



Aging & Disability Issues 2021

A Guide for Hawai'i's Legislators, Organizations & Citizens



Double rainbow over taro fields at Hanalei overlook, Kaua'i, Hawai'i

Lives Well Lived.
In Memory of...



Rose Sadako Nakamura
July 11, 1928 – July 10, 2020



Francine O. Wai
September 6, 1951 – December 2, 2020

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About the Hawai'i Family Caregiver Coalition, the Maui County Office On Aging, the Hawai'i Pacific Gerontological Society, and St. Francis Healthcare System of Hawaii.



As caregiving touches everyone, the mission of the Hawai'i Family Caregiver Coalition (HFCC) is to improve the quality-of-life of those who give and receive care by increasing community awareness of caregiver issues through continuing advocacy, education, and training.

Over the years, the Hawai'i Family Caregiver Coalition has supported our community by sponsoring the annual Aging & Disability Issues report, Family Caregiver Awareness Day at the State Capitol, and the annual HFCC Members and Friends Luncheon.

For more information, please email Gary Simon, President, at gsimon@aarpp.org or visit hfccoalition.org.



The Maui County Office on Aging (MCOA) takes the lead role in aging issues on behalf of older persons in Maui County.

As the designated lead agency at the local level, MCOA promotes and protects the well-being of elderly individuals in Maui County.

For more information about MCOA or to request assistance, please call 808-270-7774. MCOA's mailing address is: Maui County Office on Aging, J. Walter Cameron Center, 95 Mahalani Street, Room 20, Wailuku, Hawai'i 96793.



hawaii pacific gerontological society

Organized in 1979, the Hawai'i Pacific Gerontological Society (HPGS) is a not-for-profit organization whose mission is "to increase awareness of and interest in the field of gerontology by providing networking and educational opportunities, as well as scholarships to Hawai'i's workforce or other interested parties in which to support the creation of needed policies and programs that will enhance the quality and age-friendly services to our Kūpuna in Hawai'i."

If you are interested in pursuing this mission, you are invited to join HPGS by visiting online at www.hpgs.org. You may also mail inquiries to P.O. Box 3714; Honolulu, Hawai'i 96812, or call Sherry Goya, HPGS Executive Director, at (808) 722-8487.



St. Francis Healthcare System offers a growing spectrum of home- and community-based services to meet the medical and social needs of seniors and family members. Our team is dedicated to caring for Hawai'i's seniors and families with the following services:

- Adult Day Care (Diamond Head, Mānoa, and 'Ewa)
- Care Coordination (case management)
- Caregiver Education and Wellness Classes
- "Comforting Hands" for Private Duty Care
- Bathing and Personal Care Services
- St. Francis Hospice
- St. Francis Preschool
- Hale O Meleana (Senior community with memory care at the St. Francis Kūpuna Village)
- Transportation Services
- Outreach to the Homeless in Waianae

We consider it a privilege to carry on the legacy of caring and compassion that began with Saint Marianne Cope and the Sisters of St. Francis, who came to Hawai'i to care for those with Hansen's disease in 1883.

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Introduction & Overview

By Gary Simon, President, Hawai'i Family Caregiver Coalition, & Vice Chair, Policy Advisory Board for Elder Affairs

This 2021 issue of the Aging & Disability Issues report is the 16th annual publication that offers an overview of legislative issues dealing with aging, disability, caregiving, and

long-term care services and supports in Hawai'i. This report calls attention to the priority issues that deserve the earnest attention of our lawmakers, advocates, and the public. It is a joint project of the Hawai'i Family Caregiver Coalition (HFCC), the Policy Advisory Board for Elder Affairs (PABEA), the Executive Office on Aging (EOA), the Hawai'i Pacific Gerontological Society (HPGS), the Maui County Office on Aging (MCOA), and St. Francis Healthcare System of Hawaii. Their support is gratefully acknowledged.

This report has eight sections:

Section 1 offers an overview of the report, as well as some general observations of the political and economic changes in Hawai'i in 2021.

Sections 2 through 6 describe the priority issues for the legislature in the 2021 session as designated by the major groups that advocate for the frail elder and disabled populations and their caregivers. These sections explain why these are important issues and offer background information concerning these issues. The six sections also discuss the specific bills that address these priority areas and their status at the time of writing this report.

Section 7, the Conclusion, provides a brief summary and a look ahead.

Section 8 contains a listing of information, education, and research resources relevant to aging and disability issues that may be helpful to those seeking additional information and education on these topics.

Additionally, personal stories from caregivers regarding the issues they face and the significance of public policies in enabling them to care for their loved ones can be found throughout the report. These stories demonstrate the emotional strains and rewards experienced by our beleaguered caregivers and describe the difficulties any of us could experience when faced with aging or disability. These stories provide a human face to legislative issues by illustrating how they are embodied in the very human experiences of individuals and families.

The Political Context of 2021

The confounding past 12 months of the COVID-19 pandemic provided us with a year of extreme contradictions. Time passed both quickly and slowly. Many were forced from the office to work at home and attend numerous virtual meetings from morning to evening, including on weekends. We were shut in our homes and had quality time with our loved ones, but other loved ones in care facilities were isolated from us. We were encouraged to maintain our social connections, but we

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were instructed to do so either from six feet away or by phone. Some of us walked into restaurants wearing our masks and removed them as soon as our entrees arrived, conversing with each other without our masks as we ate our meal. We had more time for physical activity, but, for long periods, we were barred from our parks, beaches, gyms, and recreation areas. Some shoppers in our stores and warehouse outlets were seen hoarding and stockpiling groceries and household items. However, throughout the pandemic, the citizens of Hawai'i have been magnificently generous to those experiencing hardship. COVID-19 vaccines were developed and approved in record time, but demand far outstripped supply.

Although the arrival of effective vaccines provide us with guarded optimism, the continuing severe negative economic effects of the global pandemic are grave. As of this writing, the state of Hawai'i is facing a \$1.4 billion per year shortfall. Billion dollar budget shortfalls also are anticipated for the following two years. Elected leaders have remarked that all options, including reductions in program funding, are on the table to balance the budget.

With threats to the funding of programs benefiting kūpuna and persons with disabilities, we are united in protecting their health and welfare. Many of them are living on the edge and will fall off the edge if funding reductions result in cuts to services and supports to kūpuna, persons with disabilities, and their caregivers. Twenty twenty-one is the year for us to maintain and fortify the foundation built over the last 30 years.

According to *Caregiving in the U.S. 2020*, a report by the National Alliance for Caregiving and AARP, an estimated 53 million family caregivers provide care to a loved one in the United States.¹ AARP's 2019 *Valuing the Invaluable* report notes that caregivers provided approximately 34 billion hours of care valued at \$470 billion — more than total out-of-pocket spending on healthcare in the U.S. that year (\$366 billion) or all money spent on paid caregiving in 2016 (also \$366 billion). The report also notes that family caregivers spent an average of nearly



\$7,000 on caregiving expenses, such as transportation and home modifications, in 2016. Research has shown that family caregivers report higher rates of loneliness than their non-caregiving peers in midlife and beyond.²

Family caregiver support is now firmly established as a national priority with the formation of the RAISE Family Caregiving Advisory Council, which acknowl-

edges that everyone's quality-of-life is positively impacted by providing support to our often emotionally, financially, and physically taxed family caregivers. Established by the bipartisan RAISE Family Caregivers Act for which the Hawai'i Family Caregiver Coalition advocated, the Council has adopted twenty-six recommendations aimed at establishing a national approach to addressing the

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needs of family caregivers of all ages and circumstance. The recommendations will be included in the Council's initial Report to Congress this year and serve as the foundation for the National Family Caregiving Strategy that will begin this year. The Strategy will outline critical actions that can be taken at federal and state levels by local communities, as well as by health, long-term services providers, and others to better support family caregivers in ways that reflect their diverse needs. The Strategy will focus on areas such as person and family-centered care; assessment and service planning; information, education, and training supports; respite options; and financial and workplace security issues. The Strategy will provide a road map for the nation to strengthen its support and recognition of the critical role family caregivers play in our healthcare and long-term support systems.³

The Hawai'i Family Caregiver Coalition was pleased to work with the U.S. Department of Health and Human Services to advocate for the appointment of Deborah Stone-Walls, Executive on Aging for the Maui County Office on Aging, to the Family Caregiving Advisory Council.

Also on the federal front, Congress reauthorized the Older Americans Act (OAA) in 2020.⁴ This vital federal program serves every community in the

country. The OAA connects older adults and their caregivers to services that help older adults age with health, dignity, and independence in their homes and communities. The OAA funds critical services that keep older adults healthy and independent—services like meals, job training, senior centers, caregiver support, transportation, health promotion, benefits enrollment, and more.

Here in Hawai'i, Governor David Ige and the state legislature have supported innovations such as Kupuna Caregivers, the first program of its kind in the nation designed to provide working family caregivers with financial assistance to help pay for costs associated with caring for their elders.

In its *Outlook for the Economy 4th Quarter 2020 Report*, the Hawai'i State Department of Business, Economic Development & Tourism projected that Hawai'i's economic growth rate, as measured by real gross domestic product (GDP), declined by 11.2 percent in 2020, and then will increase by 2.1 percent in 2021, 2.0 percent in 2022, and 1.2 percent in 2023.⁵ On January 7, 2021, the State of Hawai'i Council on Revenues forecasted State General Fund tax revenues for Fiscal Year 2021 (FY 2021) will decrease by 6.5% from FY 2020. The Council forecasted General Fund revenues for FY 2022 will increase by 6.0% from FY 2021.⁶

The governor and state legislators are exploring every possible avenue to enhance revenue, including transferring unspent balances in state special funds to the state general fund, eliminating or suspending tax exemptions, establishing new taxes and fees, increasing existing taxes and fees, and borrowing. They are also examining all possibilities to reduce expenditures, including cutting the budgets of state departments.

