

Aging & Disability Issues 2017

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





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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 Hawai'i.



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 Francine.wai@doh.hawaii.gov, or at (808) 586-8121. The DCAB mailing address is: 919 Ala Moana Boulevard, Room 101; Honolulu, Hawai'i 96814.



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 Hawai'i 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

THIS ISSUE OF *The Aging & Disability Issues Report 2017* is the 12th annual publication that offers an overview of legislative issues dealing with aging, disability, caregiving, and long-term services and supports in Hawai‘i. The purpose of this Report is to call attention to the priority issues that deserve the serious 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 eight sections:

Section 1 offers an overview of the report, as well as some general observations of the political and economic changes in Hawai‘i in 2017.

Sections 2 through 6 describe the priority issues for the Legislature in the 2017 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 7, the Conclusion, provides a brief summary, as well as a look ahead.

Section 8 contains a listing of available 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 importance of public policies

in enabling them to care for their loved ones can be found throughout the report. These stories convey the emotional strains and rewards experienced in caregiving, 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 2017

Two Thousand Seventeen is a year to intensify attention to the needs of our elderly and disabled populations. At the same time, we must acknowledge that great challenges are ahead. The economic recovery, both nationally and in Hawai‘i, has continued to progress. Accordingly, more resources are available to continue building a safety net of services and financial assistance to support the vulnerable. At the federal level, the Administration on

"Aging and disability advocates are determined to preserve the safety net of services for our vulnerable populations."

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. However, at the state level, any additional resources will need to fulfill multiple acute needs.

The Federal Older American's Act authorization had expired in 2011. The Older Americans Act (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. Nearly five years after it expired, legislation to reauthorize the Act was passed by Congress with unanimous, bipartisan support. The bill was signed into law by President Barack Obama on April 19, 2016.

We are 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 timelier 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 education and affordable housing. Other priorities include renovating the State's public housing facilities, transitioning the homeless to more permanent housing, and supporting the development and completion of public transit systems, including bus and rail transportation. These priorities require huge funding. However, aging and disability advocates are determined to preserve the safety net of services for our vulnerable populations.

In this post-election year, candidates at all levels of government should be constantly and assertively reminded of their commitment to the expansion of services to the rapidly aging population.



Kūpuna Care, ADRCs, Healthy Aging Partnerships, & Long-Term Care Ombudsman Program

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, *i.e.*, 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 private and/or public sectors. Much of the funding for these programs comes from a combination of federal and state resources, although in Hawai'i, county governments also provide funding. This section will discuss four such programs and the bills that contain funding provisions for them:

1. Kūpuna Care (**HB 608/SB 528**)
2. Aging and Disability Resource Center (ADRC) (**HB 612/SB 533**)
3. Healthy Aging Partnership (**HB 615/SB 531**)
4. Long-Term Care Ombudsman Program (**HB 610/SB 530**)

