



Aging & Disability Issues 2018

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



In Memory of
Anthony "Tony" Lenzer, Ph.D.
December 19, 1929 – February 8, 2018
A Life Well Lived.



Aging & Disability Issues 2018

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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'uuanu; 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 issue of the *Aging and Disability Issues Report 2018* is the 13th annual publication that offers an overview of legislative issues dealing with aging, disability, caregiving, and long-term services and supports in Hawai'i. This report calls attention to the priority issues that deserve the solemn 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.

The report has nine sections:

Section 1 provides an overview of the report, as well as some general observations of the political and economic changes in Hawai'i in 2018.

Sections 2 through 7 describe the priority issues for the legislature in the 2018 session as designated by the major groups that advocate for the frail elder and disabled populations and their caregivers. These sections explain why these are important issues and offer background information concerning these issues. The six sections also discuss the specific bills that address these priority areas and their status at the time of writing of this report.

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

Section 9 contains a list 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. The 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 2018

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

According to estimates from the National Alliance for Caregiving, during the past year 65.7 million Americans (or 29 percent of the adult U.S. adult population involving 31 percent of all U.S. households) served as family caregivers for an ill or disabled relative. Seventy-eight percent of family caregivers incur out-of-pocket costs due to caregiving, spending an average of \$6,954 per year.¹

A national strategy is required to research, develop and plan, and implement a cohesive, purposely built system of support for family caregivers. To this end, in September of 2017, Representative Gregg Harper of Mississippi sponsored the RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act. Congressional cosponsor of the legislation included representatives Kathy Castor, Lujan Grisham, and Diane Black, and senators Susan Collins, Tammy Baldwin, Lisa Murkowski, and Michael Bennet. With wide bipartisan support, the legislation passed the House in December of 2017; the Senate Committee on Health, Education, Labor, and Pensions unanimously in January of 2018; and the Senate in that same month. President Trump signed the bill into law on January 22, 2018.

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. This Council will be comprised of relevant federal agency representatives, as well as family caregivers, older adults with long-term services and support needs,

(Continued on next page.)

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 caregiver strategy include identifying actions that government, communities, health providers, employers, and others can take to support family caregivers, including:

- Promoting greater adoption of person-centered care 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 of information about innovative family caregiving models
- Assessing federal programs around family caregiving
- Addressing disparities and meeting the needs of the diverse caregiving population³

The Hawai'i Family Caregiver Coalition and others are working with Hawai'i's congressional delegation to strongly encourage HHS to have an appropriate representative from Hawai'i on the Family Caregiving Advisory Council.

Locally, our state's economy is projected to improve in 2018 due to the increase in business and household income resulting from the federal tax reform. Consequently, more resources might

be available to address "care" issues, including aiding family caregivers.

Similarly, the national economy continues to recover. 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 has launched aggressive new supports for the aging veteran population.

"Aging and disability advocates are determined to ensure that funding is also allocated for the preservation and continuous building of the safety net of services for our vulnerable populations."

The federal Older Americans Act (OAA) authorization had expired in 2011. OAA legislation passed the full U.S. Senate in 2015. The senate subsequently unanimously approved the U.S. House amendments in 2016 and President Obama signed the bill into law on April 19, 2016, providing for a three-year reauthorization of the OAA. 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.

We remain deeply grateful to congress for this strong 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.

The Executive Office on Aging continues to work with public and private agencies in innovative efforts to restructure the service delivery system and to develop

more efficient operations by adopting data systems that enable them to target resources to the greatest needs. Governor David Ige and the state legislature generously have supported innovations such as the development of Aging and Disability Resource Centers (ADRCs) by the counties. ADRCs have improved access to services, enabling persons to obtain appropriate services in a more timely manner, and consequently have reduced costly episodes such as hospitalizations, emergency room visits, and nursing home placements, and in other ways have shown themselves to be very cost-effective.

The Governor's top priorities include public education, affordable housing, and preservation of our 'aina. Other state priorities include, but are not limited to, improving our health system; promoting economic diversification and economic growth; focusing on a renewable energy future; expanding our agricultural industry; preserving, protecting, and managing our environment; supporting the Native Hawaiian community; supporting the development and completion of public transit systems, including bus and rail; and modernizing our tax system.⁴ These many priorities require enormous funding. However, aging and disability advocates are determined to ensure that funding is also allocated for the preservation and continuous building of the safety net of services for our vulnerable populations.

In this election year, candidates at all levels of government must be committed to the expansion of services to the rapidly aging population, and we need to hold them accountable.

¹AARP, Family Caregiving and Out-of-Pocket Costs: 2016 Report.

²National Alliance for Caregiving.

³Forbes, January 10, 2018, <https://www.forbes.com/sites/nextavenue/2018/01/10/what-the-new-raise-family-caregivers-act-will-do/#490a3c0770b9>. Accessed February 10, 2018.

⁴David Y. Ige. <http://governor.hawaii.gov/>. Accessed February 10, 2018.

Kūpuna Care, ADRCs, Healthy Aging Partnership Program & Adult Day Care

by Sarah Yuan, PhD

Chair, Legislative Committee,
Policy Advisory Board for Elder Affairs

In our rapidly aging society, a wide range of support services has evolved to keep older people healthy, active, and where they would most like to live: in their own homes. Many of these service programs were initiated by federal and state agencies, and some were developed at the local level through the private and public sectors. Much of the funding for these programs comes from both federal and state resources, although in Hawai'i, county governments also provide funding. This section will discuss three such programs and the bills that contain funding provisions for them:

- Kūpuna Care
(**HB 1913/SB 2588; HB 608**)
- Aging and Disability Resource Center (ADRC) (**HB 1914/SB 2589; HB 612/SB 533**)
- Healthy Aging Partnership
(**HB 1918/SB 2593; SB 2438**)

Kūpuna Care

Established in 1999, Hawai'i's Kūpuna Care program provides long-term services and support 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, home-maker/housekeeping, personal care, and home-delivered meals. With annual base budget funding of \$4.85 million, the state has supported services that enable older adults to remain in their homes and com-



munities, delaying premature placement in costly residential care facilities. Annual base 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 largest increase being those age 85 and over, ensuring adequate and economical care in the least restrictive environment is crucial. The EOA's base budget for Kūpuna Care has remained at \$4.85 million since 2002, while the older adult population in Hawai'i has increased significantly.