The economic turbulence caused by COVID-19 has energized the initiatives to diversify the state's economy. Priorities include investments in agriculture and information technology, including broad-band and Wi-Fi connectivity and telehealth.

However, investments in critical services for our rapidly aging population and those with disabilities are also priorities. The efforts of the legislature's Kupuna Caucus will be vital. Representative Gregg Takayama has handed the baton as co-convenor of Kupuna Caucus to Representative Troy Hashimoto. We are deeply grateful to Representative Takayama for his unwavering commitment to our kūpuna, persons with disabilities, and their caregivers. Representative Hashimoto joins Senator Sharon Moriwiki as co-convenor. Their leadership will be instrumental in our endeavors. Now, more than ever, aging and disability advocates must be steadfast in ensuring that elected officials at all levels of government are committed to our elders and those with disabilities.

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Keeping Kūpuna Healthy

Three Services Keep the Elderly Healthy & Active

By Sarah Yuan, PhD

Chair, Legislative Committee
Policy Advisory Board for Elder Affairs

In our rapidly aging society, a wide range of services has evolved to keep older people healthy and active, and support them to remain living in their own home and community, regardless of ability level. Many of these service programs were initiated by federal and state agencies, while others were developed at the local level through private and public entities. Much of the funding for these programs comes from federal and state governments, although in Hawai‘i, county governments also provide funding. This section will discuss three such programs:

- Kupuna Care
- Aging and Disability Resource Centers (ADRC)
- Healthy Aging Partnership (SB 2335/HB 1866)

Kupuna Care

Hawai‘i’s Kupuna Care program was established in 1999 to provide long-term services and supports (LTSS) to frail and vulnerable adults age 60 and over who lack access to

other comparable services. The program aims to enable older adults to remain in their homes and communities, delaying premature placement in expensive residential care facilities. Kupuna Care is administered by the state’s Executive Office on Aging through the Area Agency on Aging (AAA) in each county, with program services provided by non-profit and for-profit agencies. The program offers eight core services: Adult day care, assisted transportation, attendant care, case management, chores, home-delivered meals, homemaker, and personal care. With a budget of \$8.73 million, the state served more than 8,000 older adults through Kupuna Care in FY20.

Except for case management and home-delivered meals, the number of people receiving Kupuna Care services has generally decreased due to social distancing and other public health measures caused by the COVID-19 pandemic. Many program participants chose to self-quarantine and stop receiving services that they still needed. The service delivery system has also seen a significant reduction in its capacity to serve during the pandemic, with many service agencies struggling with financial survival and workforce availability.

Given the grim economic outlook, Governor Ige’s biennium budget for 2021-

2023 (**HB 200, SB 1229**) proposed a 21.5% reduction for the Kupuna Care program (i.e., decreased to \$6.85 million per year). The pandemic has put our frail and vulnerable kūpuna at increased risks for unmet LTSS needs, social isolation, and loneliness. As the EOA noted in its annual report to the legislature, the home- and community-based LTSS model needs to adapt and expand to meet frail elders’ needs during these uncertain times and beyond.

Aging and Disability Resource Centers (ADRCs)

Older adults, people with disabilities, and their families are often unprepared when the sudden onset of a severe health condition or sudden decline in function occurs. Once faced with the need for long-term services and supports (LTSS), families find it challenging to navigate the complexities of care systems. Aging and Disability Resource Centers (ADRCs) are designed to simplify the process of obtaining information and accessing services. ADRCs reduce the fragmentation of care systems, recognizing that the care needs of older adults and people with disabilities are often similar. Through a single coordinated system, the County’s ADRC ensures access to high-quality care and person-centered services, optimizes choice and independence, encourages personal responsibility, and provides support so individuals and their families can make informed decisions about LTSS.

Hawai‘i’s ADRCs are administered by the state’s Executive Office on Aging (EOA) and implemented by county Area Agencies on Aging (AAAs). It started in 2006 when the EOA received a federal grant to pilot the system and was subsequently supported by funding from several federal grants and Hawai‘i’s state legislature. Since 2016, the ADRC system has been fully implemented statewide, with customized operation by each AAA while adhering to a standard set of functional criteria across counties. The system offers a full range of information on long-term support programs and benefits; conducts the assessment on individuals’ need for

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services to maintain independent living in the community; and is a single entry point for Kupuna Care and Older Americans Act (OAA) services. In FY20, the state's funding for the ADRCs was \$3.1 million. The total number of contacts was nearly 49,000, and assessments were about 4,200. The pandemic's impact on ADRCs was mixed: compared to the pre-COVID period, the months from April to June had a 12% increase in contacts but an 8% decrease in assessments.

In the 2021 legislative session, Governor Ige's biennium budget package (**HB 200, SB 1229**) requested \$2.3 million in the general fund for ADRCs, representing a 25% reduction in program funding. The EOA's next steps for ADRCs include: retooling the ADRC website for improved outreach; leveraging federal resources for the program; streamlining assessments; and monitoring and evaluating ADRC processes to ensure standardized and responsive services are available across all county sites.

The Healthy Aging Partnership Program

By Eldon L. Wegner, PhD, and Michiyo Tomioka, DPH

The Healthy Aging Partnership Program was founded in 2003 to improve the health status of older adults by empowering residents to make healthy decisions and engage in healthier lifestyles. The Partnership has received support from multiple funding streams, including grants and state and county budgets. It is a public-private partnership, with largely public funding of private providers who offer the programs to the public. The University of Hawai'i Center on the Family successfully adapted evidence-based health promotion and disease prevention programs for Hawai'i's multicultural population and conducted continuous evaluation of program outcomes. Since the onset of the pandemic, the Partnership program has been operating remotely.

The Partnership offers two evidence-based programs: 1.) Better Choices, Better Health,

a six-week program on the self-management of chronic disease; and 2.) EnhanceFitness, a three-times a week ongoing exercise program designed for older adults.

Better Choices, Better Health has had a total of 3,073 participants. The workshops complement medical professional-recommended treatment plans. Participants learn skills to help manage their health conditions and interact with their healthcare providers. A six-month follow-up evaluation found participants had a decreased number of visits to physician offices and emergency rooms, and a cost-savings analysis estimated net savings of \$656.01 per participant. Participants also reported increases in strength and aerobic exercise and fewer symptoms of pain, fatigue, shortness of breath, and stress. The Partnership has offered the workshops through online, virtual, and phone methods as alternative solutions during the pandemic.

EnhanceFitness has served 1,784 persons; 65% were age 70 to 89. After 16 weeks, *(Continued on next page.)*

participants reported fewer falls and increased number of days of being physically active. Improvements occurred in measures of physical function, such as arm curls, chair stands, and up-and-go exercises. The National EnhanceFitness study estimated a net savings of \$945 per participant. Prevention programs are always cost-effective with regard to chronic disease. During the pandemic, the exercise program has been offered via TV airing (Maui County) and Zoom (Kaua'i County).

The Healthy Aging Partnership Program in Hawai'i has received several national awards, including the 2013 multicultural aging award from the American Society on Aging.

Inconsistent Support from the Legislature

Despite the achievements of the Healthy Aging Partnership Program, the legislature has been sporadic in its support of the program and has not provided resources to allow the program to expand. The award-winning program is one of the few state programs that implements evidence-based interventions, has conducted systematic evaluations of program outcomes, and offers documented evidence of cost savings to the state.

Any appropriation for this program failed to pass in the 2018-19 budget year. As a result, the City and County of Honolulu had to close its sites for EnhanceFitness. Kaua'i and Maui received some county funds to keep some of their programs open. Due to budget restrictions, a number of the trainers lost their jobs. The Executive Office of Aging had to suspend the program evaluation contract with the Center on the Family at the University of Hawai'i. Funding for the 2019-20 fiscal year was restored, and the Healthy Aging Partnership has been rebuilding its staff and programs statewide.

However, the same level of appropriation of \$550,000 was proposed for the coming fiscal year, and even though the bills cleared the Subject Matter committees, they were not heard in the Senate Ways and Means Committee or the House Finance Committee. As a result, there is no appropriation in the coming fiscal year.



During the pandemic, the exercise program has had to rely on TV airings and Zoom.

The Executive Office on Aging will do its best to work with the County Offices on Aging to use carry-over funds from the previous budget. Additionally, the counties are trying use some of their funds to support the Healthy Aging Partnership.

The Healthy Aging Partnership has demonstrated its value to the quality-of-life of our disabled and frail kūpuna and furthermore has concrete evidence of financial savings for healthcare services and public programs serving the frail and disabled members of our community. The current situation will have negative impacts on our vulnerable population, as well as increases in avoidable public expenditures caused by reduced preventive services. The Healthy Aging Partnership Program continues to have strong advocates and we have hope that it will rebound and have brighter days in the future.

Report on COVID-19 Related Long-Term Care Issues¹

By John G. McDermott, LSW, ACSW,
M.Div, State Long-Term Care Ombudsman

Since March of 2020, COVID-19 has been the *only* issue everyone is concerned about regarding long-term care residents and LTC facilities.

