

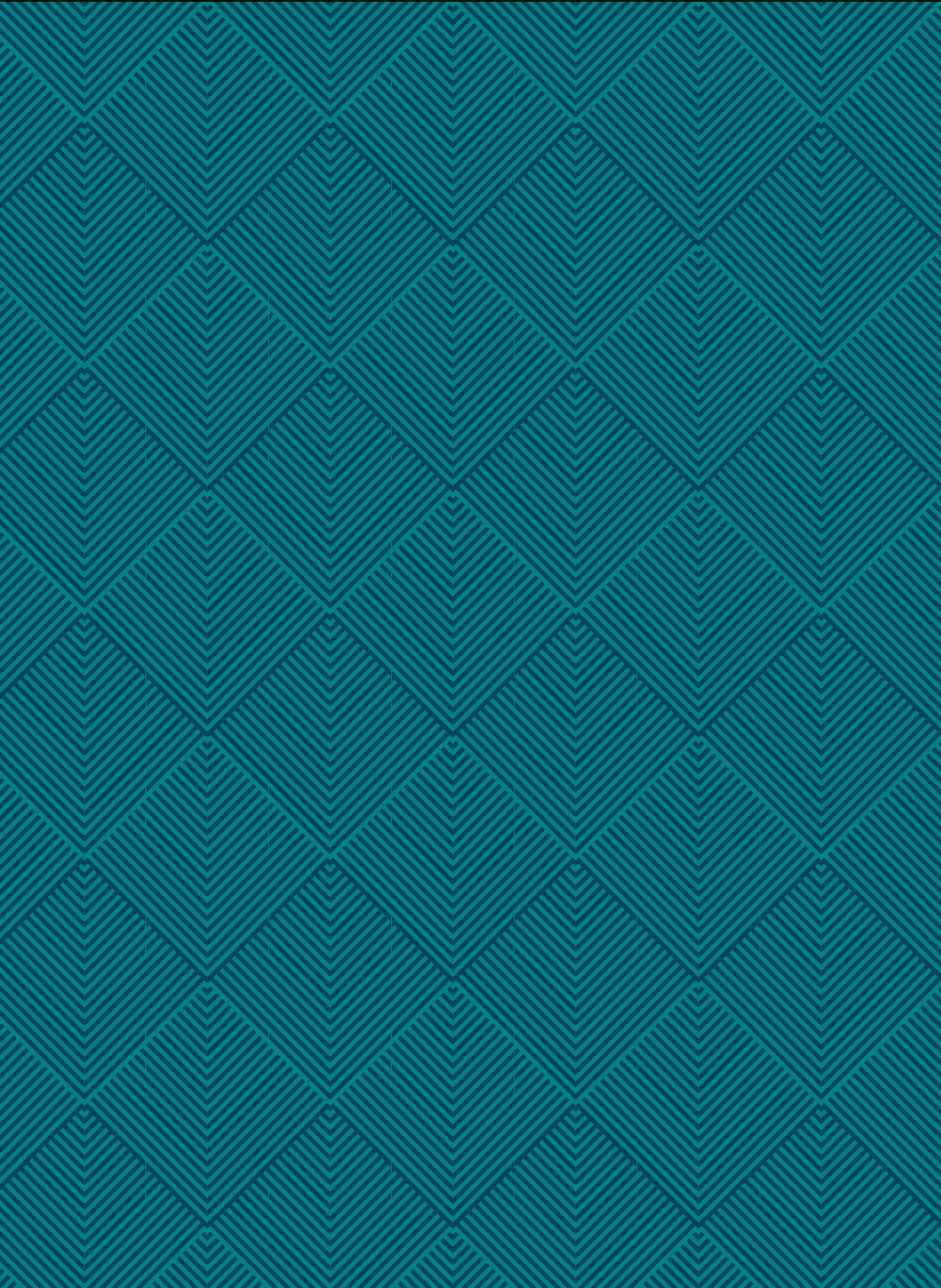
The background of the cover is a photograph of a tropical scene at sunset. Several tall palm trees are silhouetted against a sky with soft, orange and blue clouds. In the lower right, a portion of a modern building with a balcony is visible. In the lower left, a group of people is sitting on a grassy area near the water.

Aging & Disability Issues 2020

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



Sunset, Kaua'i, Hawai'i



Contributing Authors

- Kevin Dusenbury, BS
- Craig Gima, BA
- Cullen Hayashida, PhD
- John G. McDermott, LSW, ACSW, MDiv
- Ian Ross, BA
- Gary Simon
- Eldon Wegner, PhD
- Kathy Wyatt, RN, MSN, MBA, LNHA
- Sarah Yuan, PhD

Authors of personal stories acknowledged with respective stories where known.

Hawai'i Family Caregiver Coalition Board of Directors

- Kevin Dusenbury, BS
- Cullen Hayashida, PhD
- Lyn Moku
- David Nakamaejo
- Cyndi Osajima, MPH
- Gary Simon
- Audrey Suga-Nakagawa, MPH
- Helen Wagner
- Francine Wai, MA
- Eldon Wegner, PhD
- Kathy Wyatt, RN, MSN, MBA, LNHA



Ageing & Disability Issues 2020

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

Section 1

Introduction & Overview..... 3

Section 2

Keeping Kūpuna Healthy: Kūpuna Care; Aging & Disability Resource Centers;
Healthy Aging Partnership Program; Long-Term Care Ombudsman Program..... 6

Section 3

Aid to Caregivers: Kūpuna Caregivers Program; Paid Family Leave; Caregiver Education 12

Section 4

Alzheimer's Disease & Related Dementias..... 16

Section 5

Affordable Prescription Drugs 18

Section 6

Retirement Years: Hawai'i Saves Program & Active Aging 19

Section 7

Conclusion: A Path Forward 21

Section 8

Information, Education & Research Resources..... 24

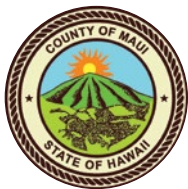
About the Hawai'i Family Caregiver Coalition, the Maui County Office On Aging, the Hawai'i Pacific Gerontological Society, the Disability and Communication Access Board, and St. Francis Healthcare System of Hawaii.



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@aarp.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.

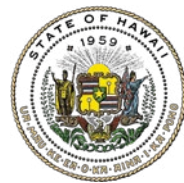
For more information about MCOA, please call Deborah Stone-Walls, Director, at (808) 270-7774. MCOA's mailing address is: Maui County Office on Aging, J. Walter Cameron Center, 95 Mahalani Street, Room 20, Wailuku, Hawai'i 96793.



hawaii pacific gerontological society

Organized in 1979, the Hawai'i Pacific Gerontological Society (HPGS) is a not-for-profit organization whose mission is "to provide professionals and students in the field of aging with vital information, workshops, networking, and scholarships to enhance the gerontology workforce; to support the creation of needed policies and programs; and to deliver excellent service to the aging population in Hawai'i and the Pacific."

If you are interested in pursuing this mission, you are invited to join the HPGS. Please visit the HPGS online at www.hpgs.org or mail your inquiry to: P.O. Box 3714, Honolulu, Hawai'i 96812.



DISABILITY AND COMMUNICATION ACCESS BOARD

The Disability and Communication Access Board (DCAB) is a governor-appointed state agency whose mission is to promote the independence and civil rights of individuals with disabilities. DCAB supports family and caregiving programs, as well as universal and accessible design to allow individuals to live in the community versus institutional settings.

For more information, contact Kirby Shaw, Executive Director, at dcab@doh.hawaii.gov, or at (808) 586-8121. The mailing address is: 1010 Richards Street, Room 118, Honolulu, Hawai'i 96813.