Legislative proposals. The Ige administration has included Kūpuna Care in the FY19 budget and recommended an increase in the DOH base budget of \$3.9 million for this EOA program. The Kūpuna Caucus and senior advocacy groups have requested \$4.15 million (via **HB 1913/SB 2588; HB 608**), which is the same level of special appropriation this program received before FY18. If appropriated, the additional funding will enable the EOA to serve up to

3,600 kūpuna per year in the community setting, and to use comprehensive person-centered intake and assessment tools developed statewide for targeting public supports to persons in greatest need.

Aging and Disability Resource Centers

Older adults, people with disabilities, and their families are often unprepared when the sudden onset of a serious health condition or abrupt decline in function occurs. Once faced with the need for long-term services and support, families find it challenging to navigate the complexities of care systems. Aging and Disability Resource Centers (ADRCs) 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 ensure access to high-quality care through person-centered services, which optimizes choice and independence, encourages personal responsibility, and pro-

(Continued on next page.)

vides support so that 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 common set of functional criteria. The ADRC system offers a full range of information on long-term support programs and benefits; conducts the assessment on individuals' needs for services to maintain independent living in the community; and is a single point of entry for Kūpuna Care and Older Americans Act (OAA) services. In FY17, the ADRCs received 35,007 contacts/calls, nearly half from people who called before. Over 90 percent of ADRC consumers were satisfied with their experience.



Legislative proposals. The Ige administration has identified Hawai'i's ADRC system as a priority and requested an increase of \$1.7 million to EOA's budget for ADRC, bringing the total to \$3.1 million for FY19. The Kūpuna Caucus and senior advocacy groups have requested the same amount of appropriation (\$1.7 million) through **HB 1914/SB 2589** and **HB 612/SB 533**. 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 in accordance with federal requirements; and integrate participant-directed supports as a function of the ADRC.



Healthy Aging Partnership Program

by **Lori Tshako, MSW**, Wellness Coord., Maui County Office on Aging & **Eldon Wegner, PhD**, Professor Emeritus, Dept. of Sociology, University of Hawai'i at Mānoa, Member, Legislative Committee, Policy Advisory Board for Elder Affairs

Chronic disease and disability severely affect quality-of-life and also entail high expenses 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 address the need to reduce chronic disease and disability, and to manage these conditions to minimize their effects. Led by the Executive Office on Aging and the Chronic Disease Branch of the Department of Health, HAP is delivered through classes offered by non-profit agencies throughout the state.

HAP offers two evidence-based programs, Better Choices, Better Health (BCBH), which focuses on teaching skills for managing chronic conditions; and EnhanceFitness, which offers exercise programs designed for older adults. Researchers at the University of Hawai'i evaluate the impact of these programs, assessing clients prior to beginning the program and then conducting a post-program assessment of the clients to determine program impact.

Better Choices, Better Health (BCBH)

is a six-week self-management workshop for older adults with chronic conditions designed to help individuals manage their health and improve their quality-of-life. The program was developed and tested by Stanford University to supplement the medical treatment of chronic diseases. People learn skills to help them manage their health conditions and interact with their health care providers.

Over 2,772 individuals across the state have participated in BCBH. The largest number entering the program have hypertension, arthritis, diabetes, and cancer. Offering diabetes- and cancer-specific programs, the program resulted in a net cost-savings of \$614.62 per participant. Program results show that participants have decreased visits to physicians' offices and emergency rooms, experience fewer symptoms, and have increased frequency of exercising.

EnhanceFitness is an exercise program of one-hour classes that improve cardiovascular fitness, strength, flexibility, and balance. Many individuals enjoy exercising in groups because it is more fun and they receive social support from peers. The program protects against heart attacks, lowers blood pressure, lowers cholesterol levels, increases strength and flexibility, improves mental functioning, and reduces the risk of falls. These impacts have been confirmed through pre- and post-assessments of the participants. The program has thus far served 1,419 participants.

Legislative proposals. Despite the proven success of these workshops in increasing quality-of-life and reducing health care

costs, the Healthy Aging Partnership program continues to struggle to obtain funding from the state. In 2016, the legislature failed to pass proposed funding, with the result that a number of the programs had to cease, although some counties stepped in to keep their programs going. Funding for one year was passed in the 2017 session. However, the governor did not include funding in his 2018 budget. With the urging of senior advocacy groups, the legislature has introduced several bills to fund the Health Aging Partnership.

SB 2593 Healthy Aging Partnership and **HB 1918** Healthy Aging Partnership are companion bills in the state senate and state house that would fund the Healthy Aging Partnership program for the next biennium at \$550,000 per fiscal year, the same level as in past years. However, Senator Josh Green, Chair of the Senate Human Services Committee, introduced **SB 2438** Healthy Aging Partnership, which calls for an increase in funding to \$605,000 per fiscal year, believing that the program should be expanded to serve even more qualified kūpuna. The additional funding would go toward expanding programs to additional sites on O'ahu and the County of Hawai'i, and expanding programs for cancer patients, and possibly assisting Kaua'i and Maui in support of their existing sites.

At this point, both senate bills have passed their first hearings, but the house bill has not been scheduled for a hearing. Hopefully, the house will hear **HB 1918**. As the bills move to the next hearings, we will advocate for the higher level of funding proposed in Senator Green's bill.

Adult Day Care

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

As of November 2016, there were over 138,000 seniors age 70 or older in Hawai'i, according to the Aging and Disability Resource Center. Hawai'i has the fastest growing aging population and the longest life expectancy in the United States (81 vs. 79 on the mainland). Currently, only a fraction of these seniors who seek resources and care services are able to get help. The need for se-

nior services and care options will grow as the population continues to age. There are many organizations that are focusing on the ever increasing needs, such as AARP, the Alzheimer's Association, the Executive Office on Aging, Aging and Disability Resource Centers, and others. There are many options for senior care, such as adult day care, care homes, foster homes, home care, assisted living, and skilled nursing facilities. The Kūpuna Caregivers bill passed last July 2017, granted \$600,000 in funding for an adult day care pilot program that began in February 2018. In 2018, **HB 1912 HD 1**, **SB 2587**, and **SB 2988 SD 1** to increase the allocation to continue this program are being discussed. The house Committee on Health and Human Services has recommended passage of **HB 1912 HD 1**. The senate committees on Commerce, Consumer Protection, and Health and Human Services have recommended passage of **SB 2988 SD 1**. The bill includes an appropriation of \$4 million for Kūpuna Care.

