



Aging & Disability Issues 2019

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





Cover photo: Haleakala National Park

Aging & Disability Issues 2019

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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 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 following projects:

- Holo Imua Kakou Legislative Reception
- Family Caregiver Awards Program—a joint venture with KHON2's Elderhood Project
- *Aging & Disability Issues* report
- Family Caregiver Awareness Day
- Education/Resource Fairs
- Family Caregiver Speakers' Bureau
- Family Caregiver's Kit for Businesses

For more information, please contact Gary Simon, President, at (808) 547-8140 or by email at gsimon@stfrancishawaii.org. Mailing address: 2630 O'ahu Avenue, Honolulu, Hawai'i 96822.



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: 2200 Main Street, Suite 547; 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 Hawai'i Pacific Gerontological Society. 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 Francine Wai, 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 day care
- 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.

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Introduction & Overview

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

This 2019 issue of the *Aging & Disability Issues* report is the 14th 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 nine 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 2019.

Sections 2 through 7 describe the priority issues for the Legislature in the 2019 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 five sections also discuss the specific bills that address these priority areas and their status at the time of writing this report.

Section 8, the Conclusion, provides a brief summary and a look ahead.

Section 9 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.



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 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 2019

Two Thousand Nineteen is the year for us to continue elevating family caregiver support to a national priority, and to acknowledge that everyone's quality-of-life is positively impacted by providing support to our often emotionally, financially, and physically taxed family caregivers.

(Continued on next page.)

Caregiving in the U.S. 2015, a study by the National Alliance for Caregiving (NAC) and the AARP Public Policy Institute, presented a portrait of unpaid family caregivers. Based on data collected in late 2014, the study found that approximately 43.5 million caregivers had provided unpaid care to an adult or child in the 12 months prior to the completion of data collection. Seventy-Eight percent of family caregivers incur out-of-pocket costs due to caregiving, spending an average of \$6,954 a year.¹

Congress and President Trump have recognized that a national strategy is required to research, develop, plan, and implement a cohesive, purposefully built system of support to family caregivers. To this end, in 2018, Congress passed and the President signed the RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act. Congressional cosponsors of the legislation included Representatives Kathy Castor, Lujan Grisham, and Diane Black, and Senators Susan Collins, Tammy Baldwin, Lisa Murkowski, and Michael Bennet.

The RAISE Act directs the Department of Health and Human Services (HHS) to develop, maintain, and periodically update a National Family Caregiving Strategy. The bill also calls on HHS to convene a Family Caregiving Advisory Council to advise it on recognizing and supporting family caregivers. The Council will be comprised of relevant federal agency representatives, as well as family caregivers, older adults with long-term care services and support needs, health care providers, and other key players in the caregiving community.²

Under the RAISE Act, HHS will create a national family caregiver strategy by bringing together federal agencies and representatives from the private and public sectors (such as family caregivers, health care providers, employers, and state and local officials) in public advisory council meetings designed to make recommendations. The agency will have 18 months to develop its initial strategy, and then must provide annual updates.

The goals of the National Family Caregiving Strategy include identifying actions that government, communities, health



providers, employers, and others can take to support family caregivers, including:

- Promoting greater adoption of person- and family-centered care in health settings and long-term care settings.
- Training for family caregivers.
- Respite options for family caregivers.
- Ways to increase financial security for family caregivers.
- Workplace policies to help family caregivers keep working.
- Collecting and sharing information about innovative family caregiving models.
- Assessing federal programs around family caregiving.
- Addressing disparities and meeting the needs of the diverse caregiving population.³

The Hawai'i Family Caregiver Coalition and others are working with HHS to appoint an appropriate representative from Hawai'i on the Family Caregiving Advisory Council.

Locally, Hawai'i's economy, as measured by real GDP, is forecast to continue expanding,

albeit by only 1.2 percent.⁴ Thus, more resources might be available to address "care" issues, including aiding family caregivers.

Similarly, the national economy continues to expand. At the time of this writing, U.S. GDP growth is forecast to be 3.0% for 2018 and 2.3% in 2019.⁵ Accordingly, more national resources will be available to continue maintaining and building the safety net of services and financial assistance to support the vulnerable.

At the federal level, the Administration on Community Living has continued to channel resources into elderly and disabled services, and the Veteran's Administration continues to launch aggressive new supports for the aging veteran population.

In 2016, the federal Older Americans Act (OAA) was reauthorized for three years (through 2019). 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. The 116th Congress, which convened in January 2019, is expected to consider the next Older Americans Act Reauthorization.

Not Alone with Caregiver Support

By Ren Yep

This is a note to share with others how much I appreciate attending the Caregiver's Support Group meetings twice a month. I am reasonably new to the group, but I've found it to be highly educational and supportive to my needs. The speakers are well selected and they address many of the questions that I have thought about during my past three years of being a caregiver. The subjects raise awareness about important concerns, as well as reassures my understanding that I'm doing the right thing. Quite often there are questions that arise and are answered because of the new information.

We realize that we are not alone, and that help is available. An additional bonus is en-



joying the meals together while sharing our experiences with others, and also attending other engaging outings. As important are the many sensitive members who share similar daily challenges, and graduates who have faced them before. It's supportive that there are others just like me who are fulfilling the needs of their loved ones.

We remain deeply grateful to Congress for this solid show of support for the OAA and strongly urge the same bipartisan effort in making long-overdue investments to enable these important programs to meet the needs of seniors across the country.

Also in 2017, Senator Joni Ernst of Iowa introduced nationally the Credit for Caregiving Act of 2017 (S. 1151). This bill amends the Internal Revenue Code to allow eligible caregivers a new tax credit for 30% of the cost of long-term care expenses that exceed \$2,000, up to \$3,000 in a taxable year. The bill defines an "eligible caregiver" as an individual who has earned income for the taxable year in excess of \$7,500 and pays or incurs expenses for providing care to a spouse or other dependent relative with long-term care needs.⁶ The bill has been referred to the Senate Committee on Finance.

Furthermore, the Consortium for Citizens with Disabilities (CCD) is working with Senator Charles Schumer of New York and Representative James Sensenbrenner of Wisconsin to push for the passage of the Disability Integration Act of 2017 (S 910, HR 2472).

If enacted, the bill would prohibit state and local governments from denying community-based services to individuals with disabilities who are in need of long-term services and supports or health-related tasks. In addition, it would help these individuals live and age in their communities, reducing the danger of placing persons with disabilities in nursing homes and/or institutions.

CCD is a coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of the approximately 57 million children and adults with disabilities in all areas of society.

In May of 2018, Senator Susan Collins of Maine and Senator Bob Casey of Pennsylvania introduced the Geriatrics Workforce Improvement Act (S 2888) in the U.S. Senate. The bill would establish funding for the Geriatrics Workforce Enhancement Program (GWEP), and would reestablish the Geriatric Academic Career Awards (GACAs), a previously funded program for developing clinician-educators. By establishing the GWEP and reestablishing the GACAs, the Geriatrics

Workforce Improvement Act would:

- Transform clinical training environments into integrated geriatrics and primary care delivery systems to ensure trainees are well prepared to practice in and lead such systems.
- Develop providers from multiple disciplines and specialties to work interprofessionally to assess and address the needs and preferences of older adults, their families, and caregivers at individual, community, and population levels.
- Create and deliver community-based programs that will provide older adults and their families and caregivers with education and training to improve health outcomes and the quality of care for such adults.
- Provide education on Alzheimer's disease and related dementias to families and caregivers of older adults, direct care workers, health professionals, students, faculty, and providers.⁷

The last action taken on the bill was that it was referred to the Committee on Health, Education, Labor, and Pensions.

On December 31, 2018, President Trump signed the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act (S. 2076) into law.

The bill was sponsored by Senator Susan Collins of Maine and introduced in 2017. The BOLD Act authorizes the Centers for Disease Control and Prevention (CDC) to spend \$20 million a year for five years from federal fiscal years 2020 to 2024.

The bill passed through the Senate unanimously and passed through the House by a vote of 361–3. The law:

- Establishes centers of excellence across the country dedicated to promoting the best ways to effectively deal with Alzheimer's disease and to help caregivers better understand and address dementias. The centers will also help educate the public on Alzheimer's disease, cognitive decline, and overall brain health.
 - Provides for the CDC to work with state health departments to help them promote brain health, reduce the risk
- (Continued on next page.)

of cognitive decline, and improve care for individuals with Alzheimer's.

- Requires improved analysis and timely reporting of data on Alzheimer's cognitive decline, caregiving, and health disparities at state and national levels.⁸

The BOLD Act continues the momentum to alleviate the devastation wrought by Alzheimer's disease and related dementias.

In Maine, a ballot initiative in the 2018 general election to provide universal home care sought to overcome the widespread inadequacy of the nation's long-term care system. Although many older adults want to age in place when their health starts to decline or they become frail, programs that help them do so are narrow in scope, fragmented, and poorly funded.⁹

Medicare's home care benefits are limited to seniors and adults with disabilities who are home-bound and need skilled services intermittently. State Medicaid programs vary widely, but are generally restricted to people at the lower end of the income ladder. Long-term care insurance is expensive and covers only a slim slice of our elder population.¹⁰ Many millions of middle-class families struggle to learn about and find resources when an older relative becomes dependent on others or develops a serious chronic illness.¹¹

In the AARP's 2017 "Long-Term Services and Supports State Scorecard," Maine was ranked as one of two states with the least affordable home care. The Scorecard states that home care costs would consume 102 percent of the median income in the state.¹²

Maine's ballot initiative, Question 1, had proposed that home care services be available to all residents at no cost, regardless of income.¹³ Under the proposal, adults would have been eligible for the program when they need help with at least one activity of daily living. Covered services would have included care from aides and companions; speech, physical, and occupational therapy; counseling; home repairs; transportation; respite care; devices for people with disabilities; and occasional small rent subsidies. Stipends would have been granted to family caregivers. Seventy-seven percent of program funds would be directed to home

care aides in a move to strengthen this segment of the health care workforce.¹⁴

Funding for the new program would have been raised from a new 3.8 percent tax on wages and non-wage income that is not taxed by Social Security (3.8% over the threshold of \$128,400 per person in 2018). According to estimates, between \$180 million and \$310 million would have been raised annually.¹⁵

A board would have been established to operate the home care program. The initiative called for nine members (three from home care agencies, three direct care workers, and three service recipients) elected by constituent organizations to oversee the program.¹⁶

Although no one questions the need for affordable home care for seniors and people with disabilities, the ballot initiative failed by a wide margin, with more than 70 percent of Maine voters casting a "no" vote.