St. Francis

HEALTHCARE SYSTEM OF HAWAII
A Legacy of Caring for Hawaii's People

St. Francis Healthcare System of Hawaii is one of the largest providers of multi-faceted care options for seniors and caregivers in the Islands. Sponsored by the Sisters of St. Francis of the Neumann Communities, it is the only Catholic healthcare system in Hawai'i.

St. Francis currently offers:

- Care navigation services
- Caregiving training and support
- Adult daycare
- In-home bathing & personal care services
- Preschool
- Spiritual retreat center
- Hospice care in homes, nursing homes, and at St. Francis Healthcare System's inpatient facility in Nu'uano; and
- Outreach to the homeless in Waianae.

The health and wellness programs offered by St. Francis Healthcare System of Hawaii are rooted in a legacy of caring and compassion that began with St. Marianne Cope and the Sisters of St. Francis, who came to Hawai'i to care for those with Hansen's disease in 1883.

Mailing address:

St. Francis Healthcare System
2226 Liliha Street, #227

Honolulu, Hawai'i 96817

Email: info@stfrancishawaii.org

Website: stfrancishawaii.org

Phone: (808) 547-6500



Introduction & Overview

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

This 2020 issue of the Aging & Disability Issues report is the 15th 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 Hawai'i Disability and Communication Access Board (DCAB), 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 2020.

Sections 2 through 6 describe the priority issues for the Legislature in the 2020 session as designated by the major groups that advocate for the frail elder and disabled populations and their caregivers. The sections explain why these issues are important, and provide background information concerning them. The six sections also discuss the specific bills that address these priority areas and their status at the time of this writing.

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.

In addition, 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 in 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 2020

An estimated 41 million family caregivers in the United States provided 34 billion hours of unpaid care to adult loved ones in 2017, according to AARP's 2019 *Valuing the Invaluable* report, the latest in an ongoing series of reports that look at the contributions and needs of family caregivers across the country. The report estimates the approximately 34 billion hours caregivers contributed in 2017 were worth \$470 billion — more than

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total out-of-pocket spending on health care in the U.S. that year (\$366 billion), and all money spent on paid caregiving in 2016 (also \$366 billion). The report 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 mid-life and beyond.¹

Two Thousand Twenty is the year for us to build upon the foundation built over the last 30 years. Family caregiver support is now firmly established as a national priority with the launch of the RAISE Family Caregiving Advisory Council, which acknowledges 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 HFCC has advocated, the Council is charged with

making recommendations for a national caregiving strategy.

The strategy will identify actions communities, providers, government, and others are taking and may take to recognize and support family caregivers. It will include:

- Promoting greater adoption of person- and family-centered care in all healthcare and long-term service and support settings with the person and the family caregiver at the center of care teams
- Assessment and service planning (including care transitions and coordination) involving care recipients and family caregivers
- Information, education, training supports, referral, and care coordination
- Respite options
- Financial security and workplace issues.²

The Hawai'i Family Caregiver Coalition was pleased to work with the U.S. De-

partment of Health and Human Services to advocate for the appointment of Deborah Stone-Walls, the Executive on Aging for the Maui County Office on Aging, to the Family Caregiving Advisory Council.

Hawai'i's economy is expected to continue positive growth in 2020, with real GDP growth forecast at 1.2%. According to the November 2019 Blue Chip Economic Consensus Forecasts, U.S. real GDP is expected to increase by 1.8% in 2020.³ Thus, more resources may be available to address care issues, including aiding family caregivers.

The Older Americans Act (OAA) connects older adults and their caregivers to services that help older adults age with health, dignity, and independence in their homes and communities. In 2020, Congress must reauthorize this vital federal program that serves every community in the country.⁴ 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.

In May of 2019, Governor Jay Inslee signed into law a bill making the state of Washington the first in the nation to create a state-run long-term care insurance benefit to help its residents afford the high cost of services ranging from assistance at home to nursing home stays. The Long-Term Care Trust Act will provide a lifetime benefit of \$36,500, indexed annually for inflation. Workers will be able to access their benefits once they have paid into the program for ten years. Some may be able to access benefits if they have worked continuously for three of the last six years. Beginning in 2022, employees would have just over one half of one percent deducted from their wages to pay for the insurance. Benefits will be available to active employees and retirees starting in 2025.

Here in Hawai'i, Governor David Ige and the State Legislature have supported innovations such as Kūpuna 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.

The Governor and House and Senate leadership have committed to a package of bills to make life better for our working families. Priorities include increasing the minimum wage, tax relief, reducing the cost of childcare, building affordable homes, reducing homelessness, investing in agriculture and self-sufficiency, developing clean energy sources, sustaining our economy and culture, and playing our part in preventing climate change.⁶ These priorities require enormous funding.

However, investments in critical services for our rapidly-aging population and those with disabilities are also priorities. The efforts of the Legislature's Kūpuna Caucus, led by co-convenors Representative Gregg Takayama and Senator Sharon Y. Moriwaki, will be vital. In addition, 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

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 to support them so they can remain living in their own home and community regardless of their 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:

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

Kūpuna Care

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

er comparable services. Kūpuna Care services include adult daycare, assisted transportation attendant care, case management, chore help, homemaker/housekeeping, personal care, and home-delivered meals. With an annual budget of \$8.73 million, the state has supported services that enable older adults to remain in their homes and communities, delaying premature placement to expensive residential care facilities. Annual budget funding is allocated to the Executive Office on Aging (EOA). The EOA then distributes the funds to the Area Agency on Aging (AAA) in each county, which administers the program and contracts for services with private non-profit and for-profit agencies. The services reached almost 9,000 older adults in FY19.

As Hawai‘i’s older adult population increases rapidly with the most substantial increase being those age 85 and over, ensuring adequate and economical care in the least restrictive environment is crucial. Recognizing the critical role of the Kūpuna Care program in the state’s long-term support service system, the Ige Administration requested \$8.73 million in the FY20/FY21 biennium budget for this program, which was approved in the 2019 Legislative Session. Until this year, only about half (\$4.85 million) of Kūpuna Care program funding

was in the EOA’s base budget, and the rest had to be determined annually through special budget bills. Having the Kūpuna Care program appropriately funded in the base budget helps provide a consistent and stable program foundation, which is a necessary condition for meeting the increasing needs of older adults throughout the state.

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, 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 support and services. ADRCs also 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 development and implementation of ADRCs will ensure access to high-quality care through person-centered services, which optimizes choice and independence, encourages personal responsibility, and provides support so individuals and their families can make informed decisions.

Hawai‘i’s ADRCs are administered by the Executive Office on Aging (EOA) and implemented by each of the county Area Agencies on Aging (AAA). The development of Hawai‘i’s ADRCs began in 2006 when the EOA received a federal grant to pilot the system and continued with the support from several federal grants and the Hawai‘i State Legislature. Since 2016, the ADRC system has been implemented statewide, with the operation customized by each AAA to meet county-specific needs while adhering to a standard set of functional criteria across all counties. The ADRC system offers a full range of information on long-term support programs and benefits; conducts the assessment on individuals’ needs for services to maintain independent living in the community; and

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EnhanceFitness at the Makawao Hongwanji Mission

Back to the Farm

By Claudette Medeiros

Maui County Office on Aging

Falling off a ladder while picking avocados during the peak of avocado season in the summer of 2013 was something Blanche Ito never thought would happen. “Falling would cross my mind sometimes, but I never thought it would happen,” she said. “Even at 72-years-old, I could climb ladders. I didn’t think I would fracture my back.” Blanche had

been picking fruit from a ladder almost daily for decades. After her fall, Blanche was limited in what she could do physically as she was experiencing great pain and needed to wear a back, body, and neck brace. Although she was mobile, exercise was limited. Blanche was unable to finish avocado season and needed to stay away from her farm.