Adult day care is one of the most important resources for families. It provides urgently needed respite for caregivers and often benefits persons with dementia. Getting away to be with friends or to be alone can relieve the pressures of family life. The person with dementia does not have this opportunity. They must be with the caregiver day after day, but their impairment does not take away from the need to have their own friends and time apart. Adult day care can provide for both caregivers and persons with dementia.

The burden of enforced togetherness may be difficult for the impaired person as well as for the caregiver. Statistics from AARP in 2015 show that there are approximately 154,000 caregivers in Hawai'i who put in about 144 million hours of care. Most family caregivers are between the ages of 30 and 64, and four in ten adults are caring for sick or elderly family members. About 80 percent of family caregivers work outside of the home. Even caregivers who are not working need respite from their caregiving responsibilities, time to run errands, or just go out with friends, but don't want to leave their elderly at home alone.

Caregivers know that their loved ones

want to "age in place" in their homes and communities, and with their families. A 2011 survey by AARP showed that nearly 90 percent of people over age 65 wanted to stay home for as long as possible. Living at home and staying in a familiar community may offer benefits to the emotional well-being of seniors.

One of the fastest growing segments of the aging industry, adult day care offers caregivers the respite, help with care, and personal support they need to refuel and continue to give their best. It's also the most economical option for care, as shown in a 2017 Cost of Care Survey by Genworth featured in *Generations Magazine*.

Adult day care centers are non-residential facilities that support health, nutrition, physical exercise, entertainment, and socialization, stimulating both mind and body. They may help delay admission to residential long-term care facilities. For participants who would otherwise stay at home alone, can no longer be independent, or are isolated and lonely, the social stimulation and recreational activities may improve or maintain physical and cognitive function. Adult day care centers provide needed social interaction and greater structure to the participant's daily activities. For caregivers, they provide respite care, enabling them to go to work or to have a break from caregiving. Services and activities provided include:

- Assistance with eating, taking medications, toileting, and walking
- Educational programs for mental stimulation
- Health Monitoring (vital signs, meal and fluid intake)
- Arts and crafts; music therapy
- Field trips
- Holiday and birthday parties
- Social activities
- Relaxation techniques
- Exercise programs
- Cooking demonstrations
- Games
- Pet therapy

These activities are designed with the idea of promoting a positive aging experience stimulating both mind and body, and to keep kūpuna engaged socially and physically active.

Aid to Caregivers, Kūpuna Caregivers, Paid Family Leave & Caregiver Education



by **Tony Lenzer, PhD**, Emeritus Board Member, Hawai'i Pacific Gerontological Society; Board Member, Policy Advisory Board for Elder Affairs; Professor Emeritus of Public Health, University of Hawai'i at Mānoa

Introduction

In recent years, developed countries have recognized that their populations are aging rapidly in a way never before seen. In particular, the growth of the oldest part of the population (85+) has focused attention on chronic illness, disability, and the community and institutional resources needed to serve this part of the population.

On the other hand, less attention has been paid to the needs of family members who serve as unpaid caregivers and provide approximately 80 percent of all care for frail and disabled elders. There are many reasons for societal neglect of caregivers, including the cultural expectation that this is a normal and expected aspect of family life; failure to recognize the economic value of unpaid caregiving; and lack of understanding of the personal “costs” of providing so much unpaid labor. Last year, the Hawai'i legislature passed an important bill, the CARE Act, which will help caregivers obtain the information and skills needed to perform the increasingly technical medical and nursing tasks elders require when returning home from the hospital. This year, the legislature is examining a number of bills that could provide financial aid to Hawai'i's 154,000 family caregivers.

Two types of bills are under consideration. First, legislation to provide paid family leave to allow employed caregivers time to spend with infants, children, or elders who need assistance due to serious health

problems. Second, bills that would cover the cost of a limited number of home and community-based services that provide respite for caregivers for several hours per day. These bills would authorize the creation of a Kūpuna Caregivers Program. Both types of bills will be discussed in the following sections of this report.

Kūpuna Caregivers Program

Every eight seconds, someone in the U.S. turns 65. Our local population is aging even more rapidly and living longer than any other state. By 2020, nearly 300,000 people will be age 65 or older in Hawai'i. Because the demographic makeup 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. This program helps working caregivers pay for home health care workers for extra help preparing meals, for transportation when a family caregiver is not available, adult day care, or other designated services.

Qualifications: To be eligible, caregivers must be employed at least 30 hours a week by one or more employers and provide direct care to a care recipient who is a U.S. citizen or a qualified alien, 60 years of age or older, 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 program is administered by the Executive Office on Aging (EOA), and services are delivered by the county Area Agencies on Aging (AAAs) and its 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 3 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. The Executive Office on Aging has reported over 500 unique requests for services within a few weeks of the launch of the Program in December of 2017.

With funding of \$4 million during the next fiscal year (July 2018 to June 2019), EOA projects that up to 549 caregivers state-wide could receive services from Kūpuna Caregivers twice a week.

HB 1912 HD 1 and its companion bill **SB 2587** appropriates \$2 million for the Kūpuna Caregivers Program. More robust funding is found in **SB 2988 SD 1**, which allocates \$4 million for the Kūpuna Caregivers Program.

The Kūpuna Caregivers Program will:

- *Be available to those in need:* There is a large gap in assistance for families faced with mounting long-term care costs.
- *Create high-quality home care jobs:* We need to put compassionate, trained workers in positions that pay fair wages and respect the work they do.
- *Represent our values:* Caring for our kūpuna is part of our island culture. This program does not replace the way we always have cared for our elderly. The program improves and increases access to affordable services our elderly need.

Paid Family Leave

by Tony Lenzer, PhD &

Gary Simon, President, Hawaii Family Caregiver Coalition; Chair, Policy Advisory Board for Elder Affairs

The United States is the only developed country in the world that does not offer its workers paid family leave (PFL). Federal law provides up to 12 weeks of unpaid leave for employees of large companies, while the Hawai'i Family Leave Act (HFLA) only provides unpaid leave and job protection for up to 4 weeks for businesses with 100 or more employees. As a result, only 2 percent of companies and 16 percent of the workforce are protected by the HFLA. Hawai'i's only partial paid leave is the Temporary Disability Insurance (TDI) program. However, TDI is time-limited, quasi-privatized like no other program in the nation, and has very weak enforcement. Further, state government, a major employer, is self-insured, so by providing a minimum amount of sick leave, the state does not need to provide TDI.