However, ballot proponents are to be applauded for proposing a bold policy and program to address a critical need for elders and people with disabilities.

On January 16, 2019, Governors Chris Sununu of New Hampshire and Phil Scott of Vermont announced their joint endorsement of a two-state paid medical and family leave program. The program, titled the Twin State Voluntary Leave Plan, would cover private- and public-sector employees who are residents of both states. Residents who choose to opt-in to this program would receive 60 percent of their weekly wages for a maximum of six weeks for events such as the birth of a child or caring for a family member with a serious medical condition.¹⁷

In Hawai'i, the Executive Office on Aging continues to work with public and private agencies in innovative efforts to restructure the service delivery system and develop more efficient operations by adopting data systems that enable them to target resources to the greatest need.

Governor David Ige and the State Legislature have supported innovations such as Kūpuna Caregivers and the continuing enhancement of Aging and Disability Resource Centers (ADRCs) by county. ADRCs have improved access to services, enabling individuals to obtain appro-

priate services in a timelier manner. They have consequently reduced costly episodes such as hospitalizations, emergency room visits, and nursing home placements, and in other ways shown themselves to be very cost-effective.

The Governor's top priorities include but are not limited to public education, affordable housing, and preservation of our 'āina (land).¹⁸ These priorities require enormous funding. However, aging and disability advocates are determined to ensure funding is also allocated for the preservation and continuous building of the safety net of services for our vulnerable populations.

Our elected officials at all levels of government must be committed to the expansion and enhancement of services for our rapidly aging population and those with disabilities, and we need to hold them accountable.

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Kūpuna Care, ADRCs, Healthy Aging Partnership Program, Long-Term Care Issues & Elder Care Workforce

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 to 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 and related bills in the 2019 Legislative Session:

1. Kūpuna Care (HB 465/SB 1023; HB 1422)
2. Aging and Disability Resource Center (HB 466/SB 1024; HB 1422)
3. Healthy Aging Partnership (HB 468/SB 1026)

Kūpuna Care

Hawai'i's Kūpuna Care program was established in 1999 to provide long-term services and supports to frail and vulnerable older adults who lack access to other comparable services. Kūpuna Care services include adult day care, 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 in expensive residential care facilities. Annual budget funding is allocated to the Executive Office on Aging (EOA). The EOA then distributes the funds to county offices called Area Agencies on Aging (AAA), which administer the program in their counties and contract for

services with private non-profit and for-profit agencies.

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. The base budget for the Kūpuna Care program has remained at \$4.85 million since 2002, while the older adult population in Hawai'i has increased significantly. Although the Legislature has provided generous additional funding in recent years, securing the funding in the base budget would ensure a consistent foundation to meet the increasing needs of older adults throughout the state.

Legislative proposals. The Kūpuna Care program is a priority of the Ige administration. In the Governor's biennium budget request for FY20 and FY21 (HB 1422), a total of \$8.73 million was requested for this program in the EOA's budget. The Kūpuna Caucus bills HB 465/SB 1023 rounded up the request to \$9 million. If appropriated, funding will enable the EOA to serve about 5,600 older adults per year in a community setting, and use comprehensive person-centered intake and assessment tools developed statewide for targeting public supports to persons in greatest need.

Aging and Disability Resource Centers (ADRCs)

Older adults, and people with disabilities and their families are often unprepared when the sudden onset of a severe health condition or sudden decline in functioning 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

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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 operations 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 in-

formation on long-term support programs and benefits; conducts the assessment on individuals' needs



for services to maintain independent living in the community; and is a single point of entry for Kūpuna Care and Older Americans Act (OAA) services. In FY17, the ADRCs received 35,007 calls/contacts—nearly half were repeat callers. The ADRCs linked 11,039 older adults to publicly-funded long-term services and support programs. Over 90 percent of consumers were satisfied with their ADRC experience.

Legislative proposals. The Ige administration has identified Hawai'i's ADRC system as a priority and requested \$3.1 million for EOA's base budget for the ADRC (**HB 1422**). The Kūpuna Caucus and senior advocacy groups have asked for the same appropriation amount (\$3.1 million) through **HB 466/SB 1024**. If passed, the EOA and the county AAAs will be able to enhance their capacity in operating the ADRC sites; implement and sustain ADRC's statewide fully functional status under federal requirements; and integrate participant-directed supports as a function of the ADRC.



Healthy Aging Partnership Program

By Eldon L. Wegner, PhD

Chronic disease and disability severely affect quality-of-life and entail high costs in medical care. Chronic diseases account for 86 percent of health care expenses. In Hawai'i, 82 percent of adults have at least one chronic disease and over half (53%) have two or more chronic diseases. As people age, these conditions become more prevalent. The Healthy Aging Partnership (HAP) was formed in 2003 to prevent or postpone the incidence of chronic disease and disability, and to manage these conditions to minimize their effects. HAP is led by the Executive Office on Aging and the Chronic Disease Branch of the Department of Health. The County Offices on Aging play a major role in contracting services delivered through classes offered by non-profit agencies throughout the state. HAP has received support from multiple funding streams, including federal grants, and state and country budgets. The partnership is a public-private partnership, with largely public funding of private providers who deliver the programs to the public. The University of Hawai'i Public Health Program successfully adapted evidence-based health promotion programs and disease prevention programs for Hawai'i's multicultural population, and has conducted continuous evaluation of the outcomes of the programs until this past year.

HAP offers two evidence-based programs: Better Choices, Better Health (BCBH), which focuses on teaching skills for managing chronic conditions; and EnhancedFitness, which offers exercise programs designed for older adults. University of Hawai'i researchers have provided systematic evaluations of the impacts of

these programs, assessing clients prior to beginning the program, and then conducting a post-program assessment of the clients to determine program impacts.

Better Choices, Better Health (BCBH) is a six-week self-management workshop for older adults with chronic conditions. Its purpose is to enable individuals to better manage their health and to improve their quality-of-life. The program was developed and tested by Stanford University to supplement the medical treatment of chronic diseases. Participants learn skills to help them manage their health conditions and to interact with their health care providers. Better Choices, Better Health has had a total of 1,349 participants. The evaluation research found that participants had a decreased number of visits to physician offices and emergency rooms, and a cost-saving analysis estimated a net saving of \$640.91 per participant.

The chronic conditions most frequently reported by persons entering the program were hypertension, arthritis, diabetes,



and cancer. The program offers diabetes-specific and cancer-specific programs. The program resulted in decreased visits to physicians' offices and emergency rooms. Participants also reported experiencing fewer symptoms and exercising more frequently.

EnhancedFitness is an exercise program of one-hour classes that improve cardiovascular fitness, strength, flexibility, and balance. The program protects against heart attacks, lowers blood pressure and cholesterol levels, increases strength and flexibility, improves mental functioning, and reduces the risk of falls.

Many individuals enjoy exercising in groups because it is more fun and they receive social support from being with others in similar situations. The EnhancedFitness

Program served 1,494 people. After 16 weeks, 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. Funding EnhancedFitness for 575 kūpuna is



estimated to save \$789,000 in health care costs. Prevention programs are always cost-effective with regard to chronic disease.

Inconsistent Legislative Support. Despite the achievements of the Healthy Aging Partnership Program, support has been sporadic, and resources have not been provided to allow the program to expand. The program has received numerous national awards (including the Multicultural Aging Award from the American Society on Aging), and is one of the few state programs which uses evidence-based interventions. It has also conducted systematic evaluations of program outcomes and provides documented evidence of cost-savings to the state. Nationally, Hawai'i's program is often lifted up as a model for other states.

The Legislature failed to pass any appropriation for this program in the 2018-19 budget year. As a consequence, the City and County of Honolulu had to close its sites for the EnhancedFitness program, while Kaua'i and Maui received some county funds to keep some of their programs open. Due to budget restrictions, a number of the trainers have lost their jobs. The Executive Office of Aging had to suspend the program evaluation contract with the Public Health Program at the University of Hawai'i.

If the appropriation proposed in **HB 468** and **SB 1026** fails to pass this session, the entire Healthy Aging Partnership may be ended. The consequence would be dire for the health of our citizens and also drive

Vital Help with Caregiving

By Bob Sakata

My wife's name is Nam. I'm 78 years old and my wife is 77. About five years ago, my wife suffered a stroke that caused weakness on her left side. I've been her caregiver ever since. Over the last few years, she has gone through a number of different issues, such as fractures in her spine, upper right arm, UTI, etc. She's been in the hospital and nursing facilities a few times. As a caregiver, all these physical issues are challenging in themselves, but about a year now, she's started into early dementia.

I cannot put into words or explain how seeing what my wife is going through has impacted me mentally and physically. This condition is devastating to the person and the caregiver. I was totally lost until I talked to Maria Morales at Project Dana. I cannot say enough about this organization that supports people exactly like me. They are awesome because they've been there. They support and direct you to wherever your questions lead you. You can read all the ar-

up health care costs for the state. Thus far, both bills have cleared their subject matter committees, as well as the House Finance and Senate Ways and Means committees. The appropriation bills also propose a modest increase from \$550,000 in 2017 to \$605,000 per year in fiscal years 2019 and 2020. Perhaps this portends a renewed commitment to the importance of this program and a better understanding of how everyone in the state benefits from the Health Aging Partnership.

Long-Term Care Issues for 2019

By John G. McDermott, LSW, ACSW, MDiv

Auditor's Report on OHCA. The Office of the Auditor's report to the Governor and Legislature on the Office of Health Care Assurance's (OHCA) Adult Residential Care Homes Program was released in November 2018. Some of its findings include:



ticles you can find on dementia or Alzheimer's disease, but there is nothing compared to Project Dana and what all their people do every day. One Big MAHALO!