In February 2021, Hilo's Yukio Okutsu State Veterans Home was assessed a federal civil monetary penalty of \$510,640 in the wake of a coronavirus cluster that

killed 27 residents. The facility was cited for not being "in substantial compliance" and for causing "immediate jeopardy to the residents' health and safety."

An assessment by the Hawai'i Emergency Management Agency found "multiple potential sources of infections" brought into the facility by employees who appeared to be "connected to known community outbreaks, unknown asymptomatic but infectious carriers (staff), and community outbreak exposure at a dialysis center."

The report noted complacency by staff may also have played a role in the spread of the virus, particularly in the break room where employees gathered without masks. "Loose mask usage" by some staff was noted by Dr. K. Albert Yazawa, who conducted the assessment.

"I believe the nursing home culture was one that remained entrenched in pre-COVID norms of respecting individual resident rights over the health of the general population," he wrote. "In this pandemic crisis, these were major errors that contributed to infectious spread."

Yazawa observed no warning signs for staff, hand-washing stations, or alcohol dispensers near a frequently touched time clock and said the setup of the central nursing station with resident rooms in hallways "designed like spokes on a wheel" made it hard for employees to

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“maintain distance and separate clean from dirty work stations.”

Suspected COVID-19 residents were not separated into a designated unit, and there were delays in testing until scheduled mass screening events occurred, the report said. What’s more, residents with dementia were able to wander and “probably also facilitated spread” with no use of physical barriers or signs.

A separate report by the U.S. Department of Veterans Affairs said that “there was very little proactive preparation/planning for COVID.”

In addition to the monetary penalty, the facility was denied payment for new Medicare and Medicaid admissions that took place from October 18, 2020 to January 5, 2021. The state took over management of the Veterans Home from Utah-based Avalon Health Care Group on January 1. The home had been managed by Avalon since 2008.

The media’s death count at the Veteran’s Home began in August and went on for weeks. A total of 35 staff and 71 residents (in a 95-bed facility) were infected with COVID-19. But it was not the only cluster in a long-term care facility.

At least 23 nursing homes reported cases among staff or residents in September 2020, according to the DOH website. They include 17 in Honolulu, two on Maui, and four on Hawai‘i Island.

On September 30, 2020, Liliha Healthcare Center had a COVID-19 outbreak that sickened 21 residents and six staff. The virus infiltrated Liliha after an employee tested positive on Sept. 16. A press release stated, “Out of an abundance of caution, a total of 17 non-COVID residents were temporarily transferred over the weekend to Wahiawa General Hospital, where they continue to be tested and monitored for possible symptoms.”

On October 1, 2020, the DOH reported 287 cases and 17 deaths in skilled nursing facilities; 26 cases and three fatalities in community care foster homes; 22 cases and four deaths in adult residential care homes; six cases in developmental disability residential settings; and 66 cases



in assisted living facilities for a total of 407 cases and 24 deaths since March.

On October 2, 2020, 12 residents and six staff tested positive for COVID-19 at Life Care Center of Hilo. Not even the small community at Kalaupapa was spared.

Variants

There are now at least seven new variants of the virus worldwide. On February 5, a super-spreading strain from the United Kingdom (60% more highly contagious) known as B.1.1.7, was found in an O‘ahu resident with no history of travel. At least nine cases of the Denmark L452R strain has also been found in Hawai‘i. More transmissible strains mean that it might take 80% to 90% of the population to be vaccinated to achieve so-called herd immunity instead of the state’s goal of 60% to 70%, according to Acting State Epidemiologist Sarah Kemble.

It is now predicted the B.1.1.7 strain of the virus will become dominant across the world. We don’t know how effective, or for how long, the current vaccines available will be on this strain, so a booster shot may be needed to augment what is currently being used.

Masks and other PPEs

All our facilities have struggled to obtain and maintain adequate supplies of high-quality personal protective equip-

ment (PPE). This has been especially true for the smaller adult residential care homes (ARCHs) and community care foster family homes (CCFFHs), which have had greater difficulty in obtaining enough PPE and other supplies. It was not practical for them to put confused residents into a car or van and drive to H-3 or Aloha Stadium to be COVID tested.

Vaccines (Operation Warp Speed)

Hawai‘i is now vaccinating high-risk healthcare workers in hospitals and nursing and care home staff and residents, as well as those over the age of 75, some of whom have already received the second of the two-dose regimen. In some areas of the state, lower priority groups also have begun to get shots. The state is administering 5,000 to 10,000 doses a day across the islands. It was reported on February 10, 2021 that a DOH poll showed 91% of respondents plan to get vaccinated—55% as soon as their turn comes up and 36% later.

Unfortunately, there has not been enough vaccine, states have not been getting reliable information on vaccine deliveries, and the amounts they have been sent have been unpredictable. That, in turn, has made it difficult for them to plan how to inoculate people.

On February 4, 2021, Johnson & Johnson asked U.S. regulators to approve the

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Project Dana Helps Caregiver with Multiple Issues

“The Project Dana caregiver support group meetings have been providing me with educational as well as emotional support for over a year and a half, including the last several months on Zoom. Our coordinator Maria and our support group participants have been a blessing for me as I care for my brother who is living with clinical depression, schizophrenia, muscle atrophy from inactivity, and an unbalanced walk due to a history of spinal stenosis. He is physically able but not always mentally willing to perform all his ADLs [activities of daily living] independently. His clinical depression and schizophrenia cause him to hallucinate, hear voices, and be lethargic and/or angry, and sometimes suicidal. The tips for managing mental illness have especially been helpful



Photo credit: Kathy Kimura

to me to be more understanding of his behaviors. Maria also gave me some additional resources, such as NAMI (National Alliance on Mental Illness).

Many of the educational sessions have enabled me to be more compassionate to not only my brother, and to my mother who lives on the Big Island with Alzheimer's, but it has

also helped me in my own life. The sessions on fall prevention, nutrition for older adults, legal aid services, the Blue Zones Project, cognitive behavioral activities and cognitive distortions, dealing with grief, decluttering, and lately how to live with COVID-19, have been invaluable. There have been so many topics—they all helped me to help myself, as well as others. I even shared with my brother what I learned about the effects of stress on the body, mind, emotions, and behavior; he liked the colored chart that was one of the handouts from Project Dana.

The stories and lessons that we, the participants, share during the educational sessions, the rap sessions, and Zoom meetings have shown me that people can live with and overcome challenges, and become even stronger when we support each other.

I hope and pray that our sessions and meetings will continue to enrich our lives.”

—Anonymous Caregiver, Honolulu

world's first single-dose COVID-19 vaccine, an easier-to-use option that could boost scarce supplies. J&J's vaccine was reportedly safe, offering strong protection against moderate to severe COVID-19, according to preliminary results. It doesn't appear quite as strong as the two-dose competitors Pfizer (approved on December 11, 2020) and Moderna (approved on 12/18/20) versions, but it's still worth considering. (The first FDA-approved drug was Remdesivir on Oct. 22, 2020. It is given through an IV for hospitalized patients.)

Overall, J&J's single-dose vaccine was 66% effective at preventing moderate to severe COVID-19, according to early findings from a study of 44,000 people. But it was 85% protective against the most serious symptoms—and starting 28 days after their shot, researchers found no one who got the vaccine needed hospitalization or died. In comparison, two doses of the Pfizer and Moderna vaccines prove 95% protective against any symptomatic COVID-19.

The Associated Press reported both Moderna's and Pfizer-BioNTech's shots are mRNA vaccines, made with a ground-

breaking new technology. They don't contain any coronavirus—meaning they cannot cause infection. Instead, they use a piece of genetic code that trains the immune system to recognize the spike protein on the surface of the virus, ready to attack if the real thing comes along.

Some good news. KHON-TV reported on February 16, 2021 that “Nursing facilities and other long-term care facilities in Hawai'i are demonstrating vaccination rates *far higher* than the national average,” according to a report by the Healthcare Association of Hawaii.

The report revealed that Hawai'i is vaccinating an average 78% of their staff and 90% of their residents against COVID-19, while the national average for staff is 38% and 78% for residents. Additionally, three Hawai'i facilities had 100% of their staff vaccinated, and 13 facilities had more than 90% vaccinated.

The numbers demonstrate more health-care staff are seeking vaccination as comfort levels with vaccines grow. Most found vaccination rates rose when they reached

the second of the three clinics planned as part of the federal pharmacy partnership program to vaccinate long-term care residents and staff, the report said. Survey responses were received from 41 of the state's 45 nursing facilities, or approximately 91% of Hawai'i's licensed nursing facilities. Ten of the state's 18 assisted living facilities and five adult residential care homes were also included in the survey.

Staffing

During the pandemic, many staff became ill and had to self-quarantine at home for 14 days. Some had to self-quarantine because other members of the family became infected with the virus. Some had to stay home because they had small children who couldn't be left alone while classroom learning was put on hold during the lockdown. The lockdown also revealed how much help our families provide to the facilities for free when visiting loved ones. Most of our facilities were already short-staffed, but the pandemic made it much worse and facilities struggled to do the best they could with the staff they had available. Our caregivers

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are true heroes who risked their own lives to protect our most vulnerable.