Lifetime Caregiver

by Harry Iha

I've been a caregiver since 1980, so that's 38 years of me caregiving. When I joined Project Dana's Caring for the Caregiver Support Group 15 years ago, I was taking care of my mother. I took care of my dad too but he passed away in 1983. While I was caring for my mom, my wife had kidney failure. I took care of her after my mother passed away. My wife was athletic when she was younger; it was really sudden when she got sick. For three days of every week, I would take her to dialysis treatment for three to four hours. After my wife passed, I took care of my brother-in-law and now I take care of my sister-in-law. My sister-in-law is pretty healthy and she just turned 94. She has the same routine every day. She gives me a shopping list for groceries twice a week. I go to the commissary because it's cheaper. Sometimes we both go to Costco. Every month, I take her to her medical appointments. I check-in on her to make sure she's safe and provide companionship. I'm 88-years-old, and she's healthier than me. When I get sick, she becomes my caregiver. I take care of her now because she helped my wife and I raise our two daughters.

Project Dana's family caregiver support group has really helped me with my care-

Why Paid Family Leave? Demographic data helps identify the problem in Hawai'i. By 2020, 40 percent of Hawai'i's workforce will be providing care for older parents, and family caregivers 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.¹ In 2017, women comprised almost 47 percent of the civilian labor force.² Hawai'i leads the nation in its percentage of multigenerational family households (11.3%), exceeding the national average by 5.4 points.

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 ad-



Project Dana's Caring for the Caregiver Support Group Coordinator Maria Morales with Harry Iha.

giving. I learn so much every time I attend the meetings. You get to learn how to better care for the person. I've been a caregiver for a long-time and still continue to learn from the speakers and stories from other caregivers. I realize that I have it easy compared to others having a harder time. The support group feels like an 'ohana – everybody helps each other. The information I get in the support group you really can't learn in books. If I didn't have the support group, the only way to get the information is from friends, neighbors, or family. But for a caregiver, that's not enough.

dition, 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 PFL program:

- 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 term "family."
 - A wage replacement program for caregivers that is more progressive for low-
- (Continued on next page.)

er income workers to allow low income workers 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 TDI.

Current PFL Activity in Hawai'i: Legislation was introduced in 2015 to rectify this situation, but no paid leave bill moved forward in 2015 or 2016. In 2016, the Hawai'i State Commission on the Status of Women and the UH Center on the Family received grants from the U.S. Department of Labor and the Annie E. Casey Foundation for economic analysis, feasibility studies, public education, and other work which would form the basis of a new bill to be introduced in a later year.

Several house bills and companion senate bills related to family leave have been introduced in the last and this legislative session: **HB 4 HD 1 SD 1/SD 638**; **HB 213 HD 1 SD 1 CD 1**; **HB 1362/SB 408**; **HB 1867/SB 3047**; **HB 2136/SB 2350**; and **HB 2598 HD 1/SB 2990 SD 1**.

HB 1362 and its companion bill, **SB 408**, are the most robust, as they include:

- The establishment of a family leave trust fund:
 - Placed under the Department of Labor and Industrial Relations; and
 - Consisting of employee contributions based on the employees' average weekly wage as well as interest earned and income, dividends, refunds, rate credits, and other returns received by the fund.
- Twelve weeks of family leave during any calendar year for qualifying individuals who:
 - Because of birth, adoption, or placement through foster care is caring for a new child during the first year after the birth, adoption, or placement; or
 - Are caring for a family member with a serious health condition.



- Funding for the administration of the family leave trust fund.

Unfortunately, **HB 1362** and **SB 408** have not advanced.

By helping to maintain a stable workforce, paid family leave helps businesses thrive.

HB 213 was introduced last year by Representatives Aaron Ling Johanson, Della Au Bellati, Daniel Holt, and Sylvia Luke. The legislature passed **HB 213 HD 1 SD 1 CD 1** in May of 2017. The governor signed the legislation into law as **Act 128** on July 10, 2017. The law includes four weeks of family leave during any calendar year upon the birth of a child of an employee; or the adoption of a child; or to care for an employee's child, spouse, reciprocal beneficiary, sibling, or parent with a serious health condition.

In this session, the most viable of the remaining bills are **HB 2598 HD 1** and its companion bill, **SB 2990 SD 1**. Both have wide support in the legislature. The bills:

- Require the Department of Labor and Industrial Relations to establish paid family leave for all workers by January 1, 2023.

- Authorize the Department of Labor and Industrial Relations (DLIR) to adopt interim rules.
- Establish the Paid Family Leave Implementation Board to assist DLIR and report to the legislature.
- Establish a Paid Family Leave Special Fund.
- Appropriate funds, including for one full-time equivalent (1.0 FTE) program manager to support the Paid Family Leave Implementation Board and the Department of Labor and Industrial Relations in establishing paid family leave for all workers by January 1, 2023.

Current PFL Activity in Other States: Four other states (California, New Jersey, Rhode Island, and New York) have passed laws that provide employees with paid family leave for parenting and caregiving for family members. 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, im-

proves 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 to maintain a stable workforce, paid family leave helps businesses thrive, which keeps 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 strongly encourage the legislature and the governor to pass a strong paid family leave law. Employees need subsidized time off of work 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.

¹National Partnership for Women and Families, Paid Sick Days Fact Sheet, July 2015.

²U.S. Department of Labor, 12 Stats about Working Women, <https://blog.dol.gov/2017/03/01/12-stats-about-working-women>. Accessed February 12, 2017.

Caregiver Education

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

The American Association of Retired Persons (AARP) has stated that in 2015, there were approximately 154,000 caregivers in Hawai'i who provided about 144 million hours of care. Four in ten adults are caring for sick or elderly family members. The number of seniors that need care continues to rise, and the number of family caregivers grows exponentially. How do these family caregivers know what to do for their loved ones? What does Hawai'i offer them in the way of training so that they can care for their kūpuna?

"A wealth of knowledge leads to improved health outcomes in our community," said Amy Asselbaye, executive director of the HMSA Foundation. Improved health outcomes should not only be for seniors, but also for their caregivers. There are many resources in Hawai'i

Gratitude for Grandma

by Cyndi Osajima, MPH, Executive Director,
Project Dana & the Project Dana Staff

"I am very grateful to have volunteer Melanie to spend time with my mom. She makes my mom very HAPPY!! She always looks forward having Melanie talk story and laugh having a Great Time! I really appreciate it!! Thank you for sending Melanie to us!!!" These are the words of a grateful daughter, Donna Pagan, on behalf of her 84-year-old mother Virginia Soares.