Note: Project Dana is a Faith In Action program mission is to recruit, train, and mobilize volunteers to provide in-home assistance with compassion and care without the desire for recognition or expression of appreciation. It fills important social service gaps and serves as a referral and linkage agency, and works closely with more than 130 community agencies to ensure a continuum of services to the elderly.

"OHCA deems the relicensing process complete not upon actual correction of deficiencies, but upon submission and OHCA's approval of a 'Plan of Correction,' which is the care home's planned actions intended to address identified deficiencies. However, even under OHCA's practice, care homes were often relicensed before OHCA's acceptance of a Plan of Correction and, in some cases, before an inspection was even conducted. About half of the 214 care homes we sampled were allowed to operate in 2017 with either an expired license or a license hastily issued before all required steps if the relicensing process were completed."

Residents were potentially placed at risk. The public is encouraged to read this report: <http://files.hawaii.gov/auditor/Reports/2018/18-18.pdf>.

It is clear OHCA needs to be monitored carefully by the Department of Health, the Legislature, and the public. It was
(Continued on next page.)



of an affected long-term care facility is not present for the inspection.” The purpose is “to require DOH to provide at least two hours-notice to long-term care facilities prior to unannounced visits and inspections.”

Posting of inspection results. The public has the right to know the results of a facility inspection prior to placing a loved one. Nursing home inspections are posted on Medicare’s Nursing Home Compare website

stated at a November 29, 2018 legislative briefing that OHCA has a new supervisor who has already addressed many of the auditor’s concerns, and promises were made to quickly correct all other issues.

Unannounced Inspections. Senior advocates have advocated for unannounced inspections of adult residential care homes, expanded ARCHs, community care foster family homes, and assisted living facilities since 1998. Federal law has required this of nursing homes since 1987, but the other types of homes only fall under state regulations. Unannounced inspections have become the national standard. Hawai‘i remains the only state where the regulatory agency (Department of Health) is mandated (chapter 100.1) to give notice when an inspection will be done. Under Governor Lingle, the DOH initiated unannounced visits, however, a visit is different from an inspection, and information is **not** available to the public.

Legislation mandating that all inspections be unannounced was signed into law (**Act 184**) by Governor Abercrombie on July 1, 2016, but the implementation date was extended to July 2019. This session, bills have been introduced to change this necessary protection for our most vulnerable kūpuna. **HB 692** and **SB 525** would make unannounced DOH inspections discretionary by changing the upcoming law from “shall” to “may” be unannounced. The State Auditor’s Report on OHCA does not recommend this.

Furthermore, **HB 1393** states: “The legislature notes that unannounced inspections are a misuse of State resources when the operator

because federal law requires this, but the other types of long-term care facilities do not fall under federal regulations. The OHCA performs inspections to protect the public and tax dollars are paid to the inspectors, so the information should belong to the public.



Senior advocates fought for years to pass a law to require the Department of Health to post the annual inspections of all long-term care facilities. That law (**Act 213**) would have gone into effect July 1, 2013, but the DOH was given until January 1, 2015 to implement the law.

When inspection postings began in 2015, much of the information was redacted. The postings then stopped because it was an “unfunded mandate.” The Kokua Council filed a lawsuit on July 25, 2016 to require the posting of all inspection reports with no redactions. The website (<http://health.hawaii.gov/ohca/inspection-reports/>) contains the annual

inspections of all facilities, including deficiencies and plans of correction.

Long-Term Care Ombudsman Program (LTCOP). From Lance Robertson, Assistant Secretary for Aging and Administrator, ACL (Feb. 19, 2019): “The Ombudsman program is rooted in a simple, yet powerful, principle—that all older adults and people with disabilities are entitled to equal rights, dignity, and a life free of abuse no matter where they live.”

LTCOP is entering its 40th year as a mandatory program of the Older Americans Act. Unfortunately, this program has not been adequately staffed or funded in Hawai‘i.

In 1995, the national Institute of Medicine published *Real People Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act*. This study recommended, at a minimum, that the LTCOP have one full-time, paid ombudsman per every 2,000 residents. It’s important to note that in 1995, most residents were in nursing homes, so the logistics for visiting these residents were much easier to manage. Today in Hawai‘i, there are more residents living in the community (7,849) than in nursing homes (4,456). These facilities are spread over six islands, and appropriate staffing and funding must be able to meet these challenges. With 1,700 facilities and 12,661 beds, Hawai‘i needs a minimum of six full-time, paid ombudsmen. Currently, there is only one ombudsman and one volunteer coordinator.

In 2017, the Legislature provided funding for two years for a part-time ombudsman for Kaua‘i, Maui, and Hawai‘i counties, and to restore the full-time O‘ahu ombudsman position (which was eliminated in 2015). This is a big step in the right direction, but it is not enough.

The federal Administration on Community Living (ACL) expects at a minimum quarterly visits to every facility, so residents and their families have equal access to LTCOP services. With 1,700 facilities statewide, a quarterly visit would require 28 facility visits a day, which is clearly not possible with current staffing.

Federal law charges the EOA with establishing an “Office” of the Long-Term Om-

budsman and ensuring funding and staffing can meet federal and state mandates.

Adult Protective Services (APS) and the LTCOP. When APS receives a phone call from a concerned person about possible abuse or neglect in a long-term care facility, they have an intake process and make a determination if it should be investigated. If APS investigates, they may determine there isn’t enough evidence to warrant further intervention or monitoring. LTCOP proposes that when APS receives a complaint, they also inform LTCOP for follow-up as well. LTCOP does not require the same threshold to visit a facility, talk with a resident, or find out if the resident feels safe or wants to live somewhere else. If abuse really did take place and APS has closed the case, the resident is justified in fearing retaliation. LTCOP presence may help prevent this.

Facility Discharges. In December 2017, the Centers for Medicare and Medicaid Services (CMS) sent out a letter to state Survey Agency directors regarding regulations for nursing homes per 42 CFR 483.15(c)(3)(i). This section states:

“...before a facility transfers or discharges a resident, the facility must “notify the resident and the resident’s representative(s) of the transfer or discharge and the reasons for the move in writing and in a language and manner they understand...” The facility must also “...send a copy of the notice to a representative of the Office of the State Long-Term Care Ombudsman.” Sending a copy of the notice to a representative provides added protection to residents and ensures the Office is aware of facility practices and activities related to transfers and discharges.

This is important because, for several years now, the number one complaint about nursing homes has been discharges (inadequate notice, improper or forced discharge, support services for a safe discharge missing, not informed of right to appeal, or given enough time to appeal, etc.)

Some nursing homes claim they are only “rapid recovery units,” and after therapy is completed, intend to discharge the resident, even if they may still qualify to be there because their level of care is nursing home level (skilled or intermediate).



Medicare pays 100% for the first 20 days, but if a resident stays longer, the chances that the resident (and family who may already be burnt-out) will ask to become a long-term care resident can increase, as well as the possibility the resident will eventually apply for Medicaid. Nursing homes struggle with the difficult balancing act of higher Medicare reimbursements for therapy services and much lower Medicaid reimbursements for those who stay and become long-term care residents. If therapy beds are full with long-term care residents, a facility will struggle financially. However, the LTCOP bottom line is that residents should not be required return home to a community bed (Expanded ARCH or CCFH) by the facility or their insurance provider.

Discharge of Homeless. Hospitals sometimes discharge homeless patients to a nursing home. Discharge back to the street is not appropriate even if that’s where the person came from. The *Institute for Human Services* is also not appropriate because they are only a temporary shelter and don’t have staff to provide nursing care or therapy. Also inappropriate is the YMCA or a hotel if the resident is not independent and needs help bathing, medication management, etc. The homeless can also have behavioral issues that can make them inappropriate for a care home or foster home with children who may feel frightened or threatened by someone’s behavior.

Nursing homes have three shifts and a large staff of professionals. A care home or foster home is usually comprised of a caregiver and their immediate family. The caregiver must cover all three shifts alone every day, with no holidays, vacations, or sick days. It is not viable for “problem” residents to be discharged from nursing homes to one of these smaller homes with much fewer resources. This is becoming a grow-

ing issue. The time has come to collectively work on a solution.

Case Management. “What do I get for my money?” is a common complaint about case management in Hawai‘i. Someone who requires skilled or intermediate care should be in a nursing home where there is a registered nurse on all three shifts. If that same resident chooses to instead live in the community at an expanded care or foster home, it is a requirement to have a case manager who is either a registered nurse or to hire a registered nurse to monitor care. That makes sense. What residents and their families object to is a failure of communication. It is unclear to some families what case managers do; how they help both caregiver and resident; etc. Residents and their families want some documentation of what was done during the visit to justify payment. They complain they should choose the case manager, not the caregiver. If they want a weekly visit instead of a monthly visit, why isn’t that possible? Consumers feel they have no power, even though they pay the bill. A task force of case managers and consumers (residents and family members) could help resolve some of these issues.



Health Plan as Case Manager. Related to the topic of case management, a number of younger residents who want to be placed into the community have difficulty finding a case manager to work with them. The nursing homes would like to discharge them because they recognize some younger residents don’t feel comfortable in an “old folks’ home.” There are expanded care homes and foster homes with empty beds willing to take these residents, but the law requires a case manager to make the connection. A possible solution could be to allow health insurance plans (such as Kaiser

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and HMSA) to also become licensed case management agencies. In addition to honoring clients' wishes, they have a financial interest in transferring them from an expensive nursing home to a less expensive community-based foster or care home. Alternate pathways to achieve what residents want should be made available to them.

Resident Rights in Assisted Living Facilities. Chapter 90, signed into law August 12, 1999, contains the administrative rules for Hawai'i's 17 assisted living facilities. Missing was a detailed section on residents rights. It says "The resident shall be informed of his or her rights," but does not mention what they are. The result is that each facility has its own version of resident rights. The Healthcare Association of Hawaii (HAH) convened a taskforce to come up with a consistent list of resident rights that every assisted living facility could agree to. The taskforce recently completed its work and will soon review the proposed document with residents for their suggestions, comments, and buy-in.