Blanche felt her back was starting to finally heal when she enrolled in Enhance®Fitness, an exercise program designed for seniors to improve cardiovascular fitness, strength, flexibility, and

balance. She learned about EnhanceFitness from her church and friends who were program participants. “My close friends told me about EnhanceFitness and how they thought the classes could help me, since they were feeling better after a year in the classes,” she related. Skeptical about how the program could help her, Blanche shared this information with her doctor, who agreed EnhanceFitness could be very beneficial physically, mentally, and socially. Blanche’s first class was in October 2013, the start of persimmon season. “When I joined the program, my goal was to heal my back and to get rid of my hunchback,” she said. “I needed to do something. I was suffering and persimmon season was going to start.” Blanche knew she needed to do something to help her back: “I couldn’t be on the farm with my back like that—I needed to get back.” She has been diligently attending EnhanceFitness classes three times a week at Makawao Hongwanji Mission ever since.

Blanche credits her participation in the exercise program to getting back to her two acres of trees. “I have 70 trees to take care, two sea-

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is a single point of entry for Kūpuna Care and Older Americans Act (OAA) services. In FY19, the ADRCs had nearly 53,000 contacts, representing a 50% increase in its serving capacity from FY17. The ADRCs linked about 9,000 older adults to publicly-funded long-term services and support programs and provided assessment services to nearly 5,000 individuals.

In the last Legislative Session, Governor Ige’s request to allocate \$3.1 million to EOA’s base budget for the ADRC system was approved. It was a significant milestone for the ADRC system, which went from having 55% (1.7 million) of its total budget rely on annual special appropriation, to receiving total funding in the base budget. With sustainable funding, the ADRC system will continue to grow in capacity and become fully functional according to federal requirements, and be a dependable and reliable resource for long-term support services for Hawai‘i’s residents.

The Healthy Aging Partnership Program

By Eldon L. Wegner, PhD

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 Public Health Program successfully adapted evidence-based health promotion and disease prevention programs for Hawai‘i’s multicultural population, and has conducted continuous evaluation of the outcomes of the programs until last year.

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. Enhance®Fitness, an ongoing exercise program designed for older adults held three-times a week.

Better Choices, Better Health has had a total of 2,998 participants. The workshops complement medical-professional recommended treatment plans. The participants learn skills to help manage their health conditions and interact with their health care providers. A six-month follow-up evaluation found that participants had a decreased number of visits to physician offices and emergency rooms, and a cost-savings analysis estimated a net saving of \$655.81 per participant. Participants also reported increases in

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Back to the Farm

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sons of picking fruit.” After six years of being an EnhanceFitness participant, Blanche does not climb ladders like she used to but she is on her farm almost daily. “I am now able to work on my avocado and persimmon farm,” she said. Blanche believes she has become a healthier person since joining the exercise program. During the six years she has been an EnhanceFitness participant, Blanche has witnessed many great achievements by her classmates, such as seeing an older participant’s balance, strength, and overall health improve to the point that “they walked around Disneyworld for a week with no help at 80 years old.” Another classmate, “younger than me, was hit by a bus during their morning walk.” This person

was told EnhanceFitness participation would need to be put on hold for at least 10 to 12 months, but because of the strength they had built, they came back to class after only 6 months. These achievements have kept Blanche motivated to keep participating in the program. “I know EnhanceFitness helped me heal, and when I see the others get stronger and comeback from getting hit by a bus, it makes me want to continue with the program,” said Blanche, who feels EnhanceFitness is the “perfect program” for her and many of her classmates, whose ages range from 60 to 90-plus years. “This program is designed for seniors like us,” she continued. “We’re all getting older and we need to support each other.” EnhanceFitness classes have given Blanche opportunities to meet and make new friends, as well as spend time with old friends. Ac-

ording to Blanche, “We all need socialization; for some, our classes are the only socialization they get. This year, she will be 79, and will keep going to the classes as long as they are offered. “It’s the only way I know I can keep healthy,” Blanche concluded. “Not only my balance and posture improved but my brain too with the memory exercises. EnhanceFitness has helped me regain my posture, better my body and my mind, and keeps me healthy enough to keep me working my farm.”

For more information about the Hawai’i Healthy Aging Partnership, please visit www.hawaiihealthyaging.org or call the Executive Office on Aging at (808) 586-0100. To learn more about EnhanceFitness in Maui County, please visit the Maui County Office on Aging online at www.mauicountyadrc.org, or call (808) 270-7774 or toll-free at (808) 643-ADRC.



strength exercise and aerobic exercise, and fewer symptoms of pain, fatigue, and shortness of breath.

The EnhancedFitness Program served 1,742 persons; 65% were age 70 to 89. After 16 weeks, participants reported fewer falls and an 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 exercise. Funding for EnhanceFitness for 575 kūpuna was estimated to save \$789,000 in healthcare costs. Prevention programs are always cost-effective with regard to chronic disease.

Hawai’i’s Healthy Aging Partnership

Program has received numerous national awards, including the 2013 award for Excellence in Multicultural Aging from the American Society on Aging.

Legislative Support Needed

The Healthy Aging Partnership Program is one of the few state programs that implements evidence-based interventions. Systematic evaluations of program outcomes have been conducted, and documented evidence of cost-savings to the state have been provided. However, consistent support is needed from the Legislature. Resources are desperately needed to not only continue the award-winning program, but to allow it to expand.

No appropriations were passed for the Healthy Aging Partnership Program in the 2018-19 budget year. As a result, the City and County of Honolulu had to close its EnhancedFitness program sites. Kaua’i and Maui received county funds to keep some of their programs open. Due to budget restrictions, a number of trainers were let go, and the Executive Office of Aging suspend the program evaluation contract with the Public Health Program at the University of Hawai’i. Funding for the 2019-20 fiscal year was restored, and the Healthy Aging Partnership is rebuilding its staff and programs statewide.

However, if the appropriation proposed in **HB 1866** and **SB 2335** fails to pass this session, the entire Healthy Aging Partnership program may end. The health of our citizens would be negatively impacted and health care costs for the state would increase. Thus far, **SB 2335** has cleared the subject matter committees and the Senate Ways and Means Committee, and **HB 1866** has cleared the subject matter committees in the House and is waiting to be heard in the House Finance Committee. The bills need to cross over and be heard by the other body in the coming weeks. We strongly support maintaining these programs.

Long-Term Care Ombudsman Program

By John McDermott, LSW, ACSW, MDiv

Companion bills **SB 2337** and **HB 1872** supporting the Long-Term Care Ombudsman Program (LTCOP) are of incredible importance. Variations of these bills have been introduced multiple times before without success, but with the growing numbers of Hawai'i seniors who need long-term care placement, it has never been more important than now to pass these bills.

The purpose of these bills is to appropriate funds to the LTCOP for six full-time (6.0 FTE) ombudsman specialist positions, two each on O'ahu and Hawai'i Island, and one each on Kaua'i and Maui.

The LTCOP protects our most vulnerable kūpuna, who are often hidden from sight. The LTCOP should not be confused with Adult Protective Services or the Department of Health's Office of Health Care Assurance (the licensing agency). APS only investigates cases of abuse or neglect. The Department of Health focuses mostly on annual inspections. They also investigate complaints, but the LTCOP is uniquely there to *proactively* prevent problems; work with residents, family, and staff to make facilities better; provide support and protection to the residents; and investigate complaints and address concerns by visiting at least once per quarter.

Background

In 1978, the Older Americans Act (OAA) required all states have an Office of the Long-Term Care Ombudsman Program. In 1979 **HRS 349** was amended to conform with federal law.

The National Institute of Medicine's 1995 report, *Real People, Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act*, recommended 1 FTE ombudsman per 2,000 residents at a minimum. Currently, Hawai'i has 1 FTE ombudsman per 12,889 residents; the national average is 1 ombudsman to 2,208 beds.