Project Dana volunteer Melanie Van der Tuin-Oka offers respite to a daughter who

that offer the much needed training and support for family caregivers, such as support groups, hospices, and case management providers. Formal training programs are offered by the Alzheimer's Association Aloha Chapter, Hawai'i Parkinson Association, The Caregiver Foundation, the AARP, and others.

The Alzheimer's Association Aloha Chapter, has been serving family caregivers and individuals affected by Alzheimer's and related dementias in Hawai'i since 1982. The Association offers a rich suite of programs and services, and has a team of staff serving O'ahu, Kaua'i, Maui County, and Hawai'i Island. They offer educational programs for caregivers, community groups, and professionals; and online caregiver training classes. In addition, they offer caregiver support groups that include not only support, but education components to assist caregivers. Hearing from other caregivers is an education unto itself, with caregivers learning from each other in care techniques or community services they may have tried.

The Hawai'i Parkinson Association offers an annual symposium featuring leading specialists in the field of neurology and physical therapy to answer patient and caregiver questions and to present on the latest in Parkinson disease care. They also offer dedicated caregiver support groups with an educational component



Project Dana volunteer Melanie and her friend Virginia making a gingerbread house.

works full-time and is the primary caregiver of her mother who has dementia, a respiratory condition, and lives alone. Melanie says of her respite visits, "I never really had a grandma, so now I am getting the stories, insights, and wisdom I missed – it is a very sweet relationship."

in several communities statewide.

The Caregiver Foundation provides seniors, disabled adults, and their caregivers training on caregiving, aging, and financial management. They also sponsor support groups island-wide, with an educational component for caregivers.

AARP offers and sponsors caregiver education programs statewide. They also offer online training and education for experienced caregivers and those that are just beginning their caregiving experience.

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 the Hawai'i Aging and Disability Resource Center (ADRC).

Hawai'i is rich in resources for caregivers, both experienced and new to the caregiving arena. Educational programs, online education offerings, and caregiver support groups are easily accessible to the growing number of family caregivers in our great state. Hawai'i is recognized as the state with the fastest growing population of senior citizens, and it supports the needs of the caregivers providing care for our kūpuna.

Alzheimer's Disease & Related Dementias

Alzheimer's Disease: An Urgent Public Health Crisis

by Ivy Castellanos, MHS, Director of Programs & Advocacy, Alzheimer's Association Aloha Chapter

Currently, more than 27,000 Hawai'i residents over the age of 65 are living with Alzheimer's disease, and by 2025, the number is expected to increase by 30 percent to 35,000. Alzheimer's is currently the nation's sixth leading cause of death, and in our island state, one in three kūpuna will die from the disease. Since the year 2000, deaths from heart disease have decreased by 14 percent, while deaths from Alzheimer's have increased by 89 percent. The disease kills more than breast cancer and prostate cancer combined, and is the only cause of death in the top ten that cannot be prevented, cured, or slowed.

Every 66 seconds, someone in Hawai'i develops Alzheimer's disease. We simply do not have the luxury of time.

There are over 66,000 unpaid family caregivers within our state – mostly working individuals who often need to reduce their hours or leave their jobs altogether to care for a loved one with the disease. The burden of Alzheimer's is large and the impact of the disease is significant, and the numbers will grow exponentially as our population ages.

We must intervene before it's too late, and reducing the burden of Alzheimer's will require the active engagement of both the public and private sectors.



The State Plan on Alzheimer's Disease and Related Dementias released by the Department of Health in 2013 was the result of a Task Force of more than 40 community stakeholders who worked collaboratively since 2011 to identify challenges and barriers, and seek solutions for the ever-increasing threat of Alzheimer's in Hawai'i. The Task Force identified recommendations related to: prevention and treatment of the disease by 2025; enhanced care quality; expanded supports for training, respite, legal, financial, and safety concerns; enhanced public awareness; and improved data to track and monitor progress. However, the Executive Office on Aging (EOA) has been unable to implement the Plan due to lack of funding and resources. Consequently, the Plan has been shelved for nearly five years.

SB 2591 and **HB 1916 HD 1** offers a next step in implementing the recommendations identified by the State Plan Task Force over five years ago, and would enable the EOA to carry out actions that would make Hawai'i more dementia capable. **SB 2591** and **HB 1916 HD 1** would allow the EOA to enact legislation, develop regulations, and execute much-needed programs. The measure would require the EOA to update the State Plan on Alzheimer's

er's Disease and Related Dementias with a necessary appropriation for its implementation and update. Specifically, the measure requires a work plan with tasks, timelines, and milestones for each recommendation; and appropriates funds (\$175,000) for the EOA to have the resources to implement the Plan across all counties.

Despite the array of dementia services available in the community, there are still numerous gaps in services. Many of these gaps and resolutions have already been identified in the State Plan. Implementation of the Plan and its recommended activities to fill these gaps in services require coordination and resources.

Although there are many worthy and important issues to address in the state, we cannot continue to neglect the needs of families affected by Alzheimer's disease and related dementias. The current number of individuals affected will only continue to rise as baby boomers age. In fact, every 66 seconds, someone in Hawai'i develops Alzheimer's disease. We simply do not have the luxury of time. Inaction will take a toll on local families and on our community, and we will be left to pay the hefty costs associated with the rapid increase in Alzheimer's disease in our state.

Disability Issues

by Francine Wai, MA, Executive Director,
Disability and Communication Access Board

The casual observer might conclude that the issues facing the aging and disability populations 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 people have disabling conditions but are not elderly. 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 related to civil rights and equal access to services. This section speaks to those key civil rights and equal access issues that are being discussed during the 2018 legislative session and that might not otherwise be covered under other portions of this report.

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 the elderly going to medical appointments or making leisure trips. **SB 975** and **HB 1109** clarify the ability of law enforcement to confiscate disability parking permits being used unlawfully. Another abuse is the use of permits to obtain free metered parking. **SB 974** and **HB 1108** limits the privilege of free metered parking only to individuals who are licensed to drive and are unable to reach or operate a meter due to their physical disability.