Because of COVID-19, activities for residents were reduced or even temporarily canceled. Group dining was reduced. Bathing was reduced. Therapy was reduced. The ability to answer call bells quickly was reduced (which can increase UTIs and bed sores). Mental stimulation and opportunities for socialization were reduced. Even the time it takes to put on and take off PPEs had an impact. Add to that the stress of supply shortages for our caregivers. Everyone recognizes sufficient and highly trained staff are essential, but during the pandemic, the Centers for Medicare & Medicaid Services (CMS) actually waived the federal requirement that facilities report their daily staffing so we could know how many staff were actually working on a particular day. The result: a steady decline both physically and mentally for many of our kūpuna.

Aerosols

On September 26, 2020 the AP reported COVID-19 clearly hitchhikes on small liquid particles sprayed out by an infected person. Using the University of Maryland School of Public Health's "Gesundheit II machine," researchers discovered people expel particles while coughing, sneezing, singing, shouting, talking, and even breathing. But the drops come in a wide range of sizes. The recommendation to stay at least 6 feet apart is based on the idea that larger particles fall to the ground before they can travel very far. But some scientists are now focusing on tinier par-

ticles, the ones that spread more like cigarette smoke. Those are carried by wisps of air and even upward drafts caused by the warmth of our bodies. Called "aerosols," they can linger in the air for minutes to hours, spreading throughout a room and build up if ventilation is poor. As a key piece of evidence, scientists have pointed to "superspreader" events where one infected person evidently passed the virus to many others in a single setting.

Isolation

Most of us have reached the tragic conclusion that isolating our residents to protect them from the virus was sometimes just as deadly as the virus itself. When the virus was new and we didn't know how to respond, we made mistakes. This was one of them. Like an infant never picked up by its mother, our kūpuna are also negatively impacted when no family or friends can visit and staff are too busy to stop and say hello and engage in any form of communication. We are "social" beings. We need to feel loved and valued. The majority of our residents have some degree of dementia. Forced isolation only increases their confusion, depression, weight loss, the very will to live. "FaceTime" and window visits don't always work for these residents.

In CMS's September 17, 2020 Memo to Nursing Facilities, it mandated, "effective immediately," that facilities resume family and friend visitations with some limited restrictions—unless there is a COVID outbreak or some other medical reason that might require a temporary

halt on visitations. It's time for all our facilities to again allow visitations, especially when facilities have outdoor areas where this can be done more safely.

ARCHs/CCFFHs

Throughout the pandemic, our ARCHs (Adult Residential Care Homes) and CCFFHs (Community Care Foster Family Homes) have felt forgotten. Many don't realize that in Hawai'i, we have 4,576 nursing home beds, but we also have 8,300 community-based beds (ARCHs, CCFFHs, and Assisted Living facilities), almost twice as many vulnerable seniors being taken care of in smaller homes in our neighborhoods. Federal CMS guidelines and assistance went to nursing homes, not community-based homes. AARP and legislators like Sen. Sharon Moriawaki, and then Rep. Joy San Buenaventura insisted on help for these caregivers. These homes needed procedures and protocols so they could protect the residents, their family members, and themselves. Thankfully, AARP's Audrey Suga-Nakagawa formed a committee that created the *Care Home Protocols Handbook*, which has been mailed out to every ARCH and CCFFH caregiver.

DOH Website

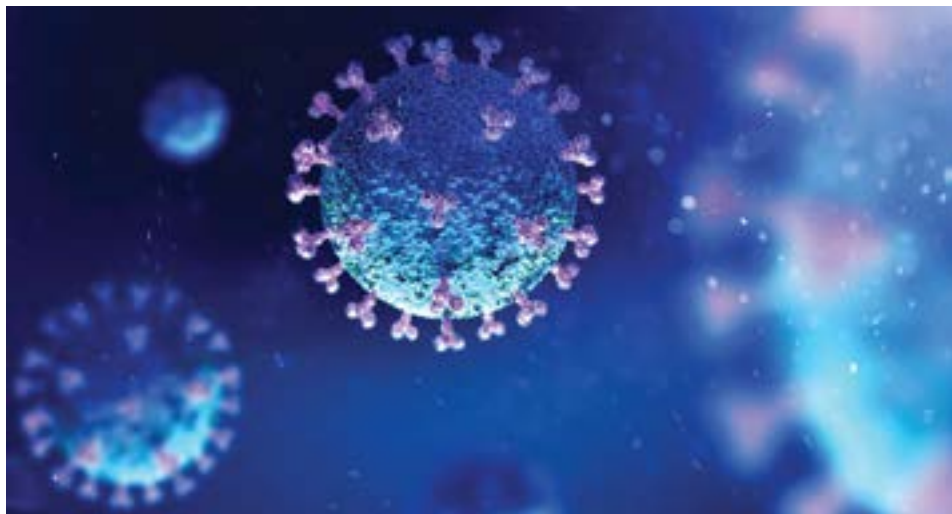
A positive result of the pandemic was a vast improvement in the [DOH website](#), which became a clearinghouse where caregivers and the public can find valuable resources. It continues to improve daily.

Conclusion

Gov. Ige has stressed "the tools to combat the variants have not changed, including mask-wearing, social-distancing, washing hands, and staying home when sick." So lucky we live in Hawai'i where most citizens listen to the science, care for their neighbors, and have a reverence for our kūpuna. So, I say open the windows! Let the fresh air in and get the contaminated air out. Enjoy the great outdoors where it's easier to social distance. It's also good for your mental well-being, and the sunshine's ultraviolet rays and our tropical breezes will help reduce the chances of catching COVID-19. Together, we will emerge victorious.

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Aid to Caregivers

Kūpuna Caregivers Program

By Sarah Yuan, PhD

Chair, Legislative Committee

Policy Advisory Board for Elder Affairs

Every minute, about seven baby boomers in the U.S. turn 65. Our local population is aging even more rapidly and also living longer than in any other state. In 2016, 17% (about 244,000) of Hawai'i residents were 65 and over. By 2030, when all baby boomers are 65 or older, Hawai'i's older adult population is projected to increase to 23% (nearly 369,000). Because the demographic make-up of our state is changing, we need to change the way we provide care for our kūpuna.

When given a choice, most kūpuna prefer aging at home. Our extended 'ohana are often incredible caregivers, but providing that care can create financial and emotional stress. In 2019, the annual cost of home health care in Hawai'i was about \$10,000 higher than the national average (Genworth Cost of Care Survey). Our caregivers need assistance too. Many caregivers make the difficult decision to leave their job or reduce work hours to care for an aging family member. In 2017, with robust championing by Senator Roz Baker and Representative Gregg Takayama, our legislators passed **HB 607**, which was signed by Governor Ige into law as the Kupuna Caregivers Program (**KCGP Act 102**, 7/6/2017).

The KCGP is administered by the Executive Office on Aging (EOA), with services delivered by the county Area Agencies on Aging (AAA) and their contracted service providers.

Purpose: The KCGP helps make long-term care for our kūpuna more affordable and provides the helping hand caregivers so desperately need. The program helps working caregivers pay for adult daycare, assisted transportation, chore services, home-delivered meals, and other designated services. It allows caregivers to continue to earn their retirement bene-



fits, helps businesses retain experienced workers, and provides peace-of-mind to caregivers that their loved one is being cared for while they are working.

Qualifications: Eligible caregivers must be employed at least 30 hours a week by one or more employers and provide direct care to a care recipient who is a U.S. citizen or a qualified alien 60 years of age or older. The care recipient must not be covered by any comparable government or private home- and community-based care service (excluding Kūpuna Care) or reside in a long-term care facility. They must have impairments of at least two activities of daily living (ADL), instrumental activities of daily living (IADL), or a combination of both, or significant cognitive impairment that requires substantial supervision.

Program Funding: The KCGP was funded at \$0.6 million for the second-half year of FY18 and \$1.2 million for FY19. **Act 126**, enacted in 2019, increased the appropriation to \$1.5 million, and it reduced program service coverage from a maximum of \$70 a day to \$210 per week per participant, with the intent of serving more working caregivers. In the current legislative session, **HB 1867 HD 1** requests a level funding of \$1.5 million.

Its companion bill **SB 2342 SD 1** seeks an increased appropriation of \$2 million and a further program change to lower the employment hour requirement for working caregivers from 30 hours per week to 20. Currently, the EOA is implementing a plan to increase the number of people served by the KCGP, so additional eligibility changes to this new program may affect the plan and its expected results.

Program Impacts: In FY19, the KCGP served 112 working caregivers. At the time of application, 40% of caregivers reported having provided care for five or more years; half spent 40 or more hours in caregiving during the past week; and 40% were sole caregivers. The average age of these caregivers was 57 years old, and almost 80% lived with the care recipients. Nearly all (92%) of care recipients received adult daycare services, and 87% received case management services. Other services used by 7% or more of seniors were personal care, homemaker, transportation, and home-delivered meals. The evaluation results reported by the EOA showed a significant decrease in the "objective" and "stress" burden scores from intake to follow-up (6 – 12 months later). These positive impacts have proved

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Kupuna Caregiver Program Vital During COVID-19 Pandemic

By Kevin Dusenbury
Maui County Office on Aging

Last year, one of Maui County's Kupuna Caregiver Program caregivers shared her inspirational story for Aging & Disability Issues 2020. Since the COVID-19 pandemic has had such a profound impact on our entire community, the Maui County Office on Aging would like to share more of her caregiving journey.

Rebecca Armato has been a loving, full-time caregiver to her mom Patricia for the past seven and a half years while also maintaining full-time employment. Rebecca shared that being the only caregiver for her 84-year-old mother while working a full-time job is an intricate juggling act. Since 2019, she has held a vital role as the manager of Physician Services at Maui Health System in Wailuku. Her primary responsibility is to recruit and retain healthcare providers for the hospital.