This study was done at a time when most residents were in nursing homes. Today's residents live in many more types of facilities: adult residential care homes, assisted living facilities, community care foster family homes, and adult residential care homes. Additionally, in Hawai'i they are spread over six different islands. The logistics are therefore more complicated than in 1995, and require greater staffing and funding.



Numbers by Island

The OAA mandates all residents "have regular and timely access to the LTCOP services." The Administration on Aging (a part of the Administration for Community Living) interprets this as "every resident, at a minimum, should be visited quarterly." Our 12,889 long-term care residents live in 1,727 facilities. A quarterly visit would mean 28.78 facility visits per day.

Kaua'i

- 5 Nursing Homes with 333 beds
- 1 Assisted Living Facility with 100 beds

- 21 Community Care Foster Family Homes with 48 beds
- 6 Adult Residential Care Homes with 26 beds
- **Total:** 33 Long-Term Care facilities; 507 beds

Maui

- 4 Nursing Homes with 459 beds
- 1 Assisted Living Facility with 144 beds
- 59 Community Care Foster Family Homes with 150 beds
- 12 Adult Residential Care Homes with 72 beds
- **Total:** 76 Long-Term Care facilities; 825 beds

Hawai'i Island

- 8 Nursing Homes with 870 beds
- 1 Assisted Living Facility with 220 beds
- 125 Community Care Foster Family Homes with 339 beds
- 42 Adult Residential Care Homes with 190 beds
- **Total:** 176 Long-Term Care facilities with 1,619 beds

O'ahu

- 30 Nursing Homes with 2,830 beds
- 15 Assisted Living Facilities with 2,379 beds

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- 1,024 Community Care Foster Family Homes with 2,616 beds
- 373 Adult Residential Care Homes with 2,113 beds
- **Total:** 1,442 Long-Term Care facilities with 9,938 LTC beds
- **Grand Total:** 1,727 facilities with 12,889 beds

Travel to a neighbor island from O’ahu includes airfare, car rental, airport parking, plus per diem. For example, on January 22, 2020, the cost was approximately \$248 per trip. There is also a time factor, which includes early arrival before departure, picking up a rental car, driving to facilities, and the journey back to O’ahu, all of which totals approximately four hours, leaving just four hours in a day to visit residents.

The time and cost involved demonstrates that it is much more effective to have ombudsmen who live on the island they serve. A local ombudsman would know the people and the community, and can be available for evening or weekend investigations, family councils, senior fairs, recruitment of volunteers, and working with local media, county councils, and local Area Agencies on Aging. Finally, as neighbor island residents pay the same federal and state taxes as O’ahu, they should enjoy the same regular and timely access to services provided by the LTCOP.

One FTE ombudsman for the entire state is clearly not enough. As our young people move away because housing and other expenses make it too expensive to live here, extended ‘ohana are less available to help and protect the kūpuna who live here. Ombudsmen help fill that loss. Residents know what they tell an ombudsman is confidential. They know the ombudsman will visit on a regular basis, so if their situation deteriorates, the ombudsman will be there to advocate on their behalf.

Alternatives to FTE Ombudsmen

Contracting

Some propose we continue contracting out these positions and not increase the size of state government and associated



liabilities. On one hand, our contractors have made a *major* difference. For the first time since 1978 when the LTCOP was established, every facility on the neighbor islands received quarterly visits by an ombudsman (monthly on Kaua’i). We resolved most of the residents’ complaints and learned of several systemic problems we need to address with the Department of Health.

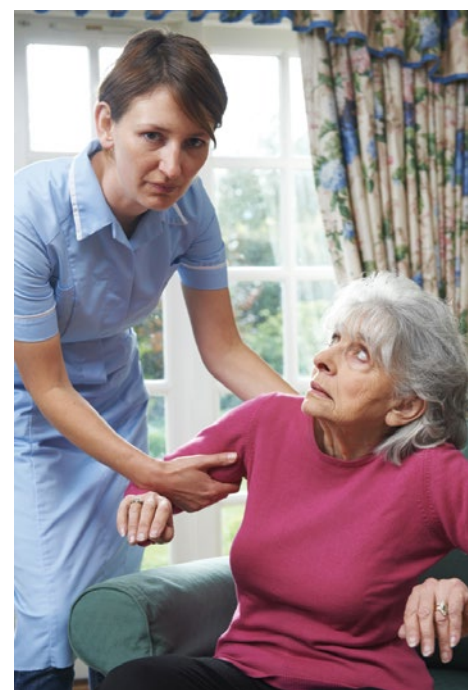
However, contractors take a long time to find and train, and when a contract is over, the process must start all over again. In this field of work, one gets better over time. The cumulative experience of working with people in crisis is critical. Further, with contracting, the focus of neighbor island service tends to be from a Honolulu perspective. These issues make it unfair to neighbor island kūpuna.

The following is a brief review of our 2017 contractor experiences:

After receiving permission to post the contracts and get the word out by various email list-servers, we received only one application for Kaua’i, one application for Maui, one application for Hilo, and after many more months, one application for Kona. This was disappointing, but not a surprise. With Hawai’i’s high cost of living, young people need full-time jobs with benefits. The labor market in Hawai’i is very tight, so there is a lot of competition for workers. All of the ap-

plicants were recent retirees who knew about the LTCOP and wanted to help, but discovered this type of advocacy within long-term care facilities is much more emotionally draining than they had expected. These contractors were all a part of the sandwich generation. Some were taking care of both parents and children who were starting lives of their own.

After her one-year commitment, our Kaua’i contractor quit on February 7, 2020 to care for multiple family mem-





bers. Her plate was full and she had to move on. We contracted with the Kaua'i Agency on Elderly Affairs after receiving no applications.

Our Maui contractor was previously an ombudsman volunteer for seven years, so he had no learning curve. We were happy he applied for the position and he was glad to earn some money for his work, as there is no funding to reimburse volunteers for their gas mileage to facilities. Unfortunately, he is now having some health issues and may need to step down.

Our Hilo contractor worked as director of social services at several nursing homes, so she also had adequate experience. However, she needed surgery on her leg after she was hired and was not able to do the amount of walking required for the job.

Fortunately, the Hawai'i Island Office on Aging connected us with a DOH public health nurse practitioner who had just retired after 40 years and wanted to help the LTCOP after unexpectedly losing her husband. However, she wants us to find a replacement, because she is now ready to move on.

We finally had an applicant from the mainland who recently retired to Waikoloa and wanted to get to know Hawai'i's

people and history through the ombudsman position. She was very good, but Waikoloa proved more expensive than she had budgeted and left to work full-time. Virtually every organization has had difficulty finding workers on the Kona side.

Volunteers

Volunteers have been proposed as a solution. A volunteer coordinator position was created in 2001 with the support of the Legislature. Since then, almost 250 volunteers have been certified. Volunteers are carefully screened, provided with 20 hours of classroom training, and 8 hours of one-on-one on-site training. They are asked for a one-year commitment (many have given years!). We all meet as a group monthly so everyone stays on the same page and we learn from one another by discussing cases and having guest speakers. As of this writing, we have 21 wonderful volunteers, but most want to be assigned to only one facility, and there are 1,727 facilities.

It is much easier to get volunteers for a

day. That's not the LTCOP, which is a commitment of one year to make weekly visits to talk story with residents, listen to their concerns and problems, then work on solutions with administration. Sometimes there is success, but not always. Vulnerable seniors with dementia or other limitations don't call for help. Many don't have a phone or even know what "ombudsman" means. They must be visited at their facility and engaged face-to-face until trust is developed and they open up about their concerns. There is always the fear of retaliation, so weekly follow-up visits to make sure the residents are safe after complaining is critical.