Communication access issues: Individuals who are hearing impaired at any age face many challenges in receiving information conveyed through auditory formats. One such situation is viewing a movie at a theater. **SB 2650** and **HB 2520** clarify state law in providing opportunities for people who are hearing impaired to view movies with open captioning, similar to foreign language subtitled movies. This will allow hearing impaired individuals to enjoy movies in the same manner as those who hear, while simultaneously improv-



ing their language skills through reading. The false missile alert in January 2018 was not only traumatic for those with hearing, but doubly traumatic for those who could not hear the follow-up announcements on television that the alert was a mistake. **HB 2675** requires each local television station to make audio emergency information during video programming to be accessible to the hearing impaired by using captioning as well. **HB 613** and **SB 535**, introduced as part of the Kūpuna Caucus in 2017, requires health insurance policies and contracts issued after December 31, 2019 to provide a minimum \$1,500 of coverage per hearing aid for each ear.

Inclusive housing: One of the primary goals of most individuals is to be able to “age in place,” meaning the ability to reside in one’s own home as aging or other infirmities occur. A big barrier to aging in place is the lack of accessible home inventory to accommodate an individual whose mobility needs require ramps, widened doorways, turnaround space, *etc.* **HB 1919** and **SB 2594** both propose to add new requirements to the construction of housing to obtain a level of visitability. (Note: The bills propose different requirements on different types of housing units). **HB 1920** and **SB 2595** take a different approach by offering a tax credit to individuals who construct or modify their homes to meet those standards. Recognizing the shortage of accessible and affordable housing, **HB 2748** requires the Hawai‘i Housing Finance and Development Corporation to study the current and future demand and supply of affordable housing suitable for individuals with special needs.

Taxation: Several bills introduced this session propose to alleviate the financial burden on people with disabilities through the use of the tax system to af-

fect social policy. **HB 2232** and **SB 2714** would assist a person or family member who purchases an adaptive vehicle, such as one with a lift. The bills would exclude the weight of lifts and ramps – and the motors to operate them – and vehicle chassis reinforcements from the net weight of non-commercial vehicles in levying the state county motor vehicle weight tax. **HB 2232** and **SB 2713** provides an income tax credit to a taxpayer who purchases or modifies a personal vehicle for use by a person with a disability for taxable years beginning after December 31, 2018. **SB 2202**, **HB 2424**, and **HB 1921** relate to the general excise tax and are broader than the motor vehicle tax bills. These bills, in varying forms as amended, 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. Regulation of those situations is stymied by differing federal regulations that limit what might be asked of a person. **HB 1823**, **SB 1599**, and **SB 2461** all attempt, in some form, to impose a penalty on a person who falsely misrepresents an animal as a service animal. Recognizing the difficulty in finding an appropriate solution, the legislature also introduced **SCR 28**, which requests the establishment of a working group to provide clarification and oversight on the role of service animals.

Active Aging in Hawai'i

Older Adults as a Growing Community Asset

by Cullen Hayashida, PhD

Sociology - Affiliate Graduate Faculty,
University of Hawai'i at Mānoa

There are two ways of viewing old age. The first is to view the old from a sick care lens and in need of chronic care management. This “aging as sick care” perspective addresses health challenges, adjustments to losses, long-term caring, and eventually, death and dying. As important as it is for these issues to be understood and prepared for, this emphasis alone may be unsustainable.

An alternative perspective called Active Aging recognizes and acknowledges that life is finite but that we have the capacity to continue to grow, engage, and contribute throughout our natural life span until our last breath. Building on the Executive Office on Aging's November 2013 white paper titled Hawai'i's 2020 Vision: A State of Active Aging, the focus is not just on increasing our life span, but more importantly on increasing our health span. The active aging perspective recognizes that increased life expectancy has resulted in an additional 20 to 30 bonus years of relatively good health. This view suggests that we must now focus on 1) increasing healthy life expectancy and 2) marshalling the vast human resources of active retirees to remain well, engaged, and continuously contributing to the greater good.

The 2018 legislature is reviewing **SB 2593** and **HB 1918**, which are related to the Healthy Aging Partnership Program. This program was established in 2003 and has been successful in documenting the value of exercise to improve the health and well-being of Hawai'i's kūpuna. The Hawai'i Family Caregiver Coalition strongly supports these companion bills. This initiative, however, represents just a small part of what will



be required for Hawai'i to pivot toward an Active Aging vision. The following are other policy recommendations for consideration to combat age discrimination, promote lifelong learning, senior volunteerism, social engagement and inclusion, employability, aging-in-place services, and supportive and affordable housing, among other things:

1. Combat negative views of older adults wherever it exists.
2. Promote an awareness campaign to support a positive view of older adults as an asset to our communities.
3. Create a clearinghouse of opportunities to assist older adults to better transition into retirement with ways of using their talents, gifts, skills, and experiences. In addition, create more opportunities for older adults to work, learn, volunteer, and connect.
4. Create and promote transition into retirement programs to help older adults plan the last third of their lives with purpose beyond themselves.
5. Adopt programs and policies that support aging-in-place in age-friendly communities, and promote the integrated use of human and technological resources in the care of older adults.
6. Support local, national, and international collaboration across academic, governmental, non-profit, and business sectors in addressing the challenges of a rapidly aging Hawai'i.
7. Advocate for better survey research on the 50 to 75 year old cohort (*i.e.*, pre-retiree, active retiree, or boomer) to better understand their health, social conditions, and issues. Promote research to address challenges faced by this cohort for the development of solutions and to maximize their ongoing involvement.

Palliative Care & Advance Care Planning

Palliative Care Task Force – A Step for Hawai‘i to Expand Access to Palliative Care

by **Davin Aoyagi, BA**, Hawai‘i Pacific Grassroots Manager, American Cancer Society Cancer Action Network;
Cory Chun, JD, Hawai‘i Pacific Government Relations Director, American Cancer Society Cancer Action Network;
Justina Clanton, University of Hawai‘i at Mānoa School of Public Health BA Senior;
 & **Jeannette Koijane, MPH**, Executive Director, Kōkua Mau

It is time for Hawai‘i to take one more step toward fulfilling its role as a model state for palliative care. Through a joint concurrent resolution with the American Cancer Society Cancer Action Network (ACS CAN) and Kōkua Mau, it is our hope to convene a task force comprised of key stakeholders and palliative care experts. Their primary tasks will be to assess state palliative care capacity, identify existing resources, and make recommendations on how to expand access to palliative care across the state.

Palliative care is specialized medical care for people with serious illnesses and focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness, whatever the diagnosis. Palliative care im-



proves quality-of-life for patients and family members, reduces suffering, and may help people live longer.