Even prior to the COVID-19 pandemic, the Kupuna Caregiver Program greatly helped Rebecca and her mom through the authorization of home- and community-based services, notably adult day care at Maui Adult Day Care Centers. However, everything changed drasti-



Rebecca and Patricia Armato

cally on March 20, 2020. The mandatory closure of the adult day care center and safer at-home orders meant that Rebecca would have to balance her caregiving and work responsibilities completely on her own.

On a normal day at adult day care, Patricia was able to socialize with the other participants and staff, partake in various activities, and even receive help with bathing and other personal care tasks. Without the interactions and routine that adult day care provided Patricia, Rebecca quickly noticed that her mother's dementia was worsening, especially with her alertness and ability to communicate. According to the Cleveland Clinic, there is a growing concern for the effects of social isolation and mental health, especially with older adults. At the Maui County Office on Aging and other Area Agencies on Aging (AAA) across the state, new services like interactive robotic animals (see photo below) and increased wellness checks have been implemented to help combat social isolation.



Since Patricia requires full-time care, Rebecca spent countless hours during the evening and on weekends so she could continue to fulfill her duties for the hospital and Maui's community. From the day that the day care closed in March until they reopened in July, Rebecca did not leave her mother or their home. All supplies and groceries were delivered. Similar to other caregivers across the state and nation, Rebecca shared that she has feelings of increased caregiver burden and stress brought on by the pandemic. According to a survey conducted by UsAgainstAlzheimer's A-LIST, "caregiving for loved ones with Alzheimer's and other forms of dementia during the COVID-19 closures is leading to high levels of symptoms often found in people exposed to severe stress."

With the reopening of the adult day care centers and resumption of services in early July, Rebecca is incredibly thankful for the caregiver respite services from the Kupuna Caregiver Program. Patricia has started to communicate again and has "a little more life in her eyes." Unfortunately, the pandemic continues to cause daily uncertainty because of temporary facility closures due to COVID-19 exposures. This means that Rebecca always has to be ready for anything each and every day, which continues to cause increased anxiety and stress. Since the pandemic has also created significant economic concerns across the state, Rebecca is concerned about the future of the Kupuna Caregiver Program. She would like legislators to know that the Kupuna Caregiver Program continues to make a remarkable difference in their lives. Since she is able to work and help recruit healthcare providers for Maui County, "the state's investment and dedication to this program has an equally important return to our community." Even during these trying times, Rebecca remains very hopeful that legislators will advocate and support Hawai'i's older adults and caregivers.

For more information about Kupuna Care services, the Kupuna Caregiver Program, robotic furry friends, and the Maui County Office on Aging, please visit www.mauicountyadrc.org or call us at (808) 270-7774 or toll-free at (808) 643-ADRC.

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to be significant among caregivers who have been caregiving for over five years or spent more than 40 hours a week in caregiving. Overall, the KCGP has shown to be effective in keeping working caregivers in the workforce while reducing their caregiving burdens.

Paid Family Leave

By Gary Simon, President, Hawai'i Family Caregiver Coalition & Chair, Policy Advisory Board for Elder Affairs

Why Paid Family Leave? Demographic data help to identify the problem in Hawai'i. Forty percent of Hawai'i's workforce provides care for older parents, and family caregivers provide 70% of all care for frail elderly persons. Furthermore, in Hawai'i, unpaid leave under the federal Family and Medical Leave Act is inaccessible for 61 percent of working people.¹

In November 2019, the Hawai'i State Legislature released a legislatively-mandated report on the viability of creating a paid family leave program in Hawai'i. A revised version of the report was released in December 2019.²

The report has helped inform legislator proposals in the 2021 legislative session.

HB 466, introduced by Representative Richard Onishi, and **SB 679**, introduced by Senator Brian Taniguchi, Chair of the Senate Committee on Labor, Culture, and the Arts, provide employees with up to eight weeks of paid family leave during a one-year period paid through an employer-based private insurance program currently used to provide for temporary disability benefits. **HB 5** requires the Department of Labor and Industrial Relations to establish and administer a family leave insurance program. **HB 5** also provides family leave insurance benefits and extends the period of family leave to sixteen weeks for businesses that have one or more employees who meet the hourly qualifications. **HB 1272**, introduced by Representative Roy Takumi, requires the Department of Labor and Industrial Relations (DLIR) to establish a family and



medical leave insurance program and to begin collecting payroll contributions to finance the payment of benefits by January 1, 2023. **HB 1272** requires the DLIR to start receiving claims and paying benefits under the program by January 1, 2024. **HB 2** requires employers to provide a minimum amount of paid sick leave to employees to be used to care for themselves or a family member who is ill or needs medical care. **HB 297** and **SB 681** include provisions that require employers to provide a minimum amount of paid sick leave to employees to be used to care for themselves or a family member who is ill or needs medical care. **SB 1275**, introduced by Senator Rosalyn Baker, Chair of the Senate Committee on Commerce and Consumer Protection, requires each state government branch to establish a shared leave program for state employees and precludes state government branches and counties that have a shared leave program from prohibiting leave sharing between employees of different departments or bargaining units because of administrative infeasibility.

We strongly encourage the legislature and the governor to pass a strong paid family leave law. Employees need subsidized time off to care for a newborn, newly adopted or foster child, or an ill

or disabled family member. Paid family leave guarantees that employees can cover the basic costs of living while providing care to family members when they need it most.

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Caregiver Education Even More Important in this Changing World

By Kathy Wyatt, RN, MSN, MBA, LNHA
President, Hale Hau'oli Hawai'i

It is well known that Hawai'i has the fastest growing population of senior citizens in the nation. According to a report from AARP in 2019, there are approximately 157,000 family caregivers who invest 131 million hours of care for their loved ones. Providing care for a loved one can be challenging, especially for someone with Alzheimer's disease or

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Project Dana Helps Caregiver Cope

"We moved to Honolulu last year in May to be close to our son since my husband was very sick. I did not know anyone here. I was so depressed and alone. Our son gave me the phone number for Project Dana. I joined the Project Dana caregiver support group and learned so much. It helped me cope with taking care of my husband. Every meeting, the coordinator invites excellent speakers. Talking and visiting with other members gave me a lot of support. Maria Morales has been an excellent caregiver coordinator for this group. I highly recommend Project Dana to anyone who cares for a sick person."

—Jaye Devendra, Honolulu



Photo credit: Kathy Kimura

other dementias. Many family caregivers begin their caregiving journey with no experience and can be understandably overwhelmed by their new responsibilities. Having no experience causes stress, uncertainty, fear, frustration, and a myriad of other emotions. One of the most effective ways to help ensure the highest quality of care for those with dementia is through caregiver education. Learning about the disease and knowing what to expect can help caregivers feel more in control and better able to plan ahead.

Hale Hau'oli Hawai'i—along with other organizations such as the Alzheimer's Association, The Caregiver Foundation, the Hawai'i Parkinson Association, and AARP—offers caregiving educational sessions throughout the year. The majority of these offerings are at no cost to participants.

A non-profit organization, Hale Hau'oli Hawai'i is offering four caregiver educational workshops in 2020 at various locations around the island of O'ahu, made possible by a generous grant from the City and County of Honolulu. The workshop, "Dementia in the Family: Care Options and Resources," features

speakers covering basic dementia facts, caregiving tools, legal and financial topics for caregivers, and other important information for caregivers. Exhibitors at these workshops will provide a multitude of resource materials. Hale Hau'oli Hawai'i offers caregiver support groups in conjunction with The Caregiver Foundation, as well as small group caregiver training sessions. The website, www.halehauolihawaii.org, provides lists of upcoming workshops for caregivers and caregiver support group locations.

The Caregiver Foundation provides seniors, disabled adults, and their caregivers training on caregiving, aging, and financial management, as well as island-wide caregiving support groups with educational components. Many resources can be found on their website at www.thecaregiverfoundation.org.

The Alzheimer's Association—Aloha Chapter offers a wide variety of programs and services, including educational programs for caregivers, community groups, and professions, as well as online caregiving training. The Aloha Chapter also offers caregiver support groups that include educational components. The Aloha Chapter's

website, www.alz.org/hawaii, offers a variety of resources and educational topics.

The Hawai'i Parkinson Association has an annual symposium where a leading specialist on the disease answers patient and caregiver questions. The organization also offers caregiver support groups with educational components. Their website, www.parkinsonshawaii.org, provides education and caregiver support group locations.

AARP offers caregiver education programs and online training and education for both new and experienced caregivers. Find educational topics on their website at www.aarp.org.

Another excellent resource for family caregivers is the Senior Information and Assistance Handbook, a publication of the Elderly Affairs Division, Department of Community Services, City and County of Honolulu.

Becoming educated about Alzheimer's disease and other dementias, learning practical caregiving approaches, and using local caregiving resources are important strategies. Armed with the resources needed to continue to provide safe, effective care for their loved ones, and the knowledge that there is help in the community to assist them, caregivers can be successful in their endeavors, and the elderly can remain at home and in their communities. Our goal is to reach as many people as possible to give them this invaluable information to make their lives and the lives of their loved ones better and easier. Caregiver education also leads to improved health outcomes, not only for kūpuna, but also for their caregivers.