Our Care, Our Choice Act. Signed into law by Governor Ige on April 5, 2018, Act 002 permits terminally ill adult patients with the capacity to make medical decisions to be prescribed an aid-in-dying medication if certain conditions are met starting January 1, 2019. Hawai'i is only the seventh state to enact such a law, but

what's next? Participation is "voluntary," so hospitals, long-term care facilities, staff, doctors, health plans, pharmacies, hospices, as well as the patients, need to decide if they want to participate, and if yes, written policies and protocols need to be developed. Of course, materials can be borrowed from the six states that have traveled this road before us, but Hawai'i's unique emphasis on the extended "ohana" will need to be taken into consideration. How to honor a patient's wishes and help the rest of the family accept this decision will be challenging.

Eldercare Workforce

By Peggy Perkinson, PhD

Predominant models of eldercare are rapidly shifting from institutional care, such as that provided in nursing homes to community- and home-based care (Landers *et.al.* 2016). This meshes well with the desire of most (87%) older adults to "age in place" (Barrett 2015) in their own homes and with efforts to lower the costs of long-term services and supports. The transition to home-based care has major implications for the eldercare workforce. From 2014 to 2024, home care is projected to add more jobs than any other single occupation, an estimated increase of 52 percent (U.S. Bureau of Labor Statistics 2015). While this projected model accounts for recent industry and employ-

ment trends, it does not factor in the substantial projected population growth of older adults, many of whom will likely require home care assistance. Current home care employment projections thus likely underestimate actual future demand. The following overview of the eldercare workforce focuses on various aspects of home care: what services are provided, who provides them, the costs and barriers to care, and recommendations for improving the system, both for those who provide home-based care and for those who receive it.

Home Care Services. *Personal care* entails assistance of a non-medical nature with the personal tasks and activities of daily living (ADLs), *e.g.*, bathing, dressing, grooming, toileting, eating, transferring, and walking. *Homemaker* or chore services include help with independent activities of daily living (IADLs), such as housecleaning, laundry, shopping, meal preparation, and transportation. *Home health care* refers to a higher level care, *e.g.*, direct or indirect skilled nursing services and other therapeutic services delivered under the supervision of a medical professional to home-bound patients. This includes checking and recording vital signs, assisting



with medications and medical equipment, wound care, *etc.* (Ridley 2018). For the purposes of this article, the phrase "home care worker" will be used to refer to all three types of care, unless otherwise indicated.

Home Care Workers. Nationally, there are approximately 2.4 million home care, home health care, and independent care providers, *i.e.*, those employed directly by consumers through publicly-funded programs (PHI 2017). This does not in-

clude "gray market" workers who are employed through informal arrangements with consumers. Little is known about this group, which could represent a significant number of providers of home care to older adults. Almost 90 percent of home care workers in the U.S. are women, with a median age of 45. The highest level of education for more than half is a high school diploma. While 87 percent are U.S. citizens, over 25 percent were born outside the U.S., and 37 percent report speaking English "not well" or "not at all" (PHI 2017). In Hawai'i, there are approximately 4,160 personal care aides and 4,330 home health aides (Hawai'i Department of Labor and Industrial Relations [DLIR] 2018).

Training. Training standards for personal care workers vary greatly from state to state. Requirements are often minimal. In Hawai'i, personal care providers must be trained in several broad areas, but training is left to employer agencies. While no formal education is required for the job, many employers prefer a high school diploma or its equivalent. Almost all personal care aides learn their skills on the job from an experienced worker (DLIR 2016). Home health aides employed by Medicare-certified home health agencies must be trained and evaluated through training programs approved by the state. Federal regulations require at least 75 hours of training, including at least 16 hours of supervised practical or clinical training, and 12 hours of continuing education per year. Hawai'i requires a minimum of 100 training hours and 70 clinical hours. The National Academy of Medicine (2008) has recommended training for home health aides be raised to 120 hours. Federal regulations list the subject areas and skills to be taught and define the competency evaluation process (DLIR 2016).

Wages and benefits. Twenty-three percent of home care workers live in households below the federal poverty line, compared to seven percent of U.S. workers overall. Two-thirds of home care workers work part-time or for part of the year. Most report wanting to work full-time but are unable to do so due to erratic scheduling resulting from the unpredictable nature of clients' needs, and employers hiring part-time workers to save costs.

The Caregiver

With a simple reply, "Sure, I'll help you..." began a five year event by helping to learn the hands-on clinical support required in changing dressings, meeting with nursing support, preparing meals and snacks prior to leaving for work, physician appointments, chemo treatments, transportation, diet changes... followed by a triple bypass requiring additional diet restrictions, an exercise regime, and more specialized physician appointments. Seemed an endless circle – growing larger at times, contracting at others.

Searching for coping information, I abruptly walked into a session at the Honpa Hongwanji Hawaii Betsuin Temple and was surprisingly introduced to the Project Dana Caregivers Support Group by Kim Cannon. This was an opening to the door to hear of others having gone through their experiences and sharing their comments, feelings, adjustments, most much, much more than I had and was going through. The guilt of taking self time out was negated. I sincerely appreciate the opportunity to have joined this magnanimous group and with the most dedicated staff from Project Dana, for all their efforts.

The median yearly wage for personal care aides is \$21,920 nationally and \$24,690 in Hawai'i; for home health aides, the median yearly wage is \$22,600 nationally and \$26,580 in Hawai'i (PHI 2017).

Access to Home Care. Affordability is a major factor in accessing home care services. The median annual cost for homemaker services in Hawai'i is \$57,200, compared to \$48,048 nationally. The median annual cost for a home health aide is \$68,640 in Hawai'i, compared to the national median cost of \$50,336 (Genworth Cost of Care Survey 2018). Medicare will pay for limited home health services and only those provided by a certified home health agency. Medicaid will pay for a greater range of services for those clients meeting the financial criteria. Long-term care insurance pays for home care services to a limited degree, but the plans are expensive, leaving a gap for those in the middle-income range.

Lack of staff is an additional barrier to care. Despite growth in demand for home care workers, the pool of likely applicants will be considerably smaller from 2014 to 2024 than in the previous decade (CBO 2013). This bodes ill, given earlier cited statistics regarding future demand for services.

Recommendations. Two avenues of reform seem especially worth exploring: (1) improving home care training and career development opportunities, and (2) considering alternate models of home care service provision.

Home care training. Given low salaries and status associated with this field and the relative dead-end nature of home care work trajectories, it is not surprising that many potential home care workers are lured to other jobs that provide better working conditions and opportunities for advancement. To attract more and better home care providers, we must revamp the ways home care workers are trained, compensated, and mentored into professional career development. Training content and delivery models are available from other states and could be adapted for workers in Hawai'i. The federally-funded Personal and Home Care Aide State Training (PHCAST) program developed competency-based training and credentialing systems for personal care aides to be used as the "Gold Standard" for future training efforts. The curriculum consists of 13 stackable, universal core modules that cover the following topics: roles and responsibilities; communication skills; culture and diversity; health care support: body systems and common diseases; infection control; basic restorative skills (*e.g.*, proper body mechanics, repositioning); personal care skills (*e.g.*, proper techniques for oral care, bathing, *etc.*); nutritional skills; housekeeping skills; client needs-specific training; safety and emergency training; consumer rights and ethics; and life skills (*e.g.*, stress and time management). The modules provide flexibility and a foundation for progressive career development in the health care field.

Alternate Models of Home Care Delivery. Consumer-Directed Services (also called Self-Direction, Cash and Counseling, Community Living Participant Direction

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Program, and in Hawai'i: Hawai'i Community Living Program). While home care agencies provide important services, few older adults can afford agency-based care for an extended period. Consumer-directed service is a Medicaid-based program that pays for home care and allows the consumer/older adult to hire and manage their choice of care providers. Some states allow family members and/or friends to serve as personal care providers and be compensated. This would seem a sensible approach, given approximately 87 percent of persons who need long-term care receive it from family members (AARP 2009). It has been estimated that consumer-directed services cost between 20 to 30 percent less than agency-based services (Tritz 2006). The premise underlying consumer-direction is that the person who receives the service is able to determine what he or she requires and can use good judgement in purchasing those services and overseeing their delivery. The program supports the consumer throughout this process. Participants are trained to select and oversee care attendants and are coached in developing their own care plans. While consumer-directed services allow greater independence in choice of services, there is a trade-off. The service recipient faces more responsibilities which are labor-intensive and involve considerable paperwork. Depending on the program, a person comparable to a case manager (sometimes called a "service consultant") may provide guidance and review spending plans and receipts. A surrogate may be designated to act on behalf of the older adult/service consumer. This person assumes self-direction responsibilities without pay. Payroll Service Companies are another option. For a relatively small fee (typically around \$800 per year, far less expensive than enlisting the aid of a home care agency), the company will provide necessary start-up services (e.g., background checks, drawing up contracts, providing a policy for workers' comp, etc.) and manage payroll and withholding tax payments.

Hawai'i also offers the Veteran-Directed Home and Community Based Services Program (VD-HCBS), which enables eligible veterans with high care needs to remain at home. Family members, including spouses, can be hired as personal



care providers. The veteran must require nursing home-level care (e.g., requiring assistance with three or more ADLs) and be enrolled in the VA Health Care program. Under this program, personal care providers receive between 50 to 75 percent of the average hourly rate for personal care providers in the region.

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Service Registries. Several states are experimenting with ways to more efficiently connect consumers with home care workers. The "matching service directory" allows consumers to tap into a registry of screened, available workers and allows workers to signal their availability for employment. Matching registries collect data on the needs and preferences of consumers and the availability, training, skills, and preferences of workers, creating a centralized, region-specific online resource through which both sides can "match" with each other. The consumer may either search the worker database, using search criteria such as years of experience or training, or consult with trained staff who conduct the database search and report back to the consumer (PHI 2017).

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Aid to Caregivers

Kūpuna Caregivers Program

By Pedro Haro, MPH

Every eight seconds, someone in the U.S. turns 65. Our local population is aging even more rapidly and living longer than in any other state. By 2020, nearly 300,000 people will be age 65 or older in Hawai'i. Because the demographic make-up of our state is changing, we need to change the way we provide care for our kūpuna. When given the 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 2016, the cost of home health care in Hawai'i was almost \$10,000 higher than the national average.