Partnerships

We have and will continue to partner with anyone interested in protecting our kūpuna.

Conclusion

I have been doing this for 22 years, but I am getting ready to retire. FTEs who will make the commitment to be there for 25 years are needed. Our contractors, volunteers, and partnerships are greatly appreciated, but they are not substitutes for permanent FTE staff. Our senior population is growing rapidly, and our young residents continue to move away. The need for LTC ombudsman advocates is growing in numbers and importance. Please support **HB 1872** and **SB 2337** so we can better protect our seniors who are responsible for everything we have and love about Hawai'i.





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 re-

duce 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 Kūpuna 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 service, home-delivered meals, or other designated services. It allows caregivers to continue to earn their retirement benefits, helps businesses retain experienced workers, and provides peace-of-mind to the caregiver 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) or 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 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 the working caregivers in the workforce while reducing their caregiving burdens.

Kūpuna Caregiver Program Helps Caregivers & Community

By Kevin Dusenbury

Maui County Office on Aging

For the past six and a half years, Rebecca Armato has lovingly cared for her aging parents. While Rebecca was working at her previous job at Huntington Hospital in Pasadena, California, she received a phone call from her dad, Andrew, who lived in Kansas, who said he needed help caring for himself and for Rebecca's mom, Patricia. Rebecca boarded the next flight to Kansas and quickly realized her parents could no longer live independently because the stress of caregiving was taking a significant toll on her father's health. To avoid placement in a long-term care facility, Rebecca moved her parents from Kansas to her tiny apartment in Newport Beach, California. Upon her parents' arrival, Rebecca realized she had to temporarily step away from her career to focus on her parents' healthcare and overall health. After living in her apartment for almost two years, Rebecca decided to make a change for the "Three Musketeers."

After traveling to Hawai'i for over 35 years, Rebecca always dreamed of calling Maui her



Patricia and Andrew Armato

home. In May 2015, the Armatos embarked on their journey to Wailuku. Not knowing how long they had together, the first year was a bucket list of exploring Maui for the Three Musketeers. When it appeared her parents' health would allow it, Rebecca accepted a position at the Pacific Cancer Institute and hired an agency to come into their home while she was at work. It was very

costly. Due to her mother's Alzheimer's disease diagnosis and her father's dementia, Rebecca made a commitment to care for her parents in her home for as long as they lived and make them as safe and as comfortable as possible. According to Rebecca, she read every book she could find on how to prepare to be a full-time caregiver. She also prepared a home that would meet their needs for aging-in-place, including carpet removal and the addition of solid surface flooring to make it easier for shuffling; a stair lift; wheelchair access; and security gate and door locks to prevent wandering. She also "parent-proofed" the kitchen, laundry, and other

areas for safety. Since her parents were experiencing much of their world through sight and smell, Rebecca planted fruit trees, pikake, and night-blooming jasmine so there would be visuals, smells, and tastes they could continue enjoying as their ability to communicate verbally diminished. The Armatos grew up on a farm in rural Michigan,

(Continued on next page.)

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 helps 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, just over 40% of Hawai'i's workforce does not have access to a single day of leave from work, paid or unpaid.¹

In November of 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 of 2019.²

The report has helped to inform legislators' proposals in the 2020 Legislative Session.

HB 2219, introduced by Representatives Aaron Ling Johanson and Linda Ichiyama, and its companion bill, **SB 2491**, introduced by Senator Brian Taniguchi, provide family leave insurance benefits and extends the period of

family leave to 16 weeks for businesses that employ one or more employees who meet the hourly qualifications.

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.

(Continued on next page 15.)

Kūpuna Caregiver Program Helps

(Continued from page 13.)

so having plants and flowers are what they remember best.

In June 2016, Andrew passed away in his daughter's home at 89 years of age, just shy of the Armato's 60th wedding anniversary. After the death of her husband, Patricia's Alzheimer's worsened significantly to the point she required constant supervision and care. Rebecca had no choice to resign from her job because she could not afford reliable in-home care for her mom. As her mom's condition worsened, Rebecca experienced a whirlwind of emotions, including despair and uncertainty. However, she persevered with her commitment to keep Patricia safely in her home for as long as possible.

Over the year, Rebecca began to suffer from caregiver burnout. She had heard about the annual Caregivers' Conference presented by the Maui County Office on Aging from a case manager at Maui Memorial Medical Center. In addition to registering for her first conference, Rebecca requested caregiver support services from the Office on Aging in October 2017. After the Office on Aging determined eligibility for Kūpuna Care services, the case manager authorized person-centered services, which included adult daycare and adult daycare respite. While the addition of these services provided great relief, the cost of in-home care over the previous few years had depleted all of Rebecca's personal savings. Patricia could not contribute to care, as her Social Security benefit barely covered the cost of health insurance, medication, and incontinence supplies.

To pay for the additional days of adult daycare not covered by Kūpuna Care, Rebecca obtained a TSA position in Kahului. While she was thankful to be employed, Rebecca continued to struggle with the costs of care and the balance of caregiving and working full-time. However, she continued to work and care for her mom because of her com-



Rebecca and Patricia Armato

mitment to her mom's well-being. According to Rebecca, 2019 was a life-changing year for the Armatos.

Leveraging her medical practice management experience and expertise from her career at Huntington Hospital in Physician Services, Rebecca secured a job as manager of physician services at Maui Health System in Wailuku. She now works full-time recruiting and retaining physicians to live and practice on Maui.

While the new position is a great fit for Rebecca professionally, there was still a need for her mother's care while she worked during the day. As the adult day care bills continued to grow, Rebecca continued to struggle balancing her caregiving duties with her new position. In July 2017, Governor David Ige signed the Kūpuna Caregiver Program into law, which originally permitted the authorization of home- and community-based services with a value of up to \$70 per day for a caregiver employed at least 30 hours per week. While the Kūpuna Caregiver Program was amended in 2019 to limit the service amount per week, the program continues to be largely successful and beneficial to working caregivers who need the extra assistance to remain in the workforce.

The Office on Aging's care manager believed the Armatos would greatly benefit from the Kūpuna Caregiver Program, which has helped them since October 2018. Rebecca shared that being the only caregiver

er for her 83-year-old mother while working a full-time job is an intricate juggling act. According to Rebecca, "The Kūpuna Caregiver Program provides not just financial support, but much needed emotional support by relieving the stress of worrying how I can continue to care for her in my home, helping me understand I am not alone, and gaining strength from others who are going

through the same feelings and challenges as I am. With the help to continue to send my mom to daycare, I am able to keep her living with me at home – which is what she wanted and what I promised her. The program allows me to find time for me and build in time to replenish myself so I can continue to get up each day and care for both of us. I find myself living both in her past – as the past is the best place for her to linger over her sweet memories, where her happiness still resides – and still see I have my own life and future, and am able to work, helping our medical staff and recruiting new physicians to care for our community members."

Rebecca shared that she does not know if the lawmakers fully realize all of the lives they have touched through Kūpuna Care and the Kūpuna Caregiver Program, but she would like them to know she is truly blessed and thankful for the assistance provided in the programs. If Patricia could still speak, Rebecca knows her mom would express deep gratitude as well, because she sees it in her smile each morning. In addition to helping the Armatos, care and help has enabled Rebecca to continue work that saves the lives of Maui's community members through physician recruitment and retention at Maui Health System.

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

(Continued from page 13.)

The Importance of Caregiver Education

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 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,



Caregivers at an educational workshop

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.

References

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²https://lrh.hawaii.gov/wp-content/uploads/2019_Paid-FamilyLeaveProgramImpactStudy.pdf. Accessed February 24, 2020.