Many caregivers work outside the home and care for elderly loved ones. Along with education, working caregivers need help to care for their kūpuna. We strongly urge the legislature to continue funding the Kūpuna Caregiver Program, which helps working caregivers remain in their jobs and not be financially burdened by caregiving, nor become a financial burden on the state if they have to leave their jobs to continue caregiving.

Disability Issues

By Gary Simon, President, Hawai'i Family Caregiver Coalition & Vice Chair, Policy Advisory Board for Elder Affairs

Some issues affect both people with disabilities and older adults. Members of the Hawai'i Family Caregiver Coalition (HFCC) join forces to address these issues. Other issues affect only older adults or only people with disabilities. The HFCC advocates for these two individual populations as well. This section describes legislative measures being discussed in the 2021 legislature and that might not be addressed in other sections of this report.

Service Animals

The regulation, or lack thereof, of service and other emotional, comfort, and support animals continues to be a major problem for many in the community. The proliferation of fake service animals by individuals wishing to access environments that prohibit the presence of pets is well documented. **Act 217** of 2018 established a civil penalty for knowingly misrepresenting an animal as a service animal and conformed Hawai'i law to the definition of "service animal" under the Americans with Disabilities Act of 1990. In 2021, bills have been introduced to offer more clarity on the service animal/assistance animal/emotional support animal issue. **SB 280** and **HB 381** propose to codify the administrative rule definition of "assistance animal;" clarify the type of verification an individual may provide to substantiate a reasonable accommodation request for a specific assistance animal; and specify that possession of a vest or other distinguishing animal garment, tag, or registration document commonly purchased online and purporting to identify an animal as a service animal or assistance animal does not constitute valid verification of a disability-related need.

Community Living

A number of bills have been introduced to improve the lives of people with disabilities.



SB 739 requires all places of public accommodation to comply with accessibility guidelines established under the Americans with Disabilities Act.

An exemption from paying minimum wage to people with disabilities has existed for many years, beginning at the federal level with the Fair Labor Standards Act of 1938. Historically, minimum wage exemptions were considered necessary to help people with disabilities gain employment.¹ Experience over the past two decades has shown that workers with disabilities can succeed in jobs earning minimum wage or more. **SB 793** and **HB 603** propose to repeal the exemption of persons with disabilities from minimum wage requirements.

The casual observer might think that the worst consequence of poor dental health would be lost teeth. However, some studies have linked common oral problems to illnesses including heart disease, stroke, diabetes, premature birth, osteoporosis, and even Alzheimer's disease. In most cases, the strength and exact nature of the link is unclear, but they suggest dental health is important for preserving overall health.² **SB 1294** and **HB 866** appropriate funds to restore diagnostic, preventive, and restorative dental benefits to adult Medicaid enrollees.

Individuals who are deaf or hard of hearing at any age face many challenges in receiving information conveyed in an auditory manner. Hearing impairment can

impose a social and economic burden on individuals and families. In adults, hearing impairment often makes it difficult to obtain, perform, and maintain employment. It also makes it difficult to respond to warnings or hear doorbells and alarms, and to understand and follow a physician's advice and directions. Hearing impairment can lead to depression, withdrawal, or isolation, as it can be hard to make conversation with friends and family and can lead to frustration or embarrassment.³ **SB 1140** and **HB 986** amend the newborn hearing screening statute to mandate reporting of diagnostic audiological evaluation results to improve hearing follow-up of infants. **SB 539** and **HB 839** propose to require health insurance policies and contracts issued after December 31, 2021 to provide coverage for the cost of hearing aids at a minimum of \$1,500 per hearing aid for each hearing-impaired ear every 36 months in their base plans.

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COVID-19 & the Advantages of Living in Paradise

By Kathy Wyatt, RN, MSN, MBA, LNHA, Hale Hau'oli Hawai'i, and

Gary Simon, President, Hawai'i Family Caregiver Coalition & Vice Chair, Policy Advisory Board for Elder Affairs

Our great state of Hawai'i has the lowest number of COVID-19 cases in the nation.¹ We have had too many deaths from the virus, but our numbers have been among the fewest in the country. Bottom line, we have been doing things right!

Now we need to get Hawai'i vaccinated. As of February 16, 2021, nearly 262,000 doses have been injected into arms and nearly 11% of the population has had at least one shot. About 50,000 people 75 and older have had at least the first shot of the two-dose vaccines.

Demand for vaccines is great. A Department of Health survey found 91 percent of respondents plan to get vaccinated. Interest is particularly high among those age 65 and older—78% say they want the vaccine as soon as it is available. But because of the lack of vaccine supply, many are frustrated about not being able to get appointments. On O'ahu, the two mass vaccination sites are in urban Honolulu and residents outside of the area want more vaccination sites closer to their homes.

There are indications that more supply is on its way and more sites are or will open soon, including in rural areas. President Biden's administration announced that more vaccine will be released to federally qualified community health centers like Waianae Coast Comprehensive Health Center to reach underserved and vulnerable communities.

President Biden, who ran for office on a promise to administer 100 million doses of vaccine in his first 100 days in office, also announced that the federal government will have enough vaccine to vac-

Wide Ranging Learning at Project Dana

"I have both enjoyed and benefited greatly from attending Project Dana's bi-monthly support group meetings. The meetings have helped me provide better care for my wife who has Alzheimer's, and enhanced my ability to cope with the stresses and difficulties of caregiving. Project Dana arranges for a wide variety of informative speakers and topics, including: stages of Alzheimer's, self-care, communication with loved ones, considerations for end-of-life, searching for care homes, Social Security, dental care, funeral options, how to smile and have a positive outlook, positive care, resilience, exercise, and available resources. The meetings have enabled me to improve my wife's care, bolster my own care, and prepare me for future events. In addition, I have learned from the many hands-on experiences of other care-

givers, and really enjoy their support, companionship, and camaraderie. I hope you will approve funding for this very valuable program that has made a big difference in my family's life."

—Anonymous Caregiver, Honolulu



Photo credit: Kathy Kimura

inate 300 million people by July 2021. An emergency use authorization of the Johnson & Johnson vaccine will also increase the supply.

What's not clear is how quickly the vaccines will arrive in Hawai'i and when the supply will be enough so that anyone who wants a vaccine will be able to get it when and where they want it. Will it happen as soon as March or April, or will we only have enough vaccine to meet demand this summer?

Kūpuna also have questions about whether they should take the Moderna, Pfizer, or Johnson & Johnson vaccine. The Moderna and Pfizer vaccines require two doses, but have been shown to have high effectiveness in preventing COVID-19. The Johnson & Johnson vaccine is less effective, but still prevents serious illness in 85 percent of cases, and it only requires one shot.

For now, until there is more vaccine supply, the Department of Health says you should probably take whatever vaccine is offered when you can get an appoint-

ment. It may be several more weeks or months before supplies increase to the point where you can be picky about what vaccine to get.

If you want to learn more about the different vaccines, you can go to the [HawaiiCOVID19.com](https://hawaiiCOVID19.com) website or to aarp.org/vaccines. You can also learn more about vaccinations in Hawai'i at aarp.org/HIVaccine.

Caregivers who are not in priority groups to get the vaccine have also expressed concern about getting the vaccine so that they don't infect their loved ones. Initially, caregivers were able to get vaccinated at some vaccination sites, but the state is prioritizing vaccines for those 75 and older, and until supplies increase, only eligible kūpuna should get vaccinated.

Some side effects, such as pain or swelling around the vaccine site, have been reported after getting the vaccine, especially after the second shot. People may also get a fever, chills, nausea, tiredness, or a headache. Doctors say this is a sign
(Continued on next page.)

the vaccine is working and generating an immune system response. In rare cases, serious side effects due to an allergic reaction to the vaccine have been reported. As with all allergies, anaphylactic shock could result and that could be life threatening. However, doctors are used to treating allergic reactions, even serious ones. People who have allergies and had anaphylactic shock in the past should consult their physicians before taking the vaccine. They may not be eligible to get the vaccine for now, or they may need to take the vaccine in a medical center so doctors can respond to an allergic reaction.

The vaccine is being offered at no cost to recipients. Insurance will cover the full cost and there is federal funding for those that do not have insurance. It is possible that a small administrative fee may be charged, but so far, no vaccine distribution site in Hawai'i are charging a fee.

Because so many people want the vaccine and are anxious to get it, there are reports that scammers are using people's concerns to steal money. The state has issued a warning about vaccine scams. In general, if you get an unsolicited call, text message, or email offering to give you the vaccine for a fee or a chance to cut in line and move up in priority for money, it's likely a scam. People should



also be careful about giving their insurance account numbers or other personal information to strangers soliciting information in an email, text message, or phone call. You will have to give your insurance information to get the vaccine, but make sure you know who you are giving

the information to and that it is to a legitimate provider.

Meeting everyone's needs for the vaccine is an impossible task for now, but vaccinating as many people as we can is an imperative. If you are frustrated about not being able to get the vaccine now, remember that everyone who wants one will eventually be able to get a vaccine. The key word is eventually. It is likely not going to be tomorrow, but it will hopefully be by this summer.

Our wonderful state of Hawai'i is doing an admirable job with vaccinations so far. Although there is still much more to do, getting back to a near normal may not be too far away. Due diligence is a priority, however, in getting the vaccine out to as many people as possible. By working with our leaders and including the citizens of this state, it can be accomplished.