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 created a program to help caregivers provide care for our kūpuna: Kūpuna Caregivers.

Purpose: The program helps make long-term care for our kūpuna more affordable and provide the helping hand caregivers so desperately need. Currently, it allows up to \$70 a day in services, such as adult day center care; home health care workers for extra help preparing meals; for transportation when a family caregiver is not available; or other designated services.

Qualifications: To be eligible, caregivers must be employed at least 30 hours a week outside the home 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, and not covered by a comparable government or private home and community-based care service other than Kūpuna



Care. The care recipient cannot reside in a long-term care facility and must have impairments of at least two activities of daily living; or two instrumental activities of daily living; or one activity of daily living and one instrumental activity of daily living; or substantive cognitive impairment requiring substantial supervision.

Program Administration: The Executive Office on Aging (EOA) administers the program, and services are delivered by the county Area Agencies on Aging (AAAs) and their partner agencies.

Estimated Need and Cost: Data from the Hawai'i LTC actuarial model (Actuarial Research Corporation, 2016) indicates that there could be 2,566 individuals in 2019; 3,572 in 2020; and 4,016 in 2021 for the Program. Informal estimates of the number of working individuals between age 50 and 70 suggests that about three percent are also caregivers. This age bracket is about 30 percent of the total population, which suggests that there are potentially 12,000 working caregivers in the community. The majority of these caregivers have not applied for existing Kūpuna Care services, which currently helps approximately 4,600 clients.

The Kūpuna Caregivers Program was allocated only \$600,000 for FY18 for six months of a program year. The program was provided \$1.2 million for a full fiscal year in FY19. The Executive Office on Aging reported over 500 unique requests for services within a few weeks of the launch of the Program in December of 2017.

Paid Family Leave

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

The United States remains the only developed country in the world that does not offer its workers paid family leave (PFL). The Federal Family Medical Leave Act (FMLA) provides up to 12 weeks of unpaid leave during a 12-month period to care for a newborn, adopted or foster child; a family member; or to attend to the employee's own serious medical health condition. The law applies to private employers with 50 or more employees. The Hawai'i Family Leave Act (HFLA) provides up to four weeks of unpaid leave for the birth or adoption of a child or to care for the employee's child, spouse, reciprocal beneficiary, or parent with a serious health condition.¹

Why Paid Family Leave? Demographic data helps identify the problem in Hawai'i. By 2020, 40 percent of Hawai'i's workforce will provide care for older parents, and family caregivers will provide 70 percent of all care for frail elderly persons. Further, just over 40 percent of Hawai'i's workforce does not have access to a single day of leave from work, paid or unpaid.² In 2017, women comprised almost 47 percent of the civilian labor force.³ Hawai'i leads the nation in percentage of multigenerational family households (11.3%), exceeding the national average by 5.4 points.

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Shedding Light on the Difficult Side of Caregiving

By Kevin Dusenbury
Maui County Office on Aging

In 2007, Ruth Misaki began caring for her elderly parents. At that time, her father required total assistance with his activities of daily living, such as bathing, eating, dressing, and personal hygiene. After her father passed away, Ruth's mother's condition worsened, and she has required full-time caregiving since 2010.

While Ruth believes most television commercials and advertisements only show the pleasant side of caregiving with a cooperative care recipient, she would like readers to know that there is also a difficult side to caregiving. Due to cognitive decline, Ruth's mom, Jean Misaki, has lost the ability to reason and often displays aggression toward others. Ruth shared, "Being a caregiver is not an easy task. It is quite challenging and requires a whole lot of patience. Your personal "me time" life is basically put on hold, and mine has been on hold since 2010."

In 2016, Ruth became concerned about leaving her mom at home alone by herself while she was gone all day at work. For her mom's safety and her peace of mind, Ruth enrolled Jean into the Na Pu'uwai Senior Enrichment

Program. However, in March 2018, due to the overwhelming stress and cost of caregiving, Ruth contacted the Maui County Office on Aging to seek caregiver support services.

After seeking help from the Maui County Office on Aging and discussing her concerns, the assessment process commenced to determine eligibility for Kūpuna Care services. A caregiver



assessment identified significant caregiver burden. Since Ruth is employed full-time in addition to providing full-time caregiving for her mother, the Maui County Office on Aging determined that Ruth

would be an ideal candidate for the Kūpuna Caregivers Program, a caregiver support program that permits 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.

When Ruth learned about Kūpuna Care services, she was glad she inquired. She stated, "Caregivers should not be skeptical about applying for services, and it's not for them to determine their care recipient's eligibility. Allow the program to determine their eligibility. They may be surprised about how well the state of Hawai'i and County of Maui care for our kūpuna and caregivers."

Since enrollment in the Kūpuna Caregivers Program, Jean attends adult day care at Na Pu'uwai on Moloka'i five times per week, which has greatly helped Ruth maintain her full-time job while relieving some of the caregiving burden. Ruth stated, "If not for Kūpuna Care and the Kūpuna Caregivers Program, my mom would probably have had to be in some type of adult foster home or care facility by now." The respite scholarship has also been a vital financial support as the day care cost consumed a large portion of Jean's income.

While the Kūpuna Caregivers Program has been critical in relieving the burden of caregiving and maintaining employment, Ruth also wanted to credit her sister on O'ahu for providing crucial caregiver respite when she needs to "get away."

As the fate of the Kūpuna Caregivers Program is being determined, Ruth hopes that members of the Legislature remember both sides of caregiving and how difficult it can be for everyone involved. She thanks the Legislature for their continued support of caregivers through Kūpuna Care and the Kūpuna Caregivers Program. Ruth also expresses her gratitude to the Maui County Office on Aging for their expertise and unfaltering support through case management and service authorization for caregiver support services.

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

At the other end of the age spectrum are mothers with newborns or young children. The evidence indicates the importance of maternal child bonding as a prerequisite to the successful growth of infants. In addition, there are the needs of families with disabled members of all ages, including disabled veterans of our recent wars. Thus, the evidence suggests that paid family leave supports overall family well-being. Unfortunately, due to Hawai'i's high cost of living, few local families are able to meet their needs by taking unpaid leave for any length of time.

Elements of an ideal paid family leave program are as follows:

- Universal paid family leave—all employees pay into the program and all employees can access paid family leave.
- A broad definition of family to encompass Hawai'i's cultural views of the concept of family.
- A wage replacement program for caregivers, with a more progressive replacement for lower income workers to allow them to be able to actually use the leave.
- Capitation on wage replacement to prevent exhaustion of the paid family leave fund by higher income workers who need to access the fund.

- A minimum benefit of 12 weeks. Biological mothers should not be excluded from also using Temporary Disability Insurance (TDI).

National Paid Family Leave Activity: Paid family leave is a critical policy on which Democrats and Republicans agree. However, little cross-party consensus on how to pay for PFL benefits exists.

In 2017, Senator Kirsten Gillebrand of New York reintroduced the Family and Medical Insurance Leave Act or the FAMILY Act. The bill establishes the Office of Paid Family and Medical Leave within the Social Security Administration (SSA). The bill entitles

every individual to a family and medical leave insurance (FMLI) benefit payment for each month beginning on the first day of the month in which the individual meets the criteria specified below. The benefit ends 365 days later (benefit period), and is not to exceed 60 qualified caregiving days per period. An individual qualifies for such a benefit payment if he or she:

- Is insured for disability insurance benefits under the Social Security Act at the time an application is filed;
- Has earned income from employment during the 12 months before filing it; and
- Was engaged in qualified caregiving (any activity for which the individual would be entitled to for leave under the Family and Medical Leave Act of 1993), or anticipates being so engaged during the 90-day period before the application is filed or within 30 days after.⁴

Benefits would be funded by employer and/or employee payroll contributions.

In August of 2018, Senator Marco Rubio of Florida introduced the Economic Security for New Parents Act (S. 3345). The bill would allow new parents to receive early Social Security benefits to use for paid leave in exchange for delaying the collection of Social Security benefits by about three to six months when they retire.⁵

Ivanka Trump, with President Trump's support, continues to advocate for paid family leave from the White House, and attended a July 2018 bipartisan Senate hearing.

The Bipartisan Policy Center has established the Task Force on Paid Family Leave to turn bipartisan support for PFL into actionable, bipartisan policy. The Task Force is led by Maria Contreras-Sweet, the 24th administrator of the U.S. Small Business Administration, and former Senators Chris Dodd and Rick Santorum.⁶

Current PFL Activity in Hawai'i: On July 5, 2018, Governor David Ige signed SB 2990 SD 2 HD 2 CD 1, Relating to Family Leave, into law as Act 109 of 2018. The law requires the Hawai'i State Legislative Reference Bureau (LRB) to conduct a sunrise analysis of the impacts of and best framework for the establishment of paid

family leave. It also requires a report and proposed legislation to be submitted to the Legislature by September 1, 2019. Act 109 appropriates \$350,000 for FY 2018–2019 for the LRB to conduct the analysis.

PFL in Other States: Four states—California, New Jersey, New York, and Rhode Island—currently provide for paid family leave. Washington, D.C., en-



acted a paid family leave measure in February 2017 that will take effect on July 1, 2020. The state of Washington passed a measure to create a paid family leave program in July 2017. Benefit payments will commence at the start of 2020.

The paid leave programs in California, New Jersey, New York, and Rhode Island are administered through pre-existing temporary disability insurance programs and funded via employee payroll deductions. Washington, D.C., created a Universal Paid Leave Implementation Fund that will receive monies from a payroll tax on the employees of covered employers and self-employed individuals who opt into the program. Washington State created a similar Family and Medical Leave insurance account in the state treasurer's office.⁷

A 10-year study of the California law found increased employee loyalty, a healthier workforce, longer breastfeeding rates, lower rates of postpartum depression, and more gender equity in child care and caregiving. Businesses report little negative consequences after the law was enacted,

and laws such as this do not impose additional financial burdens on the state.

Employers also benefit in that such legislation reduces absenteeism, improves worker morale and productivity, and helps employers retain experienced workforce members. Furthermore, studies in New Jersey and California show that employees do not abuse paid family leave programs

and generally take less than the maximum time allowed. By helping maintain a stable workforce, paid family leave helps businesses thrive, keeping the economy strong. Finally, such a program can be established at little or no cost to employers, and with a very modest cost to employees.