Alzheimer's Disease & Related Dementias

By Ian Ross

The number of older Hawai'i residents is growing, and with it the number of new and existing cases of Alzheimer's disease. Alzheimer's is the sixth leading cause of death in Hawai'i today, and there are more than 29,000 individuals over age 65 living with the disease.

Hawai'i isn't alone in this trend; 5.8 million people in America have Alzheimer's disease today. Alzheimer's disease is the only one of the top 10 causes of death in the United States that cannot currently be prevented, cured, or even slowed. Although deaths from other major causes have decreased significantly, official records indicate that deaths from Alzheimer's disease have increased significantly. Between 2000 and 2015, deaths from Alzheimer's disease as recorded on death certificates increased 123%, while deaths from the number one cause of death (heart disease) decreased 11%.

Individuals with Alzheimer's or other dementias face enormous costs for health care and long-term care, and the cumulative financial burden amounts to one of the most expensive diseases in the country. When controlled for other conditions, people with Alzheimer's or other dementias have twice as many hospital stays per year. Furthermore, Medicare beneficiaries with Alzheimer's or other dementias are more likely than those without dementia to have other chronic conditions, and they make up a large percentage of all elderly people who receive adult day services and nursing home care.

The average senior with Alzheimer's spends \$10,798 per year in out-of-pocket healthcare costs compared to the average senior who spends \$2,336 per year. In the



last five years of life, the out-of-pocket cost increases to \$76,774 annually. Families shoulder 70% of these costs and many caregivers are forced to take drastic financial action. Forty-three percent of caregivers report cutting back on savings and 20% spend their only retirement savings.

This rapid rise in medical costs is clearly an enormous burden nationally, to our state, and, most of all, to people with Alzheimer's disease and their families. Fortunately, long-term care planning can curb some of these costs and improve quality-of-life.

The State of Diagnosis & Dementia-Specific Care Planning

Only about half of those with Alzheimer's have been diagnosed, and most people who have been diagnosed are not aware of their diagnosis. Among those seniors who have been diagnosed, only 33% are aware they have the disease. Even when including caregivers, less than half of those diagnosed or their caregivers are aware of the diagnosis. This is drastically different than awareness of other serious diseases. Ninety percent or more of those diagnosed with cancer or cardiovascular disease and their caregivers are aware of that diagnosis.

Studies have found one of the reasons physicians do not diagnose Alzheimer's in the first place—or do not disclose a

diagnosis once it is made—is because of the lack of time and resources to provide this information and support to patients and caregivers. We need to change to a model where following a diagnosis of Alzheimer's disease, individuals and their caregivers receive information about the diagnosis and available support services.

Sharing a diagnosis is necessary before care planning can occur, which is crucial in improving outcomes for the individual. Care planning allows diagnosed individuals and their caregivers to learn about medical and nonmedical treatments, clinical trials, and support services available in the community—resulting in a higher quality-of-life for both patients and their caregivers. Individuals who receive care planning specifically geared toward those with dementia have fewer hospitalizations, fewer emergency room visits, and better medication management. Alzheimer's complicates the management of other chronic conditions, but care planning can significantly improve care coordination and managing those other conditions. This is a common problem, as more than 95% of people with Alzheimer's and other dementias have one or more other chronic conditions. For example, a senior with diabetes and Alzheimer's costs Medicare 81% more than a senior who has diabetes but not Alzheimer's.

As of January 1, 2018, CPT® billing code 99483 has allowed clinicians to be reimbursed for providing care planning to cognitively impaired individuals. This billing code is available to clinicians treating those with cognitive impairment, including Alzheimer's disease. Physicians, physician assistants, nurse practitioners, clinical nurse specialists, and certified nurse midwives can currently be reimbursed. With this code, clinicians are given the time and resources to provide a comprehensive set of care planning services to patients and their caregivers.

Billing code 99483 requires clinicians to provide detailed, person-centered care planning to receive reimbursement. The new code requires clinicians to provide several services, including:

- Evaluating cognition
- Assessing function/ decision-making capacity
- Reviewing/reconciling prescription medications
- Measuring behavioral symptoms
- Evaluating safety (including driving ability)
- Identifying and assessing a primary caregiver
- Developing advance care directives
- Creating a care plan, including referral to community resources

These services are ultimately used under the code to develop detailed care plans, including referrals to community resources, which are shared with both the beneficiary and their caregiver.

Limited Use of Billing Code 99483

Is the comprehensive care planning benefit reaching people? The short answer is no. In 2017, the first year the benefit was available, 18,669 fee-for-service Medicare beneficiaries received the care planning benefit nationwide. Even after accounting for individuals in Medicare Advantage plans, fewer than 1% of those with Alzheimer's and other dementias received the care planning benefit in 2017.

The initial low rate of usage shows that patients and providers are generally not aware of the existence of the benefit. The good news is that as more people become aware of the benefit, usage it increases. In 2017, usage increased steadily throughout the year to 3.3 times greater in the fourth quarter of 2017 than in the first quarter.

Federal and State Legislation to Improve Reach

Alzheimer's disease is a public health crisis. People with the disease, as well as their families, need this service. Nationally, the Improving HOPE for Alzheimer's Act (**S 880 / HR 1873**) would speed this process up, and the Hawai'i State Legislature is considering action on the state level



(**HB 1873 / SB 2340**) to conduct a one-time outreach program to physicians and appropriate non-physician practitioners.

The Improving HOPE for Alzheimer's Act would build on the care planning benefit by addressing the low usage. The legislation includes provisions of the original HOPE for Alzheimer's Act not implemented by the Centers for Medicare and Medicaid Services (CMS) when it created the new billing code. Specifically, the

Act would require the U.S. Department of Health and Human Services to educate clinicians on care planning services available under Medicare, as well as the care planning billing code. It would also require a report identifying the barriers to individuals receiving care planning services and recommend ways to increase the rate of usage.

SB 2340 would establish an outreach program in the Department of Health to provide a one-time education initiative to inform physicians and appropriate non-physician practitioners participating in Medicare that comprehensive care planning services for those with Alzheimer's disease and related dementias are a covered benefit under Medicare. This

outreach effort would include materials on appropriate diagnostic evaluations, explanations of the requirements for eligibility for comprehensive care planning services, and a required report to the Legislature.

The Alzheimer's Association is here to help people with Alzheimer's disease or related dementias and their families. You can learn more at www.alz.org or call the 24/7 help line at (800) 272-3900.

Affordable Prescription Drugs

Stop Excessive Cost for Prescription Drugs

By Craig Gima

Emile Sloboda, a diabetic who uses the insulin drug Humalog to control his condition, has had to ration his use of the drug because of its cost.

Rationing insulin or any other drug is a dangerous practice and should never happen in a country like America. But it does, and Emile is not alone. A Yale University study found one in four diabetics have skipped meals or used less drug than recommended because of its high cost.

When Humalog was first introduced in 1996, it cost \$21 a vial. But as more people used Humalog and needed it to live, the price skyrocketed past the rate of inflation, to about \$275 per vial today. Most people use about two vials a month.

“Rationing insulin means I can’t eat unless I have insulin to balance out the glucose,” Slobodan said. People should not have to choose between food and the medicine they need to live. But it’s happening. And it has to stop.

It’s not just diabetics who are suffering from high medication prices. In Hawai’i, the price of the cancer drug Revlimid jumped from \$147,413 a year to \$247,496 a year between 2012 and 2017. The price of the brand-name drug Aggrenox, which treats heart disease, increased from \$3,030 a year to \$5,930 annually.



Medicines don’t work if people can’t afford to take them. That’s why the AARP is taking on the drug companies and the prescription drug lobby. High drug prices disproportionately affect older Americans, who generally take four or more prescription drugs regularly.