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Retirement Years

Hawai'i Saves

Craig Gima, BA

When I was in my 20s and fresh out of college, I didn't think much about retirement. My first job at a TV station in California paid \$12,000 a year. I lived paycheck to paycheck and I spent whatever was left in discos every Saturday night. But I still managed to save about a hundred dollars a month toward my retirement.

How? My company had a 401k, and through payroll deduction, the money was taken out before I had a chance to spend it. If it wasn't easy, I would have saved zero for retirement.

That's why I support AARP Hawai'i's resolution to create a task force to study the establishment of a Hawai'i retirement savings program. Every worker deserves a chance at a secure retirement, but an estimated 216,000 Hawai'i workers don't have an easy way to save at work. Unless you work for government, pensions are rare, and about half of all small businesses do not offer 401(k)s or other payroll savings programs.

That may be why the average household in America has only \$2,500 saved for retirement, and the average household near retirement has only \$14,500 in savings.

AARP Hawai'i has been trying to pass bills and resolutions to study and create a retirement savings program for five years. The bills have gone to the floors of both the state house and senate for second readings. No one voted against it, but the bills still died.



Powerful and monied special interests in the insurance and financial services industries, who profit from the status quo, oppose even studying whether a program to help workers save would work in Hawai'i.

In the meantime, 12 states have passed retirement savings program legislation, and workers in three states—Oregon, California, and Illinois—have started saving. According to the Brookings Institute, about 276,000 workers have saved nearly \$170 million in the three programs.

Hawai'i's workers are being left behind, and Hawai'i taxpayers will end up paying the bill for the lack of retirement savings. If workers without savings get sick and can't work or retire broke, they will need government help to survive. Social Security alone is not enough to live on. A university study estimates that if workers can save enough to generate an extra \$1,000 a month in income, the state would save \$32 million in reduced spending on social programs over 15 years, and combined state and federal savings would be more than \$160 million.

The retirement savings program proposed would allow businesses who don't currently have retirement programs to offer an automatic IRA to workers at no cost to the business. The state would facilitate and oversee the program in partnership with private businesses. The money would stay in workers' accounts and be invested by private financial secu-

rities companies. The state will have no control over the workers' money.

The key to the program is payroll deduction. Workers are 15 times more likely to save if money can be taken out of their paychecks. It's human nature. If it's easy to save, people will save. If you have to work to figure out how to save, people will not save. Studies have shown that only one in 20 people will open an IRA on their own.

That's great if you're in the five percent of people who are dedicated enough to save by yourself. I'm in the 95 percent who are lazy, but I am eternally grateful that I will be able to retire comfortably because of payroll savings. Every worker should be as fortunate.

COVID-19 & the Promise of Active Aging

By Cullen T. Hayashida and Barbara Yamashita

The year was 2020. The COVID-19 pandemic affected the entire world. While there is hope, given the emergence of several vaccines, 2021 will continue to see mask-wearing, physical distancing, disinfectants, travel bans, and disruption of graduation ceremonies and sports gatherings, to name a few. Hawai'i, a mecca for tourists, is experiencing hotels and businesses that are on shaky ground, and unemployment spiking while many stay at home, remain online, and engage

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in remote conferencing. Indeed, there is a sense of numbness when our everyday practices of meeting friends have drastically changed and when things that were possible cannot be done or are now only possible with caution.

Hawai‘i state government officials are informing the public to anticipate up to seven years for economic recovery. Given the COVID-19 pandemic’s economic impact, state financial support for new eldercare initiatives will be next to impossible. This may be a message that will repeat year after year. Depleted tax coffers limit the state’s ability to help. General state services will be cut, and taxes may need to be raised. What do elected lawmakers who have been sensitive to the political strength of older adult voters do?

Given this dire situation, is it possible for older adults to have an active and contributing role in Hawai‘i? Aging is not just about chronic illness, frailty, and long-term care. Yes, older adults may be more vulnerable to the COVID-19 virus. And yes, they may be less immune to diseases in general, and yes, many are home alone, lonely, vulnerable, and depressed. However, population aging can also be understood in terms of the explosion of active older adults representing a fast-growing human resource with vast potential. Our retirees and older adults have skills,



talents, experience, personal connections, and an enormous amount of time on their hands. Many are also financially independent. The question is, what can be done to encourage this cohort of active older adults to maintain their health, stay engaged, and contribute to the greater good. This is about pivoting from aging as sick care to aging as an asset for our community. This is active aging!

Public policy should address ways of promoting the active aging life as advocated by the World Health Organization and others. To that end, active aging requires the promotion of:

1. Health (physical, medical, nutritional, mental, and emotional);
2. Participation (social engagement, recreation);
3. Security (financial, consumer protection);



4. Intergenerational relations;
5. Lifelong learning;
6. Purpose; and finally,
7. Fourth-age planning in anticipation of the end-of-life and an opportunity to leave a legacy.

Among these, it is purpose beyond ourselves that may be the most important. Purpose is our rudder and provides us with a reason for living. All the facets of active aging need to be regularly addressed so our life work, our meaning in life, can be achieved.

The question is, what can be done to encourage this cohort of active retirees to maintain their health, stay engaged, and continuously contribute to the greater good? Can we tap active retirees to assist as volunteers, mentors, consultants, teachers, entrepreneurs, and workers, full-time or part-time, paid or unpaid, to begin addressing the numerous challenges that our communities are faced with? Many are already lending a hand, but many more are available if the pathways to solicit their services are seamless. Hawai‘i needs a new social infrastructure promoting an active aging lifestyle via budgetary changes, pre-retirement workshops, resource directories, older adult training, and employment agencies, among other avenues. Take what has been done to create the aging as sick-care infrastructure and mirror it for new opportunities for retirees seeking an encore career, a second act. A lot needs to be done and can be done to invest in and create an active aging infrastructure to marshal this natural resource for a sustainable Hawai‘i.





Conclusion: A Path Forward

By **Gary Simon**, President, Hawai'i Family Caregiver Coalition, & Vice Chair, Policy Advisory Board for Elder Affairs

The Legislative Process

Sections 2 through 6 of this publication illustrate the kind of aging and disability issues legislators face each and every year with regard to aging and disability. At the beginning of each legislative session, a great number of bills are offered in these subject areas. However, within a brief time, the number of viable bills rapidly decrease as they are either not heard by committees or deferred indefinitely. Advocates must be prepared at the very beginning of a legislative session to respond rapidly to identify and support favorable legislation and to testify rationally and robustly in opposition to legislation deemed harmful to kūpuna or persons with disabilities.

Advocacy

Effective, successful advocacy is comprised of six key elements:



- 1. Teamwork.** As an individual, an advocate needs to join organizations that are effective in creating change; aligned with the individual's goals; and welcoming of the individual's contributions, no matter how great or limited those contributions might be. Similarly, stakeholder agencies and organizations need to ally, collaborate, and partner to effect change. Advocacy is a joint venture. Find allies and work with them. The potential for success is much greater when a number of organizations and people are on your side. Ensure that you and your allies have the same message.¹ The collective voices of multiple groups can be the fundamental and vital difference in demonstrating the critical

mass demanding change.² Avoid completely dismissing an organization which might disagree with some items on your legislative agenda. If the organization is in favor of any of your issues, then it is an ally. The relationship you build might benefit your future advocacy efforts. Additionally, representatives of the organization might be inclined to hear your rationale on issues where your positions differ.

- 2. Relationships with legislators and their staff.** Nurture relationships. Personal, face-to-face contact or personal phone contact with key legislators and their legislative staff to educate them about important issues is the difference between success and failure. Make your voice heard. Say mahalo. Remember that our legislators and their staff are busy during the legislative session and that their time is limited and valuable.
- 3. Testimony.** Demonstrate broad support for bills being heard with a substantial number of clear, concise, compelling, and convincing written testimonies and personal appearances at legislative committee hearings.

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4. **Statistics.** Know and use the facts. Increasingly, the need for services and the effectiveness of programs must be demonstrated clearly via solid scientific evidence and reliable data.

5. **Personal Stories.** Personal stories can matter as much as statistics. Dramatic stories spark change effectively and can be a great source of clout for advocates.³

Presenting real life stories of actual people and putting faces on kūpuna or persons with disabilities is the most powerful method to influence legislators and have them seriously deliberate the consequences of their actions. The effectiveness of personal stories is amplified if the person telling the story is a constituent or is someone the legislator personally knows.

6. **Incremental change.** Advocates must take advantage of opportunities for incremental change and then build upon these. Press for whatever incremental advances are politically possible at any given time. Never give up. Continue to push. Exercise strategic patience. Prepare for the eventuality when the window of opportunity that change agents have been cultivating arises.⁴

The Silver Tsunami, with its many thousands of additional elders and unprecedented numbers of the very old, arrived in the 1990s. This tsunami has not yet

Project Dana Helps Daughter Help Dad

"The most important thing I've learned in this program is acceptance. My dad's life will never be the same, BUT, I can change what I think or do to hopefully make it easier for him. My parents made a wonderful life for us. Mom says they were not well off financially, but that the five of us were their treasures. I am most grateful for my sessions with the Coordinator and her kind and gentle nature guiding me in problem-solving difficult day-to-day situations. I thank God for her commitment to the program and am 100% assured that I can call upon Maria and Project Dana resources as needed."