We await with great interest the recommendations to be pre-

sented by the LRB study to be submitted to the Legislature in September 2019. We strongly encourage the Legislature and the Governor to subsequently 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

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

Hawai'i is recognized as the state with the fastest growing population of senior citizens. Family caregivers in Hawai'i number approximately 154,000 and provide about 144 million hours of unpaid care! These numbers continue to grow, both in the number of elderly who need care and in the number of caregivers. The majority of family caregivers work outside of the home. They may care for independent elderly who can stay at home alone while the caregiver works, but many are caring for elderly family members who cannot safely stay at home alone and they therefore need help with their caregiving responsibilities.

Many families start their caregiving experience with no experience. Having no experience causes stress, uncertainty, fear, frustration, and a myriad of other emotions. The stories we hear from caregivers are heart-wrenching. They don't know where to turn for help.

Because of this, many caregiver educational offerings are presented by the Alzheimer's Association–Aloha Chapter, the Hawai'i Parkinson Association, The Caregiver Foundation, AARP, and Hale Hau'oli Hawai'i, to name a few.

The Alzheimer's Association–Aloha Chapter offers a wide variety of programs and services, including educational programs for caregivers, community groups, and professionals, and online caregiver training classes. They also offer caregiver support groups that include an educational component. The Aloha Chapter's website, <https://www.alz.org/hawaii>, is a goldmine of resources and educational topics.

The Hawai'i Parkinson Association has an annual symposium in which leading specialists on the disease answer patient and caregiver questions. They also offer caregiver support groups with an educational component. Their website, <https://www.parkinsonshawaii.org>, provides education and caregiver support group locations.

The Caregiver Foundation provides seniors, disabled adults, and their caregivers



ers training on caregiving, aging, and financial management, as well as island-wide caregiver support groups with an educational component. Many resources can be found on their website at www.thecaregiverfoundation.org.

AARP offers caregiver education programs statewide, and online training and education for experienced and new caregivers. They offer educational topics on their website at <https://www.parkinsonshawaii.org>.

Hale Hau'oli Hawai'i, a non-profit organization, offers caregiver workshops several times each year with generous grants from HMSA and the Hawai'i Community Foundation. Experts in dementia, financial experts, and caregiving training programs offer much needed information to caregivers. Hale Hau'oli Hawai'i also offers caregiver support groups and works with The Caregiver Foundation in facilitating these groups island-wide. The website, <https://halehauolihawaii.org>, provides lists of upcoming workshops for caregivers and caregiver support group locations.

Many resources are provided in the *Family Caregiving Guide*, a publication of the Elderly Affairs Division, Department of Community Services, City and County of

Honolulu. Area Agencies on Aging (AAA) located on O'ahu, Kaua'i, Hawai'i Island, and Maui are also resources for caregivers, as well as the State Executive Office on Aging and Hawai'i Aging and Disability Resource Centers (ADRC).

Education for caregivers not only gives them the tools to provide care for their elderly, but leads to improved health outcomes for the elderly and caregivers alike.

Caregivers who work outside the home and care for elderly who cannot safely stay at home by themselves need help to care for them so they can stay in the workforce to provide for their families. The Kūpuna Caregivers Program is for these caregivers. We strongly urge the Legislature to continue funding this program so caregivers can remain in their jobs and not be as financially burdened from the care the elderly so desperately need.

Armed with the resources needed to continue to provide safe, effective care for their loved ones, caregivers can be successful in their endeavors, and the elderly can remain at home and in their communities. The majority of the educational opportunities for caregivers are provided free of charge, as well as resource materials.

Alzheimer's Disease & Related Dementias

By Ian Ross, BA

As the number of older Hawai'i residents grows, so too will the number of new and existing cases of Alzheimer's disease, the sixth leading cause of death in the state, affecting more than 28,000 individuals over age 65.

Hawai'i isn't alone. Someone in the United States is diagnosed with Alzheimer's disease every 65 seconds; by mid-century, it will be every 33 seconds. Alzheimer's disease is the only one of the top 10 causes of death in the U.S. 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, death certificates from Alzheimer's show an increase of 123 percent, while deaths from the number one cause of death, heart disease, decreased 11 percent.

Alzheimer's places a huge burden on our country's health care system, with annual costs exceeding a quarter of a trillion dollars. In 2018, the direct costs of caring for those with Alzheimer's in the U.S. will total an estimated \$277 billion, including \$186 billion in Medicare and Medicaid payments. Unless something is done, Alzheimer's is projected to cost more than \$1.1 trillion (in 2018 dollars) in 2050. This dramatic rise includes more than four-fold increases in both government spending under Medicare and Medicaid, and from out-of-pocket spending.

Health care and long-term care for individuals with Alzheimer's or other dementias are one of the costliest to society. People with Alzheimer's or other dementias have twice as many hospital stays per year as other older people. Medicare beneficiaries with dementia are more likely than those without dementia to have other chronic conditions. They also make up a large portion of elderly people who receive adult day services and nursing home care.



This rapid rise in medical costs is clearly an enormous burden nationally, to our state, and most of all, to people with Alzheimer's and their 'ohana. Fortunately, with forward-thinking policies and research, much of these costs can be contained.

According to the 2018 *Alzheimer's Disease Facts and Figures* special report, early diagnosis alone reduces medical and long-term care expenses for both families and the government. If all Americans who have Alzheimer's disease today were diagnosed when they had mild cognitive impairment before dementia, it would collectively save \$7 trillion to \$7.9 trillion in health care and long-term care costs.

But what if we could diagnose Alzheimer's disease before symptoms started?

The hope is that future treatments could then target the disease in its earliest stages, before irreversible brain damage or mental decline has occurred. Research on new strategies for earlier diagnosis is among the most active areas in Alzheimer's science, and funding from the Alzheimer's Association has spurred significant advances and steady progress.

Current diagnosis of Alzheimer's disease relies largely on documenting mental decline, at which point the disease has already caused severe brain damage. Re-

searchers hope to discover an easy and accurate way to detect Alzheimer's before these devastating symptoms begin.

Experts believe biomarkers offer one of the most promising paths. Several potential biomarkers are being studied for their ability to indicate early stages of Alzheimer's disease. Examples include beta-amyloid and tau levels in cerebrospinal fluid (CSF) and brain changes detectable by imaging. Recent research suggests these indicators may change at different stages of the disease process.

Before a biomarker can be used to diagnose Alzheimer's, it must be validated by multiple studies with large groups of people to ensure it accurately and reliably indicates the presence of the disease. Furthermore, the laboratory methods used to measure the biomarker must be shown to be stable and reliable.

There are currently no validated biomarkers for Alzheimer's disease, but researchers are investigating several promising candidates, including brain imaging, proteins in CSF, blood and urine tests, and genetic risk profiling. We know that early diagnosis of Alzheimer's provides a number of important benefits to diagnosed individuals, their caregivers, and loved ones, as well as to society as a whole.

(Continued on next page.)



Biomarker research is making it possible to detect Alzheimer's disease and provide an accurate diagnosis earlier than ever before. In addition to providing significant medical, emotional, and social benefits, and facilitating participation in important clinical trials, early diagnosis enables individuals to prepare legal, financial, and end-of-life plans while they are still cognitively able to make decisions and share their wishes. This would dramatically reduce the personal, family, and governmental burdens caused by this disease. This raises a question: Can we do better than just detecting Alzheimer's disease earlier?

Last year, the Alzheimer's Association successfully persuaded Congress to increase Alzheimer's research funding to the National Institutes of Health to \$2.3 billion. This is in line with the Alzheimer's Association's mission to eliminate Alzheimer's disease through research, and is a part of the National Alzheimer's Plan to develop preventions and effective treatments by 2025. There are reasons to be hopeful that these goals are achievable. It would require enormous breakthroughs and increased research funding, but our understanding of the disease has already advanced incredibly in the past decade alone.

These goals are ambitious but pragmatic when you consider that current annual research spending toward finding preventions and treatments is only a small fraction of the cost of care for people with Alzheimer's disease. Compared with the enormous current and future costs, we can afford to be ambitious.

The Crozier's: A Caregiver Success Story

By Kevin Dusenbury
Maui County Office on Aging

For the past four years, Naomi Crozier has been the primary caregiver for her mom, Fumiko Crozier, in Upcountry Maui. Fumiko, who retired as a registered dietitian at Kula Hospital, experienced cognitive decline over the past few years. According to Naomi, she became very concerned about her mom after she came home from a grocery store trip with dents and scrapes on the side of her car. When Naomi asked her mom what happened, her mom did not remember what had happened or where the scrapes came from.

After a discussion about safety, an agreement was made that Fumiko should no longer drive. The loss deprived Fumiko of her independence, which saddened her and made her feel socially isolated. After she gave up driving, she also suffered an unexpected illness requiring rehabilitation at Hale Makua, a skilled nursing facility in Kahului, Maui.

While her mom was at Hale Makua, Naomi had feelings of desperation and uncertainty until she contacted the Maui County Office on Aging, which serves as Maui County's Area Agency on Aging, and Aging and Disability Resource Center. They assessed Fumiko for Kūpuna Care eligibility. A Maui County Office on Aging care manager authorized homemaker service to help Fumiko remain independent in her own home. After a year, Fumiko's case manager noticed further decline upon her annual reassessment and authorized additional services, including adult day care, adult day care respite, home delivered meals, and assisted transportation. Naomi stated, "The Maui County Office on Aging has been wonderful and a savior to my mother and I." She also shared that the adult day care service, which is contracted through Maui Adult Day Care Centers, makes her mom feel more independent and active.

The home and community-based services were helpful, but are limited to available funding and service provider capacity. Naomi continued struggling to balance her work as a full-time mental health case manager and full-time caregiver. The Kūpuna Caregivers Program, which can authorize home- and community-based services with a value of up to \$70 per day for a caregiver employed at least 30 hours a week, would have been extremely helpful. Unfortunately, the Maui County Office on Aging had expended all funding, and the Croziers were placed on a waitlist.