We support several measures in the Legislature that would help reduce the cost of prescription medications. As of this writing, the bills were moving along in the Legislature.

HB 2561, HD2 – Requires the Insurance Commissioner to conduct a study on the feasibility of establishing a mechanism to review prescription drug costs and rates.

HB 1608, HD2 – Allows the Department of Health to start a program to allow importation of cheaper drugs from other countries, such as Canada.

SB 2276 – Requires drug manufacturers to notify prescription drug benefit plans and pharmacy benefit managers if a proposed increase in the wholesale price of certain drugs will result in a 16% or more price increase over a two-year period. It also requires drug manufacturers to identify widely used drugs whose wholesale costs have risen significantly and report to the Insurance

Commissioner information about the cost increases.

SB 2009, SD1/HB 1796 HD2 – The Senate bill caps the amount diabetics have to pay for prescription insulin drugs covered by insurance at \$100 a month. The house bill would establish a task force to study whether cost limits should be placed on insulin drugs.

In Congress, the Lower Drug Costs Now Act passed the House. It would lower prescription drug costs, cap costs for Medicare beneficiaries, and save taxpayers money by allowing Medicare to negotiate directly with drug companies for bulk purchasing discounts.

In the Senate, there is bipartisan support for the Prescription Drug Pricing Reduction Act, but the bill has yet to come to the floor. The Senate version would also cap out-of-pocket costs for Medicare beneficiaries and requires drug companies to pay a rebate to Medicare if they raise prices more than the rate of inflation, but does not call for Medicare to negotiate directly with drug companies.

If the Senate is able to vote on the measure and it passes, the differences between the bills would have to be worked out before it could go to the President for his signature.

Retirement Years

Hawai'i Saves

By Craig Gima

About half of Hawai'i's kūpuna lack the financial resources to pay for basic needs, according to the United Way's ALICE (Asset Limited, Income Constrained, Employed) report and a separate University of Massachusetts study. Both studies looked at the cost of food, rent, medicine, and other basic necessities and the income needed to pay for them.

The ALICE report estimates that 47% of households 65 and older are in poverty or not making enough to pay for minimum expenses in Hawai'i. It suggests the problem of financially-struggling kūpuna may not improve and could get significantly worse because of a lack of savings by current working families.

That's why AARP Hawai'i is pushing again for a Hawai'i Saves program to make it easier for working families to save their own money for retirement and have a chance to enjoy their golden years instead of struggling.

The UMass study estimates a single person in Hawai'i 65 and older in good health needs a minimum income of \$32,048 to barely get by as a renter. The cost is \$34,728 if you are in poor health. The average Hawai'i Social Security benefit is about \$17,898, so the gap must be made up by savings, pensions, or by



continuing to work past the traditional retirement age.

Research suggests that one of the biggest factors in whether people have retirement savings is access to a payroll savings program, the easiest and most



effective way to get people to save. People are 15 times more likely to save if it can be done easily at work. If you are a worker with a pension, money is automatically taken out to help pay for the pension. If your employer offers a 401K, money can be taken out of your paycheck before you get a chance to see or spend it.

However, about half of Hawai'i's private sector workers, many of whom work for small businesses, do not have any kind of payroll savings. That is significant because if it's not easy to save, most people don't save.

Only one in 20 people will go out on their own, do the research, and open an IRA or other savings vehicle. The rest, the other 95% of workers, need a workplace savings program.

Why should government step in to help people save? Because there is a cost to doing nothing. As more people retire broke, taxpayers will likely have to pay more for social programs to help kūpuna pay for food, medicine, and housing.

An AARP study found that if low and moderate income workers saved enough to generate \$1,000 a year in extra income, the state could save \$32.7 million over 15 years and the combined state and federal savings would be \$160 million.

Oregon, California, and Illinois are now helping small businesses and workers save with state-facilitated retirement programs. OregonSaves has helped 61,000 workers save more than \$44 million over two-and-a-half years. Many are first-time savers. The average income of the savers is \$29,000, and most put in about \$100 a month.

The Senate, House, and Governor have put forward a package to help working families with affordable housing, tax relief, and an increase in the minimum wage. We applaud that effort. But we also ask lawmakers to look for long-term solutions that could make a difference in reducing the number of kūpuna who struggle as they age and retire into poverty.

(Continued on next page.)



Active Aging: Hawai'i's Fastest Growing Natural Resource

By Cullen Hayashida, PhD

What are old people for? This is the question Dr. William Thomas poses in his book. Despite the best of intentions, anti-ageism is pervasive in our youth-oriented culture. The elderly, as they are called, are often assumed to be weak, disabled, technologically challenged, diseased, and “has-beens.” Step aside and head to the pasture!

In the meantime, the older adult population continues to grow unabated. They find politicians particularly sensitive, given their disproportionate tendency to vote. To date, while there may be those who feel older adults need more care and support from the government, much of what has been created has been heavily directed to address the health and long-term care needs of the growing frail and disabled population. The state's Medicaid budget, now more than \$2 billion, has grown more massive than the state's education budget. Our various health plans are feeling the pitch. They have tried to manage the rise of health-care costs by addressing eligibility, utilization, pre-authorization, and a managed care reimbursement arrangement. All our attention to date seems to have been understandably driven by focusing on frailty, disability, and chronic illness. Necessary, but hardly sufficient.

In the meantime, as our older adult population continues to increase, young people are leaving Hawai'i, and labor force growth and the entire population is flat.



Perhaps our efforts at eldercare policy development, which focuses primarily on those at the very end-of-life, may be shortsighted. The health and medical needs of the older adult population may overwhelm us if we view them from that orientation alone.

Gerontologist Marc Freedman has referred to older adults as America's fastest growing natural resource. We cannot assume life is limited to just three stages. Childhood is not only followed by working adulthood and then by a short retirement, frailty, and death. Instead, after 65, older adults are blessed with an additional 20 to 30 years of life. Indeed, there are many health and financial issues they need to cope with, but at the same time, in Marc Freedman's words, this is a natural resource that Hawai'i needs to figure out how to tap. Older adults have talent, skills, experience, and time on their hands. The question is, how can we create the necessary social infrastructure to marshal this human resource for the greater good? While this can help the community, it will also help older adults find purpose and meaning, remain useful, and to matter. Having a purpose in life using skills and talents we all have will go a long way to keep us well.

There is so much work we need to do. We need to build a different type of social infrastructure to promote an active aging culture with:



1. An awareness campaign;
2. The development of an active aging resource directory;
3. Non-financial pre-retirement workshops;
4. Intergenerational initiatives; and
5. A commission to create an active aging strategic plan for all four counties and the entire state.



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 7 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 are deferred indefinitely. Advocates must be prepared at the very beginning of a legislative session to respond rapidly to identify and support favorable legislation and 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 how 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

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.

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 power for advocates.³

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 which 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 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 these accumulate over time and with age. They are at risk for 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 the “oldest old” currently receive outside of institutional settings is informal care from family.⁶

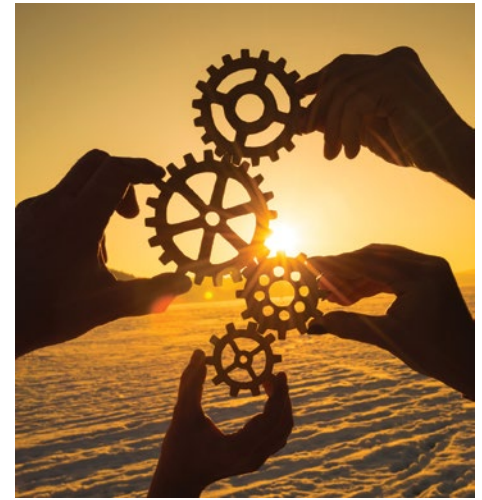
The state and federal governments have taken a significant leap with the Kūpuna Caregivers Program and the RAISE Family Caregivers Act, respectively. However, even if all the legislation described in this report were enacted, it would not meet all the needs of Hawai‘i’s next generation of elders and persons with disabilities. We must

continue to think five to 10 years ahead, as well as beyond.