—Wanda I., Waipahu



Wanda's Father walks her down the aisle in 2015.

peaked. Thirty percent of Hawai'i's total population (approximately, 475,000 individuals) will be 60 years or older by the year 2035.⁵ The fastest growing segment of the population are those who are 85 and older. They are the ones who will have the larger number of chronic conditions because they accumulate over time and with age. These kūpuna are at risk to have the highest rates of Alzheimer's disease and other dementias, and to have the highest care needs. Fewer caregivers

will be available. Tremendous stress will be placed on the system of care. The majority of the care that the "oldest old" currently receive outside of institutional settings is informal care from family.⁶

The state and federal governments have taken significant leaps with the establishment of the Kupuna Caregivers Program and the RAISE Family Caregiver Advisory Council, respectively. However, even if all the legislation described in this report were enacted, it would not meet all the needs of Hawai'i's next generation of elders and persons with disabilities. We must continue to think five to 10 years ahead, and beyond.

The Challenges

We must strongly consider and robustly address five challenges:

1. How do we create cohesive, comprehensive, coordinated, efficient, purposefully-built, wide networks and systems of support for caregivers and their care recipients, ones that will meet the needs of all our island populations, especially in rural areas which are often inadequately and poorly served?
2. How many professionals and paraprofessionals are required to meet the care needs of our kūpuna and disabled?





3. How will we develop (*i.e.*, recruit, educate, continuously educate, and retain) the necessary numbers of professionals and paraprofessionals, as well as provide appropriate training for family caregivers?
4. Given the limitations of both state and federal government ability to finance programs and services, how can government develop more extensive and effective partnerships with the private, for-profit sector to meet colossal and enormous future needs?
5. We recognize that older adults play a key role in building strong, resilient communities. Community members learn from the successes, failures, joys, and difficulties of kūpuna. How can we encourage kūpuna to connect and engage with the community to support and inspire others?⁷

We are called to:

- Intensify our work to overcome the challenges of the Silver Tsunami;



- Advance, enact, and (when prudent) adjust policies and programs that work not just for the present, but for a future where never before have so many lived so long; and
- Develop strategies and implement systems that promote and support the health, safety, and independence of our aged, disabled and their family caregivers.

Currently, COVID-19 threatens the policies and programs that protect the welfare of our kūpuna and persons with disabilities. Regardless of the crisis at

hand, their health and well-being must always be secured as a continuing facet of a just society.

References

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Information, & Education & Research Resources

Public & Nonprofit Agencies

Hawai'i Aging and Disability Resource Center

The Hawai'i Aging and Disability Resource Center (ADRC) helps older adults, individuals with disabilities, and family caregivers find options for long-term supports and services available in the state of Hawai'i. The ADRC is a highly visible and trusted source of information to where people of all incomes and ages can turn. ADRC staff will help determine if you are eligible for government paid programs, assist you in finding providers you may pay for yourself, and work with you to develop an individual plan to meet your future long-term care needs. The assistance is paid for by the state and counties at no cost to you.

Phone: 643-ADRC (643-2372)
TTY Line: 643-0889
Email: ADRC@doh.hawaii.gov
Web: hawaiiadrc.org

Executive Office on Aging

The Executive Office on Aging (EOA) is the designated lead agency in the coordination of a statewide system of aging and caregiver support services in the state of Hawai'i, as authorized by federal and state laws.

The federal Older Americans Act establishes an Aging Network and provides federal funding for elderly support services, nutrition services, preventive health services, elder rights protection, and family caregiver support services. Chapter 349 of the Hawai'i Revised Statutes establishes the Executive Office on Aging as the focal point for all matters relating to older adults' needs and the coordination and development of caregiver support services within the state of Hawai'i.



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Web: health.hawaii.gov/eoa

Elderly Affairs Division

City & County of Honolulu
Derrick Ariyoshi,
County Executive on Aging
Kapalama Hale
925 Dillingham, Suite 200
Honolulu, Hawai'i 96817
Information and Assistance
Senior Helpline: (808) 768-7700
Web: www.elderlyaffairs.com

Hawai'i County Office of Aging (HCOA)

William Horace Farr
Acting County Executive on Aging
Website: www.hcoahawaii.org
Hilo: Phone: (808) 961-8626
Kona: Phone: (808) 323-4392

Kaua'i Agency on Elderly Affairs

Kealoha Takahashi,
County Executive on Aging
Agency On Elderly Affairs
Pi'ikoi Building
4444 Rice Street, Suite 330
Lihue, Kaua'i, Hawai'i 96766
Phone: (808) 241-4470
Email: elderlyaffairs@kauai.gov
RSVP (Volunteer Program): rsvp@kauai.gov
Web: www.kauai.gov/Elderly

Maui County Office on Aging (MCOA)

Deborah Stone-Walls
County Executive on Aging
95 Mahalani Street, Room 20
Wailuku, Hawai'i 96793
Phone: (808) 270-7774
Email: mcoa.adrc@mauicounty.gov
Web: www.mauicounty.gov/255/Office-on-Aging

Hana Senior Center

5101 Uakea Street, Building G
Hana, Hawai'i 96713
Phone: (808) 248-8833

West Maui Senior Center

788 Pauoa Street, Suite 103
Lahaina, Hawai'i 96761
Phone: (808) 270-4387

South Maui

16 Ehiku Street, Suite 1
Kihei, Hawai'i 96753
Phone: (808) 875-0033

Moloka'i

290 Kolapa Place, Suite 1
Kaunakakai, Hawai'i 96748
Phone: (808) 553-5241

Lana'i Senior Center

309 Seventh Street
Lana'i City, Hawai'i 96763
Phone: (808) 565-6818

AARP Hawai'i

Keali'i Lopez, State Director
1001 Bishop Street, Suite 625
Honolulu, Hawai'i 96813
Toll-Free: 866-295-7282
Email: hiaarp@aarp.org
Web: states.aarp.org/hawaii

Disability and Communication Access Board

Kirby Shaw, Executive Director
1010 Richards Street, Room 118
Honolulu, HI 96813
Main Office Phone:
(808) 586-8121 (Voice)
(808) 586-8162 (TTY)
(808) 586-8129 (Fax)
Email: dcab@doh.hawaii.gov
Website: health.hawaii.gov/dcab/

Call DCAB toll free from your county:
Hawai'i County, 974-4000 ext. 6-8121#
Kaua'i County, 274-3141 ext. 6-8121#
Maui County, 984-2400 ext. 6-8121#
Moloka'i & Lana'i, 1-800-468-4644 ext. 6-8121#



Hawai'i Family Caregiver Coalition

Gary Simon, President
Email: garysimon@hawaii.rr.com
Web: hfccoalition.org

Hawai'i Pacific Gerontological Society

Debbie Kim Morikawa, President
P.O. Box 3714
Honolulu, Hawai'i 96812
Web: hpgs.org/index.html
Sherry Goya, HPGS Executive Director
Phone: (808) 722-8487
Email: sgoyallc@aol.com

Medicare Nursing Home Compare

Nursing Home Compare has detailed information about every Medicare- and Medicaid-certified nursing home in the country. A nursing home is a place for people who cannot be cared for at home and need 24-hour nursing care.
Web: www.medicare.gov/nursinghomecompare/search.html

Project Dana

Project Dana is a Faith In Action program that provides a variety of services to the frail elderly and disabled to ensure their wellbeing, independence, and dignity in an environment of their choice. Support comes from a corps of trained volunteers guided by the principle of "Dana," which combines selfless giving and compassion without desire for recognition or reward. Project Dana recruits and trains volunteers across the state to assist the frail and elderly with:

- Friendly visits
- Respite services
- Transportation to medical appointments, grocery shopping, and religious services
- Telephone visits
- Minor home repairs, light housekeeping
- Home safety assessment/education
- Family caregiver support

Volunteers are sensitive to diverse cultures and traditions. They receive initial and continual training and education from the project, and are managed by trained volunteer coordinators from partner congregations.

Cyndi Osajima, Executive Director
2720 Nako'oko'o Street
Honolulu, Hawai'i 96826-4700
Phone: (808) 945-3736
Email: info@projectdana.org
Web: www.projectdana.org

St. Francis Healthcare System

2228 Liliha Street, Suite 300
Honolulu, Hawai'i 96817
Email: info@stfrancishawaii.org
Web: www.stfrancishawaii.org
Phone: (808) 547-6500

Educational & Research Institutions

The University of Hawai'i at Mānoa

Center on Disability Studies

University of Hawai'i at Mānoa
1410 Lower Campus Road, #171F
Honolulu, Hawai'i 96822
Phone: (808) 956-5142
Email: cdsweb@hawaii.edu
Web: cds.coe.hawaii.edu

Center on Aging

University of Hawai'i at Mānoa
Myron B. Thompson School of Social Work
Gartley Hall
2430 Campus Road
Honolulu, Hawai'i 96822
Phone: (808) 956-5001
Email: uhcoa@hawaii.edu
Web: www.hawaii.edu/aging

Center on the Family

University of Hawai'i at Mānoa
2515 Campus Road, Miller Hall 103
Honolulu, Hawai'i 96822
Phone: (808) 956-4132
E-mail: cof@ctahr.hawaii.edu
Web: uhfamily.hawaii.edu

Elder Law Center

University of Hawai'i at Mānoa
William S. Richardson School of Law
Professor James H. Pietsch,
Director/Attorney
2515 Dole Street, Room 201
Honolulu, HI 96822
Phone: (808) 956-6544
Web: www.hawaii.edu/uhelp/index.html

Hā Kūpuna

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Public Policy Center

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Aging & Disability Issues 2021

A Guide for Hawai'i's Legislators, Organizations & Citizens