Recognizing the signs of potential caregiver burnout, Fumiko's case manager worked with his supervisor at the Maui Office on Aging to offer additional person-centered services, which has "changed and saved both of their lives" according to Naomi. Instead of missing more work for caregiving duties, Naomi said she feels more engaged and refreshed at work with the additional respite. Without the assistance from the Maui County Office on Aging and Kūpuna Care, Naomi fears she would be unable to continue to work and caregive for her mom, and have to choose between employment and financial security, or institutional care for Fumiko.

The Maui County Office on Aging, along with the Croziers and other waitlisted caregivers and care recipients, remain hopeful that additional funding for the vital Kūpuna Caregivers Program will be secured by the Legislature. It will enable working caregivers to continue to be gainfully employed while providing invaluable caregiving services to their loved ones.

For more information about Kūpuna Care services and the Maui County Office on Aging, please visit www.maui-county-adrc.org or call 808-270-7774 or toll free at 808-643-ADRC.



Disability Issues

By Francine Wai, MPH

The casual observer might conclude that the issues facing the aging population and the disability population are the same with respect to legislation. However, aging and disability are like two overlapping circles—some people who are elderly do not have disabilities, and many who are not elderly have disabling conditions. Those with disabilities may have similar concerns and issues as many who are elderly: the need for accessible housing and caregiving, etc. On the other hand, many have concerns relating to civil rights and equal access to services. This section speaks to key civil rights and equal access issues being discussed during the 2019 Legislature, and that might not otherwise be covered under other portions of this report.

General civil rights: A 2017 Hawai'i Supreme Court decision, Hawai'i Technology Academy and the Department of Education vs. L.E. and Hawai'i Civil Rights Commission (HCRC) strips the HCRC's jurisdiction in disability discrimination cases against state and local government if the government entity receives federal financial assistance. **SB 569** intends to restore jurisdiction to HCRC for those disability discrimination cases.

The civil rights of individuals to parents are strengthened through **SB 947**, **HB 674**, and **SB 715**. The first two bills prohibit the disability status of a parent or caregiver from being the sole factor in determining fitness as a foster parent, adoptive parent, guardian, parent seeking custody or visitation, or provider of a safe family home. **SB 715** provides similar protections, although is limited to the rights of blind parents in the context of child welfare, foster care,

family law, and adoption.

Parking for persons with mobility issues: Individuals with mobility disabilities often hold valid permits to allow them to park in stalls reserved as accessible for people with disabilities. Permittees range from young individuals who are working to elderly individuals going to medical appointments or leisure trips. **HB 696**, **HB 1010**, and **SB 1236** clarify the ability of law enforcement to confiscate a disability parking permit that is being used unlawfully; makes the sale of a permit illegal; limits the privilege of free meter parking to only those individuals who are licensed to drive and are unable to reach or operate a meter due to physical disability; and clarifies the definition of a person with a disability for the purposes of permit eligibility.

Communication access issues: Individuals who are deaf or hard of hearing at any age face many challenges in receiving information conveyed through auditory formats. One such situation is viewing a movie at a theater. **HB 1009**, **SB 1235**, **HB 1340**, and **SB 331** clarify state law to provide opportunities for people who are deaf and hard of hearing to view movies with open captioning, similar to a foreign language subtitled movie. This will allow deaf and hard of hearing individuals to enjoy movies in the same manner as those who hear, while simultaneously improving their language skills through reading.

Taxation: Several bills introduced this session propose to affect social policy by alleviating the financial burden on people with disabilities through the use of the tax system. In 2018, Act 76 was enacted to assist a person or family member who purchases an adaptive vehicle, such as one with a lift, by excluding the weight of the lift; the ramps and the motors to operate them; and vehicle chassis reinforcements from the net weight of non-commercial vehicles in the levying of state and county motor vehicle weight taxes. **HB 345**, **SB 530**, **HB 632**, **SB 332**, and **HB 523** relate to the General Excise Tax and are broader than the motor vehicle tax bills. These bills, in varying forms, would exempt gross receipts from the sale of mobility enhancing equipment, durable medical equipment, prosthetic devices, prescription drugs sold pursuant to

a doctor's prescription, diabetic supplies, medical oxygen, and human blood and its derivatives from the General Excise Tax.

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 was enacted in 2018 to impose a penalty on a person who falsely represents an animal as a service dog or service animal. **SR 8** and **SCR 9** ask for a study on the implementation of Act 217 in terms of how it might be enforced and



improved, if needed. In 2019, several bills have been introduced to offer more clarity to the service animal/assistance animal/emotional support animal issue. **HB 1074** and **SB 334** propose to codify a definition of an assistance animal for the purpose of housing, and to clarify the type of acceptable documentation to verify a person's disability and status of an animal.

Community living: Various bills have been introduced to improve or expand on community living options or services for people with disabilities. **SB 336** proposes to repeal the minimum wage exemption for people with disabilities in so-called "training" or "workshop" settings. **HB 219**, **SB 950**, and **SB 330** propose to implement an earned income disregard program as an intermediate step to a Medicaid Buy-In Program. **SB 467** and **HB 787** make an appropriation to restore adult dental benefits to Medicaid enrollees. **HB 1017** and **SB 1243** mandate reporting of diagnostic audiological evaluation results to improve hearing follow-up for infants. **SB 1027** and **HB 469**, introduced as a part of the Kūpuna Caucus, requires health insurance policies and contracts to cover hearing aids at a minimum of \$1,500 per each ear.

Retirement Years

Living Well

Hawai'i Saves

By AARP Hawai'i

About half of all Baby Boomers and Gen X workers are in danger of retiring into poverty.

Why? Because too many workers have little or no retirement savings. The typical working household has just \$2,500 in retirement savings, and households close to retirement have saved only \$14,500. Without adequate savings, too many Hawai'i workers will have to work until they drop, instead of living the life they want to live as they age.

That's why AARP Hawai'i and the Kūpuna Caucus is supporting **Senate Bill 1374** and **House Bill 1189**, which would take the first steps toward creating a Hawai'i Saves program.



Hawai'i Saves is a common sense way to provide hard-working Hawai'i small businesses and employees with an easy way to save at work through payroll deduction.

Workers are 15 times more likely to save if the money comes out of their paychecks, before they have a chance to spend it. However, about 216,000 Hawai'i workers—about half of private-sector employees—do not have access to retirement savings at work. Most of these workers are employed by small businesses, which say it is too expensive, too complicated, and too time-consuming to offer payroll-savings programs to their workers.

Hawai'i Saves is modeled after OregonSaves, the nation's first state-facilitated



Roth IRA retirement savings program for private sector workers. In Oregon, businesses that don't currently offer retirement savings plans can sign up for OregonSaves at no cost, and their workers are automatically enrolled, but can also opt out. As of the end of January, 72 percent of eligible workers are participating. The average contribution is \$100 a month, and the average savings rate is 5.6% of their paychecks. In less than 19 months, the amount saved has grown to \$12.5 million. The program is clearly working, and thousands of Oregonians who weren't saving before are now saving for retirement.

Hawai'i workers should have the same opportunity at a better future. Hawai'i Saves is not a government handout. It is a sustainable public-private partnership similar to the college 529 plans already offered by Hawai'i and other states. Workers save their own money.

The state's role is to set up the program and provide oversight. The money will be invested by private financial services companies and held in the worker's own account. The accounts can travel with the worker if they change jobs.

Hawai'i Saves is supported by small businesses. A recent AARP survey found that about two-thirds of local businesses with under 100 employees do not offer retirement savings at work. However, most would offer a state-facilitated program like

Hawai'i Saves if it were available because they want to help their employees save and want to be competitive with bigger businesses that offer retirement savings. Eight out of 10 businesses agreed lawmakers should pass a Hawai'i Saves program.

Business owners see another financial reason to support the Hawai'i Saves program: it will reduce government and taxpayer costs for services such as SNAP (Supplemental Nutrition Assistance Program) and Medicaid, which workers will likely need if they haven't saved for retirement. The average Social Security benefit for a family 65-plus is about \$17,898 per year, while Hawai'i families spend on average about \$25,400 a year just on food, utilities, and health care. Families without any savings who cannot work will likely need state help with housing, food assistance, and medical care.

The AARP estimates that in just the first 15 years, the state will save \$32.7 million in social services spending if workers save enough to generate an extra \$1,000 a year in retirement income. The combined state and federal savings will be more than \$160 million.

Think about our homeless problem now and what it might be in the future if kūpuna with no savings cannot pay rent and cannot work. There is a cost to doing nothing. Hawai'i's small businesses and employees work hard. They need an easy way to save. It's time to pass **SB 1374** or **HB 1189**.



Toward a State of Active Aging!

By Cullen Hayashida, PhD

These are confusing times. We have an International Day for Older Persons (October 1), Senior Citizens Day (August 21), Grandparents' Day (September 8), and Older Americans Month (May), to name a few. Yet, at the same time, it feels as though these token references to older adults behooves us to ask: "What purpose do older people serve?" Our intents and strategies often seem half-hearted, confusing, and conflicting at best. Where are we going? How do we get there?

Let's acknowledge that changes are rapidly occurring. Population aging is here and now. The speed of aging in Hawai'i will quicken and may overwhelm our ability to continuously patch our system of social protection for older adults. This rapid change is due in part to our longevity bonus; we have been granted an additional 20 to 30 years of life post-retirement. Certainly, retirement to enjoy these bonus years comes with a certain amount of euphoria for a while, but for many, it is followed by a sense of loss in status, of recognition and purpose. For older adults, a longer life is a gift, but for so many with-



out adequate financial resources, running out of cash becomes a curse.

Perhaps part of the dilemma is our predominant reliance on viewing older adults from the sick role perspective — to be old is to be sick, dependent, and frail. We have focused on the needs of the frail and created formal and informal support systems of services and workers. That has been well and good. However, there is also reason to believe that continued unchecked, these efforts may be unsustainable.