The goal is to improve the quality-of-life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, social workers, chaplains, and other specialists who work with the patient’s other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment (Center to Advance Palliative Care, 2011). Hospice is a type of palliative care that helps those with a life-limiting illness with a prognosis of six months or less live with dignity and comfort, either at home or in an inpatient care setting. Hospice also provides a team approach and Hawai‘i has a strong network of hospices that provide care on all islands.

Hawai‘i is seen by many as a leader in palliative care. Under the leadership of Kōkua Mau, a statewide network of committed organizations and individuals, much progress has been made over the last 15 years. Specialized palliative care is offered in the major hospitals across the state, and in several outpatient settings as well. In-home palliative care is being offered through innovative programs, such as Concurrent Care by UHA and Supportive Care by HMSA.

Additionally, there are networking and educational activities offered through Kōkua Mau and partners such as Hawai‘i Pacific Health and The Queen’s Health Systems to help professionals maintain and strengthen their skills. Hawai‘i has a robust, well-respected state-wide POLST (Provider Orders for Life-Sustaining Treatment) program. POLST is an out-of-hospital medical order that documents a patient’s wishes and is honored in any setting, including emergency medical services.

One additional step Hawai‘i can now take is the establishment of a palliative care task force to help assess state palliative care capacity, identify existing resources, and make recommendations on how to expand quality palliative care in the settings where it is needed – especially in home and long-term care settings. Establishing a palliative care task force or advisory council is not a unique idea; rather, it is modeled after the Center to Advance Palliative Care’s (CAPC) palliative care advisory council legislation adopted in 23 states. These advisory councils are comprised of palliative care experts and professionals from each state who meet regularly to make recommendations to the governor or administration officials on advancing palliative care services in that state. Building on Hawai‘i’s strengths and the

(Continued on next page.)



unique Kōkua Mau network, a task force can help to create a roadmap forward to identify key policy and legislative steps to expand and strengthen care for those with serious illness in Hawai‘i.

Over the course of 2017, ACS CAN Hawai‘i-Pacific convened with a number of stakeholders, including cancer survivorship groups throughout the state. From these meetings, there was a clear, consistent message from our constituency: cancer patients, survivors, and caregivers want to increase access to palliative care and support the establishment of a palliative care task force. They want to convene partners to continue to work on how we can best expand holistic care for those with serious and chronic illnesses in our state.

We see the work of the task force as a local effort to compliment ACS CAN’s federal push around the Palliative Care and Hospice Education and Training Act. For the past five years, ACS CAN has led the charge to raise awareness and educate lawmakers and the public about the critical need for cancer patients and survivors to have access to supportive care that treats the whole patient, not just their disease. That’s where palliative care can help.

This year, we can continue to build on the developments that already make Hawai‘i a leader in the palliative care movement. With Kōkua Mau and other partners, we will work toward ensuring that countless cancer patients and their loved ones throughout our state receive the holistic care they deserve.

For more information on palliative care and resources in Hawai‘i, visit Kōkua Mau’s website at www.kokuamau.org.

Talking Story: The Importance of Advance Care Planning

by Nicole Hawkins, BSN, RN, CPN, MSN-Ed Student, Grand Canyon University; & Jeannette Kojane, MPH, Executive Director, Kōkua Mau

Most of us make plans. We make plans for birthday parties, weddings, anniversaries, and vacations. We even make plans for the weekend. All of our plan-

ning goes into living and celebrating life. However, sometimes things don’t go as planned. Who would make decisions for you if the unexpected happens? Would they know what you want? Hopefully we have a clear vision of what matters most in our lives. While we may know what is important to us, would our own loved ones know? Facing our future with peace of mind is priceless, and that is where advance care planning comes in.

Everyone over 18 in Hawai‘i needs to talk with loved ones about what is important to them, and then complete an Advance Health-Care Directive, choose a health care agent, and document their wishes. Hawai‘i law allows you to choose whoever you want to speak for you if you cannot speak for yourself. However if you don’t do this ahead of time and there is disagreement, your loved ones may need a lengthy guardianship process to determine who will speak for you.

This year, Kōkua Mau is partnering with the American Cancer Society Cancer Action Network (ACS-CAN) and the Department of Health to pass a resolution to create a palliative care task force that will design a roadmap for palliative care, including Advance Care Planning. Kōkua Mau is a community benefit, nonprofit organization in Hawai‘i that brings together committed organizations and individuals that share the vision that “the people of Hawai‘i are treated with dignity, compassion, and love throughout their lives.”¹ Kōkua Mau’s mission is to “weave a lei of caregiving and support so that the people of Hawai‘i facing serious illness can live in the place of their choice, with relief of pain and suffering and according to their values, beliefs, and traditions.”²



The Best Gift

Some may feel that by discussing their end-of-life wishes, they might bring worry and strife to their family members. However, the opposite is true. By discussing your wishes for care if you become ill beforehand, you are removing the burden from your loved ones of having to make decisions without your input. You will be providing them with the most precious of all gifts. Your ‘ohana will be able to focus on their love for you and celebrate your life. Starting the conversation and documenting your wishes early will help prevent a crisis for your family in the future. Taking time now to make decisions will unburden your time later. The final days of your life should be filled with comfort and peace, with time for meaningful reflections and loving conversations.

Where do you begin?

You begin with a conversation. A study done in 2017 measuring attitudes and perceptions of Hawai‘i residents about advance care planning found that while 84 percent felt it was important to have discussions with their doctor about end-of-life care, only 41 percent actually had the conversation. In the same study, 76 percent of those surveyed wished to have a conversation with their family before they spoke to their doctor.³ Re-

search has shown the reasons people in Hawai'i are not completing an advance directive include: They believe they are healthy; they believe their family and health care team knows their wishes despite not having a conversation; and because the topic is uncomfortable and they are scared.

So, you begin by talking story with your loved ones. Think about what would be most important to you at the end of your life and who would be the best person to carry out those wishes. Have the conversation with your family members, spouse, siblings, children, or someone you trust. After you've had conversations, your next action should be to select a health care agent, also known as "power of attorney for healthcare." They are your voice if you cannot speak for yourself in a health care setting. Next, put your wishes in writing and complete a document called an "advance directive." Once you have completed your advance directive, you need to share it with your loved ones and all of your health care providers. Make sure it is added to the electronic medical record with your doctor and at the hospital where you receive care. It is essential that the document can be found when it is needed; therefore it should not be kept with your will or trust.

