presentations that cover dementia and legal issues including advance care planning, power of attorney, and trusts.
 - ii. Work with fiscal agents (OHA, CNHA, Hawaii Community Foundation) to develop comprehensive financial planning for kūpuna and their families.
 - iii. Collaborate with Hawai'i's Adult Protection Services and utilize their recommendations to maintain a safe environment for kūpuna and caregivers.
 - iv. Enable Hawai'i's family caregivers and families to continue to provide care while maintaining their own health and well-being.
- 2.i. Ensure safety in medication management for kūpuna.
- 2.j. Partner with Hawaiian-serving organizations and programs to develop and promote culturally competent and tailored brain health practices.
 - i. Integrate and implement indigenous and/or culturally relevant understandings of health and wellbeing into memory-care programs and services.
 - ii. Utilize relationships with stakeholders and community partners to create and disseminate culturally-tailored approaches and implementation strategies.
- 2.k. Identify sources of financial assistance that can help pay for services and supports that assist caregivers and persons living with dementia.
- 2.l. Improve digital literacy for home-bound kūpuna to access care and keep in touch with families.
- 2.m. Develop long-term care and respite care homes on Department of Hawaiian Homeland properties.
- 2.n. Increase housing and community-based services for aging Hawaiian elders.

Recommendation #3. Policy

- 3.a. Increase collaborations to monitor policies and legislation at the national, state, and local levels in healthcare and social policies related to dementia and workforce development.
- 3.b. Identify and understand current sources of financing for long-term care; explore innovative solutions to relieve the cost burden for dementia care.
- 3.c. Advocate for a life-course practice model that fights discrimination and promotes equity in income, education, and opportunity, recognizing that healthy children have more opportunities to grow into healthy, long-living adults.
- 3.d. Advocate for legislative support for making Long Term Service Support (LTSS) affordable and high quality, especially in underserved areas.
- 3.e. Monitor policies to protect Social Security, Medicare, Medicaid, and DHHS programs that fund programs for Native Hawaiian elders.

RECOMMENDATIONS (CONTINUED)

Recommendation #4. Public Awareness & Education

- 4.a. Strengthen communication pathways to isolated rural Native Hawaiian communities to raise public awareness about ADRD.
- 4.b. Utilize technology such as social media platforms and webinar capabilities to develop dementia-informed and dementia-friendly communities.
- 4.c. Develop culturally-tailored resources about ADRD for Native Hawaiians.
- 4.d. Develop literature about cognition, mental health, and spiritual beliefs and practices that focus on families and communities, not only on the individual.
- 4.e. Increase access to resources that are culturally relevant, based on traditional practices, and offered in Hawai'i's official state language, 'Ōlelo Hawai'i.
- 4.f. Educate Hawaiian families about ADRD to increase early detection and diagnosis.
 - i. Iterate that there is no cure for ADRD; prepare and equip families so they can live their best quality of life and allow their kupuna to die with dignity.
- 4.g. Increase access to training and education through community events, resource fairs, medical presentations, etc.
- 4.h. Provide community-tailored education and services for the whole family about ADRD. Incorporate kūpuna health & care such as financial literacy, safety, transportation and holistic lifestyle changes – healthy diet, minimize stress, consistent physical activity, and maintaining healthy relationships.
- 4.i. Utilize community events and spaces to educate the public on brain health and promote advanced detection of cognitive impairment.

Recommendation #5. Workforce Development

- 5.a. Increase the kūpuna healthcare workforce – train and deploy CHWs, social workers, nurses and aides, especially to increase services to isolated and underserved rural communities such as West Kaua'i (Kekaha) and Hāna, Maui.
- 5.b. Increase trained caregivers by including youth; create a high school training pathway to encourage students to pursue CNA or CHW certificates.
- 5.c. Publicize financial aid incentives such as Native Hawaiian Health Scholarships to grow the number of Hawaiian health professionals.
- 5.d. Employ and retain gerontologists and other specialty doctors in Hawai'i.
- 5.e. Offer competitive salaries to reduce high turnover rates of health providers.
- 5.f. Discuss an ethical decision-making framework that incorporates Hawaiian values, compassionate care, and cultural awareness for those who work with individuals with dementia and their families.
- 5.g. CHW Training:
 - i. How to assess a patient for dementia and what to do to refer them to appropriate care for diagnosis.
 - ii. Train and utilize CHWs for culturally-sensitive phone screenings to identify if a patient has dementia.
 - iii. Improve CHW training in Dementia.
- 5.h. Collaborate with the Hawai'i State Health Insurance Program to educate and deploy navigators through their Kūpuna Navigator Program.

NEXT STEPS

Phase-2 & Beyond (tentative CDC Implementation Grant activities):

- Seek long-term funding to pursue the community-informed recommendations of this Road Map.
- Expand POL's Road Map Advisory Council to include statewide representation and of various professions.
- Convene in-person statewide meetings with Hawaiian communities and stakeholders to plan impactful action items for prioritized Road Map recommendations.
- Develop a comprehensive list of Communities in Action and ADRD specialists in Hawai'i (Recommendation 2c.)
- Gather and analyze information and disaggregated data about Native Hawaiians to inform activities that align with Road Map recommendations.
- Meet and collaborate with Hawai'i's EOA, the University of Hawai'i Center on Aging, and Hawaiian-serving stakeholders, cultural groups, and organizations for the following:
 - Develop culturally-tailored activities for Hawaiians impacted by ADRD.
 - Collect and analyze disaggregated data for Native Hawaiians.
 - Utilize and share resources for policy-shaping, tracking, and advocacy for kūpuna with ADRD.
- Develop an end-of-life toolkit/resource manual for Hawaiians impacted by ADRD.

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- POL's Statewide Traditional Healer's Kūpuna Council Chairs
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ATTACHMENTS (AVAILABLE UPON REQUEST)

Attachment-1: O'ahu Island Report & Findings

Attachment-2: Kaua'i Island Report & Findings

Attachment-3: Maui Island Report & Findings

Attachment-4: Hawai'i Island Report & Findings

Attachment-5: Molokai Island Report & Findings