What are we to do? Perhaps part of the challenge is to pivot from our view of older adults just in terms of geriatric syndromes to a realization that 80 to 90 percent of older adults are independent and out and about. We need to focus on the power and potential of older adults as an

asset to our communities. What can we do to keep older adults well, engaged, and continuously contributing to the Greater Good? What can we do to marshal the immense experience, skill, talent, contacts, and time that active older adults have? What can we do to push back on ageism and its not so subtle forms of prejudice and discrimination? What can we do to create the necessary training and resources to keep those from 50 to 80-plus well with purposeful roles.

The Kūpuna Caucus has officially supported a number of measures for this legislative session. There are several measures that promote the active aging agenda. Please take the time to review them individually and understand how they are synergistically related. Please encourage others to provide testimonies in support of these measures. Here are three bills related to active aging: **HB 468/SB 1026** on healthy partnerships, **HB 470/SB 1049** to support a Hawai'i Retirement Savings Program for employees of small companies, and **HB 472/SB 1030** on active aging. Be on the lookout for others that may also appear. Let us not waste the talents of our boomer and recent retirees. Let us work to move Hawai'i into a State of Active Aging!



The Time is Now

Case for a Palliative Care Pilot

By Davin Aoyagi, BA, Cory Chun, JD, & Chelsea Gonzales

The United States has an aging population, which increases the burden of chronic disease.

Among these diseases, cancer is the U.S.'s second leading cause of death. It has been one of the top causes of death for many years. Palliative care is an essential field in health care. It is about comfort and living well in all stages of care. It improves patient outcomes and their satisfaction in the quality of the care they receive. As a specialty, palliative care has been growing in Hawai'i both in facilities and in the home, but there is still a large unmet need.

We could be one step closer toward advancing palliative care in our state through **HB 722**, **HB 1447**, and **SB 804**. These bills would create a pilot program within the Department of Health that promotes cul-

tural competency practices within palliative care. Cultural competency is key when addressing disparities in health.

This pilot program is the culmination of recommendations from the palliative care workgroup, including the testing of hypotheses in recent local research regarding culturally competent approaches to staff and patient engagement. The workgroup was itself a product of the Legislature. In 2018, the Department of Health convened a workgroup pursuant to SCR142 HD1 SLH 2018, which tasked the workgroup to recommend strategies to expand palliative care in Hawai'i. In partnership with the American Cancer Society Cancer Action Network and Kōkua Mau, as well as industry partners, the top recommendations were to:

1. Increase public and health care provider education;
2. Support demonstration projects in the state with public funds; and
3. Evaluate new and existing data sources to further establish community standards of care.

The pilot program's efficacy is backed by academic studies. Research by the University of Hawai'i School of Nursing—*Culturally Competent Palliative and Hospice Care Training for Ethnically Diverse Staff in Long-Term Care Facilities*, (Kataoka-Yahiro, et al. 2016) — suggests that culturally competent approaches to Asian Americans and Pacific Islanders improve patient and staff knowledge, and satisfaction with palliative and hospice care services.

Palliative care may also provide a potential answer to rising health care costs in our state. Studies have demonstrated palliative care programs that aggressively treat pain and symptoms and improve care coordination result in shorter hospital stays and lower costs, particularly for the sickest patients. A recent systemic review shows that palliative care can increase patient quality-of-life and their symptom burden, as well as lead to increased patient and caregiver satisfaction, increased advance care planning, and decreased hospital utilization (<https://www.ncbi.nlm.nih.gov/pubmed/27893131>).

What is Palliative Care?

Palliative care is specialized medical care for people with serious, complex, and/or chronic illnesses. Its focus is on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis.

The goal is to improve quality-of-life for both patient and family. Palliative care is provided by a team of doctors, nurses, social workers, chaplains, and other specialists who work with a patient's regular doctors to provide an extra layer of support. People benefit from palliative care at any stage of their illness, including from the time of diagnosis, and can be provided together with curative treatments. It should therefore be considered a key component of medical care along with all other appropriate treatments. (Definition summarized from Center to Advance Palliative Care. For more information, visit <https://www.capc.org/about/palliative-care/>)

According to the Center to Advance Palliative Care (CAPC), if palliative care were fully integrated into the nation's hospitals, total savings could amount to \$6 billion per year. However, despite increased patient quality-of-life and potential cost savings, there is a pronounced underutilization of palliative care services in Hawai'i. In written testimony, the John A. Burns School of Medicine noted, "The collective clinical experiences of JAB-SOM faculty and residents/fellows who promote and/or provide palliative care services are consistent with the numerous studies cited in HB 1447 — that palliative care services are woefully underutilized."

In 2019, state lawmakers have the opportunity to make tremendous strides for those who suffer from chronic diseases by funding a pilot program that can provide better patient and caregiver outcomes while lowering health care costs for Hawai'i.

To learn more about palliative care and the resources available in Hawai'i, visit Kōkua Mau at <https://kokuamau.org/palliative-care/>.



A Cancer Survivor's Palliative Care Story

My name is Natalie Nimmer. I strongly support **SB 804** and **HB 1447**, which would establish a culturally competent palliative care pilot program to promote palliative care, gather health care utilization data, and create at least two pilot programs for home- or community-based palliative care. All cancer patients—regardless of financial status, age, or any other factor—should have access to palliative care, and these bills could lead to greater awareness and access.

When we rang in the new year in 2015, I was a 36-year-old vegan marathon runner. In March, I was diagnosed with Stage 3 breast cancer. In addition to pointing out the shock of the news, just about everyone around me said that I needed to get used to a "new normal." I endured seven different chemo drugs over two separate multi-month periods of treatment, as well as one minor and two major surgeries and 33 rounds of radiation. In the midst of this, I suffered from debilitating nausea, extreme fatigue, and neutropenic fever (a condition sparked by a compromised immune system where everything goes wrong— head to toe rash, high fever, and a range of other maladies). There were

many days during my year and a half of treatment when I could not stay awake for more than two hours a day and could not walk to the bathroom without assistance

But I was self-employed and a doctoral candidate at UH-Mānoa, so I did not have the option to drop out of life for 18 months. My nurse practitioner and oncologist performed magic through the use of palliative care treatments. I was able to continue working and attend classes on my good days—even if it meant bringing a pillow and blanket to camp out on the floor when I didn't have the energy to sit up. In fact, I completed the Hibiscus Half-Marathon between my third and fourth rounds of chemo, and presented my graduate research at a conference in the Marshall Islands two weeks after my sixth round of chemo. I was bald and weak, but I was still living life. Without palliative care treatments, none of this would have been possible. It was a "new normal," but I could still easily be classified as "normal." **SB 804** and **HB 1447** would raise awareness about palliative care and increase access to these options. Palliative care is about dignity, but it is also about ensuring that anyone with serious, chronic, or terminal conditions can still live life while they are on this earth. Please support this "new normal" for Hawai'i by supporting palliative care.

Conclusion

A Path Forward

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

The Legislative Process

Sections 2 through 7 of this publication illustrate the kinds of 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 decreases as bills are either not heard by committees or are deferred indefinitely. Thus, advocates must be prepared at the very beginning of a legislative session to respond rapidly to identify and support favorable legislation, and to testify 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 eventual-

ity 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 state government and federal government 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 and 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 governments' 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 and their communities to contribute their time, talent, and life experiences to benefit others?⁶

We are called to intensify our work to overcome the challenges of the Silver Tsunami. We are called to advance and enact policies and programs that work not just for the present, but for a future where never before have so many have lived so long. We are called to develop



strategies and implement systems that promote and support the health, safety, and independence of our aged and our disabled and their family caregivers.

References

¹Citizens Committee for Children of New York. <https://www.cccnewyork.org/about/what-is-effective-advocacy/>. Accessed December 26, 2018.

²Griffiths, Elizabeth P., MD, MPH, June 22, 2017, http://www.nejm.org/doi/full/10.1056/NEJMp1704120?query=featured_home. Accessed December 26, 2018.

³Ibid.

⁴Ibid.

⁵Hawaii State Plan on Aging, 2011 – 2015.

⁶Administration on Aging. <https://oam.acl.gov/>. Accessed December 26, 2018.

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: <http://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.

250 South Hotel Street, Suite 406
Honolulu, Hawai'i 96813
Phone: (808) 586-0100
Fax: (808) 586-0185
Email: eoa@doh.hawaii.gov
Website: <http://health.hawaii.gov/eoa/>

Elderly Affairs Division

City & County of Honolulu
Nalani Aki, 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: <https://www.elderlyaffairs.com/site/1/home.aspx>

Hawai'i County Office of Aging (HCOA)

Kimo Alameda,
County Executive on Aging
Email: hcoa@hawaiiantel.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

Kaua'i 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: <http://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: <https://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

Barbara Kim Stanton, State Director
1132 Bishop Street, Suite 1920
Honolulu, Hawai'i 96813
State Office: (808) 545-6024
Toll-Free: (866) 295-7282
Fax: (808) 537-2288
Email: hiaarp@aarp.org
Website: <https://www.aarp.org/states/hi/>

Disability and Communication Access Board

Francine Wai, 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: <http://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

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Hawai'i Pacific Gerontological Society

Calvin Hara, 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: <http://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: <https://www.medicare.gov/nursinghomecompare/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.

2720 Nako'oko'o Street
Honolulu, Hawai'i 96826-4700

Phone: (808) 945-3736
Fax: (808) 945-0007
Email: info@projectdana.org
Website: <https://www.projectdana.org/>

St. Francis Healthcare System

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

Email: info@stfrancishawaii.org
Website: <http://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: <https://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: <http://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: <http://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: <http://www.hawaii.edu/uhelp/index.html>

Hā Kūpuna

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University of Hawai'i at Mānoa
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Public Policy Center

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College of Social Sciences
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Honolulu, Hawai'i 96822

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FAX: (808) 956-9121

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Website: <http://www.publicpolicycenter.hawaii.edu/index.html>

A photograph of a lush bamboo forest. In the foreground, a wooden boardwalk made of weathered planks leads through the bamboo. To the left of the boardwalk, there are several large, dark rocks covered in vibrant green moss. The ground is covered with fallen bamboo stalks and dry leaves. The background is filled with tall, slender bamboo stalks that create a dense, textured wall of green. The lighting is soft and natural, highlighting the various shades of green and the textures of the bamboo and moss.

Aging & Disability Issues 2019

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