Resources

Cost is always a concern living in Hawai'i, but this process doesn't need to cost money. There are many free resources available. Kōkua Mau has a wide range of materials on their website (kokuamau.org), including a tool kit of resources for hospice, palliative care, and advance care planning. Free advance directives can be printed and completed at home with easy-to-follow instructions. The forms are also available in 10 different languages.

One national resource is The Conversation Project, which has resources available on their website (<https://theconversationproject.org/>), including different Conversation Starter Kits. The Conversation Starter Kits provide a guide to questions that can help outline a conversation you could have with your loved ones or provider.⁴

Another important local resource is Kōkua Mau's free Speaker's Bureau, known as the Let's Talk Story Program. It is comprised of professionals who are trained in educating people and answering questions about advance care planning. They go out in the community where people work, live, and pray to help groups better understand how to navigate advance care planning. For more information about the Let's Talk Story Program, contact Hope Young at hope@kokuamau.org.

The Time is Now

Advance care planning has the potential to improve quality-of-life by making planned decisions about the end. Kōkua Mau provides Hawai'i communities the opportunity to encourage, educate, and empower each other and our loved ones. Being prepared can relieve

stress, prevent a crisis, and will help ensure that your health care wishes are respected. Being prepared starts with talking story. Together, we have the ability to create a community where these conversations become tailored to each individual's wishes.

We hope you will join us. Sign up for Kōkua Mau's free newsletter, attend monthly meetings, and invite the Speakers Bureau to come and talk with your group.

¹Kōkua Mau, 2017. Welcome to Kōkua Mau, <http://kokuamau.org/>.

²Ibid.

³Ward Research, Inc., 2017. Resident Attitudes and Perceptions of Advance Care Planning. Prepared for Kōkua Mau. Honolulu, HI.

⁴The Conversation Project, 2017, <https://theconversationproject.org/>.

The Unthinkable Can Happen

by Nathan Hokama, APR, Secretary of the Board of Directors, Kōkua Mau

One day, the unthinkable happened. A young driver was texting and went right through a red light, broadsiding Rodney's car while he was driving to work. Rodney was rushed to the hospital. He was unconscious. It didn't look good. Although the events in this story have been fictionalized, they do and have happened in real life.

Rodney's wife Marilyn was too distraught to think clearly. Their adult children were angry, worried, saddened, shocked. They never thought they would have to face a situation like this, but that moment had come. Fortunately, Marilyn was able to pull herself together and remembered she and Rodney had completed an advance directive and reminded her children that they had shared the information with them.

Rodney and Marilyn were by nature consummate planners. They thought to be prepared for every eventuality. Both wanted to have a say in their care, even though they may not be



able to physically speak for themselves. They took time to listen, ask each other hard questions, and researched different issues: treatment options such as resuscitation; long-term nutrition; and end-of-life pain management. Rodney even talked about his wishes on a short video he shared with everyone.

When the doctors at the hospital turned to the family to find out what to do for Rodney, there was some comfort in knowing what he wanted. The children had always avoided talking about end-of-life choices, believing that talking about these difficult subjects was bad luck and unnecessary, but deep inside, they were relieved their parents had completed advance directives. Rodney's voice was part of the conversation, and his family was able to concentrate on making him comfortable, and in the end, honored his wishes.

Conclusion

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 that legislators face each and every year with regard to aging and disability. At the beginning of each legislative session, as many as 30 or more bills may be 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 effective in creating change; are aligned with the individual's goals; and which welcome 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. The collective voices of the multiple herds can be the fundamental and vital difference in demonstrating the critical mass demanding change.¹
2. *Relationships with legislators and their staff:* Personal, face-to-face or phone contact with key legislators and their legislative staff to educate them about important issues is the difference between success and failure.
3. *Testimony:* Demonstrate broad support for bills being heard with a substantial number of convincing and compelling written testimonies and personal appearances at legislative committee hearings.
4. *Statistics:* Increasingly, the need for services and the effectiveness of programs need to be demonstrated clearly via solid scientific evidence and reliable data.
5. *Personal stories:* Personal stories can matter as much as statistics. Dramatic stories can spark change effectively and can be a great source of power for advocates.²
6. *Incremental change:* Advocates must take advantage of opportunities for incremental change and then build upon these changes. Press for whatever incremental advances are politically possible at any given time. Never give up. Continue to push. Exercise strategic patience. Prepare for the eventuality when the window of opportunity that change agents have been cultivating arises.³



Hawai'i is now in the midst of the "silver tsunami," with its many thousands of additional elders and unprecedented numbers of the very old. 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 2035.⁴

The legislation described in this report, even if all enacted, would not meet all the needs of Hawai'i's next generation of elders and persons with disabilities. State leaders, policy makers, and advocates must think progressively 5 to 10 years ahead, as well as 10 to 20 or more years ahead.



The Challenges

We must continue to strongly consider and robustly address four challenges:

1. How do we create cohesive, comprehensive, coordinated, efficient, purposely-built, and wide networks of support to caregivers and their care recipients 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 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 government ability to finance programs and services, how can government develop more extensive and effective partnerships with the private for-profit sector to meet colossal and enormous future needs?

State and federal government have each taken a quantum leap with the Kūpuna

Caregivers program and the RAISE Family Caregivers Act, respectively.

We must continue to rise to the challenges of the silver tsunami for the well-being and independence of our aged, our disabled, and their family caregivers.

¹Griffiths, Elizabeth P., MD, MPH, June 22, 2017, http://www.nejm.org/doi/full/10.1056/NEJMp1704120?query=featured_home. Accessed February 11, 2018

²Ibid.

³Ibid.

⁴Hawaii State Plan on Aging, 2011 - 2015

Information, Education & Research Resources

Public & Nonprofit Agencies

HAWAII AGING AND DISABILITY RESOURCE CENTER

The Hawaii 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 Hawaii. 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. ADRC 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 Hawaii as authorized by federal and state laws.

The federal Older Americans Act has established an Aging Network and provides federal funding for elderly services, including for support, nutrition, preventive health, elder rights protection, and family caregiver support. Chapter 349 of the Hawaii 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 Hawaii.

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West Maui Senior Center

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

South Maui

16 Ehiku Street, Suite 1
Kihei, Hawaii 96753
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Moloka'i

290 Kolapa Place, Suite 1
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Lana'i Senior Center

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Hawai'i County: 974-4000 ext. 6-8121#

Kaua'i County: 274-3141 ext. 6-8121#
Maui County: 984-2400 ext. 6-8121#
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CENTER ON AGING

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Aging & Disability Issues 2018

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