The Challenges

We must strongly consider and robustly address five challenges:

1. How do we create cohesive, comprehensive, coordinated, efficient, purposefully-built, and 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 the vitality of our neighborhoods, networks, and lives. Communities that encourage the contributions of older adults are stronger. How can we encourage older adults to contribute their time, talent, and life experiences to benefit others?⁷

We are called to:

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



- Advance and enact 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, our disabled, and their family caregivers.

References

¹Citizens Committee for Children of New York. <https://www.cccnewyork.org/about/what-is-effective-advocacy/>. Accessed February 10, 2020.

²Griffiths, Elizabeth P, MD, MPH, June 22, 2017, http://www.nejm.org/doi/full/10.1056/NEJMp1704120?query=featured_home. Accessed February 10, 2020.

³Ibid.

⁴Ibid.

⁵Hawaii State Plan on Aging, 2011 – 2015.

⁶Rx The Quiet Revolution. What the ‘Silver Tsunami’ Means for U.S. Health Care: An Interview with Thomas Gill of the Yale Center on Aging. <https://rxfilm.org/problems/silver-tsunami-united-states-healthcare-thomas-gill-yale-center-on-aging-interview/>. Accessed February 10, 2020.

⁷Administration on Aging. <https://acl.gov/oam/2019/older-americans-month-2019>. Accessed February 10, 2020.



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 to them in the state of Hawai'i. The ADRC is a highly visible and trusted source where people of all incomes and ages can turn for information. ADRC staff will help to 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. This 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
Website: 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 adult needs, and the coordination and development of caregiver support services within the state of Hawai'i.

Caroline Cadirao, Director
250 South Hotel Street, Suite 406
Honolulu, Hawai'i 96813

Phone: (808) 586-0100
Fax: (808) 586-0185
Email: eo@doh.hawaii.gov
Website: health.hawaii.gov/eoa/

Elderly Affairs Division

City and County of Honolulu
Derrick Ariyoshi,
County Executive on Aging
Kapalama Hale
925 Dillingham, Suite 200
Honolulu, Hawai'i 96813

Main Telephone: (808) 768-7705
Information and Assistance Senior Helpline: (808) 768-7700
Email: naki@honolulu.gov
Website: www.elderlyaffairs.com/site/1/home.aspx

Hawai'i County Office of Aging (HCOA)

William Horace Farr,
Acting County Executive on Aging
Email: hcoa@hawaiiintel.net
Website: www.hcoahawaii.org

East Hawai'i

1055 Kino'ole Street, Suite 101
Hilo, Hawai'i 96720-3872
Phone: (808) 961-8600
Fax: (808) 961-8603

West Hawai'i

74-5044 Ane Keohokalole Highway, Bldg B
Kailua-Kona, Hawai'i 96740
Phone: (808) 323-4390
Fax: (808) 323-4398

Kauai Agency on Elderly Affairs

Kealoha Takahashi,
County Executive on Aging
Pi'ikoi Building
4444 Rice Street, Suite 330
Lihue, Hawai'i 96766
Phone: (808) 241-4470
Fax: (808) 241-5113
Email: elderlyaffairs@kauai.gov
RSVP (Volunteer Prog.): rsvp@kauai.gov
Website: 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
Fax: (808) 270-7935
Email: mcoa.adrc@mauicounty.gov
Website: www.mauicountyadrc.org

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
1132 Bishop Street, Suite 1920
Honolulu, Hawai'i 96813
Toll-Free: (866) 295-7282
Fax: (808) 537-2288
Email: hiaarp@aarp.org
Website: states.aarp.org/hawaii/?migration=rdrc

AARP Resources for Caregivers & Families: www.aarp.org/caregiving/

Disability and Communication Access Board

Kirby Shaw, Executive Director

1010 Richards Street, Room 118
Honolulu, Hawai'i 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

2630 O'ahu Avenue
Honolulu, Hawai'i 96822

Phone: (808) 265-5716

Email: gsimon@aarp.org

Hawai'i Pacific Gerontological Society

Eileen Phillips, President

P.O. Box 3714

Honolulu, Hawai'i 96812

Sherry Goya, HPGS Executive Director

Phone: (808) 722-8487

Fax: (808) 235-3650

Email: sgoyallc@aol.com

Website: hpgs.org/index.html

Medicare Nursing Home Compare

Detailed information about every Medicare- and Medicaid-certified nursing home in the U.S. A nursing home is a place for people who cannot be cared for at home and need 24-hour nursing care.

Website: www.medicare.gov/nursing-homecompare/search.html

Project Dana

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 Caregivers Support

Volunteers are sensitive to diverse cultures and traditions. They receive initial and continual training and education, 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

Fax: (808) 945-0007

Email: info@projectdana.org

Website: www.projectdana.org/

St. Francis Healthcare System

2226 Liliha Street, Suite 227
Honolulu, Hawai'i 96817

Email: info@stfrancishawaii.org

Website: www.stfrancishawaii.org/

Educational & Research Institutions

The University of Hawai'i at Mānoa Center on Disability Studies

UH College of Education

Patricia Morrissey, Director

1410 Lower Campus Rd., #171F
Honolulu, Hawai'i 96822

Phone: (808) 956-5142

Web: www.cds.hawaii.edu/about

Center on Aging

University of Hawai'i at Mānoa

Myron B. Thompson School of Social Work
Margaret (Peggy) Perkinson, PhD, Director

Gartley Hall

2430 Campus Road
Honolulu, Hawai'i 96822

Phone: (808) 956-5001

Email: uhcoa@hawaii.edu

Website: www.hawaii.edu/aging/

Center on the Family

College of Tropical Agriculture
and Human Resources

University of Hawai'i at Mānoa

Barbara D. DeBaryshe
Interim Director & Specialist

2515 Campus Road, Miller Hall 103
Honolulu, Hawai'i 96822

Phone: (808) 956-4132

Fax: (808) 956-4147

E-mail: cof@ctahr.hawaii.edu

Website: 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, Hawai'i 96822

Phone: (808) 956-6544

Website: www.hawaii.edu/uhelp/index.html

Hā Kūpuna

National Resource Center for
Native Hawaiian Elders

University of Hawai'i at Mānoa
Myron B. Thompson School of Social Work
Colette Browne, DrPH,
Principal Investigator and Co-Director;
Kathryn Braun, DrPH, Co-Investigator;
Noreen Mokuau, DSW, Co-Investigator;
Lana Ka'opua, DSW, Co-Director
and Professor; Yanyan Wu, PhD, Assistant
Professor; Shelley Muneoka, MSW,
Project Coordinator

2430 Campus Rd., Gartley Hall
Honolulu, Hawai'i 96822

Phone: (808) 956-7009

Fax: (808) 956-5964

Website: manoa.hawaii.edu/hakupuna/

Public Policy Center

University of Hawai'i at Mānoa
College of Social Sciences
Colin Moore, Director

Saunders Hall, Room 723
2424 Maile Way
Honolulu, Hawai'i 96822

Telephone: (808) 956-4237

FAX: (808) 956-9121

Email: ppcsec@hawaii.edu

Website: www.publicpolicycenter.hawaii.edu/index.html

The background of the entire page is a photograph of a tropical beach at sunset. Several tall palm trees are silhouetted against a sky filled with soft, orange and yellow clouds. In the foreground, a group of people is sitting on a green lawn, some in chairs, looking towards the ocean. The overall mood is peaceful and scenic.

Aging & Disability Issues 2020

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