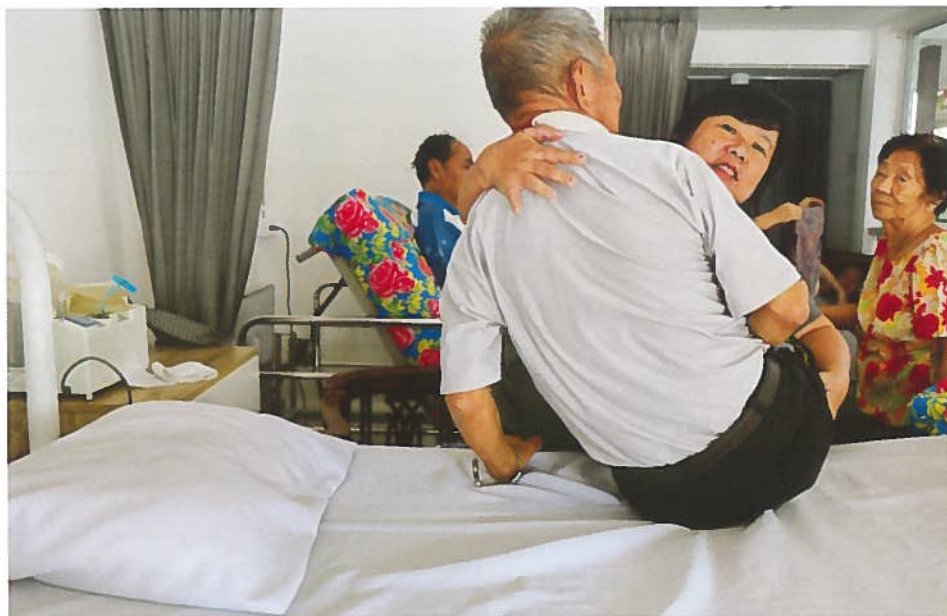
1. Kūpuna Care

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, homemaker/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 communities, delaying premature place-

ment 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 years and older, 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.



The Ige Administration has included Kūpuna Care in its FY18/FY19 budget with an increase of \$4.15 million as a supplemental budget request. The Kūpuna Caucus and senior advocacy groups have requested the same appropriation, \$4.15 million, for Kūpuna Care through **Senate Bill 528** and **House Bill 608**. If appropriated, the additional funding will enable the EOA to serve up to 3,600 kūpuna per year in a community setting, and to use comprehensive person-centered intake and assessment tools developed statewide for targeting public supports to persons with the greatest need.

2. Aging and Disability Resource Center (ADRC)

Older adults, people with disabilities, and their families are often unprepared when the sudden onset of a serious health condition or abrupt decline in functioning 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 (ADRC) are designed to simplify the process of obtaining information and accessing support and services. In addition, ADRCs reduce the fragmentation of care systems, recognizing that the care needs of older adults and people with disabilities are often similar. Through a single coordinated system, the develop-

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

Since 2006, Hawai'i has been planning and implementing ADRCs. This initiative is administered by the Executive Office on Aging (EOA) and implemented by each of the county Area Agencies on Aging (AAA). Improving access to long-term services and support, Hawai'i's ADRC initiative is designed to ensure that individuals and their families re-

ceive the right services when needed and in the right setting. ADRCs strive to divert individuals from unnecessary and costly long-term institutional care by:

1. Intervening with options counseling at critical pathways; and
2. Expediting the eligibility determination process for publicly-funded long-term services and support.

Over the years, the development of the statewide ADRC system has been strengthened through support from federal grants and the Hawai'i State Legislature. Recent EOA data show that the ADRCs received an average of 159 contacts per day through walk-ins and inquiries by telephone and website. Over 90 percent of ADRC consumers were satisfied with their ADRC experience. EOA also reported a recently completed independent assessment that two ADRCs—Maui and Kaua'i—were fully functioning, meeting all 10 criteria set forth by federal guidelines. Honolulu met 9 of 10 criteria since it began phasing in the ADRC system in July 2015, and Hawai'i County met 6 criteria and was on track to incorporate new operations. When an ADRC becomes fully functional, it will qualify for additional financial support from various federal programs such as Medicare, the Affordable Care Act, and Medicaid.

The Ige administration has identified Hawai'i's ADRC system as a priority and requested an increase of \$1.71 million to EOA's budget for ADRCs in his biennium budget for FY18/FY19, bringing the total to \$3.11 million. The Kūpuna Caucus and senior advocacy groups have requested the same amount of appropriation (\$1.71 million) through **House Bill 612** and **Senate Bill 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 fully functional status statewide in accordance with federal requirements, and integrate participant-directed supports as a function of the ADRC.

3. Healthy Aging Partnership

Established in 2003, the Healthy Aging Partnership (HAP) aims to implement

Life-Changing Circumstances

PRIOR TO HIS STROKE 9 years ago, James Ferreira planned on traveling with his wife Lenora during their retirement years. They especially wanted to rent an RV on the U.S. East Coast and travel leisurely across the country to the West Coast, stopping at little towns and landmarks along the way. Unfortunately the stroke left Mr. Ferreira paralyzed on his left side and bedridden. With no way to ever prepare for such a circumstance, Lenora was faced with life-changing decisions. Since she was working full-time and unexpectedly became the full-time caregiver of her husband, she was forced to retire from her employment at Hawai'i Gas in Kahului. Even though she was fortunate enough to have the years of service to retire at her place of employment, Lenora was struggling with the full-time duties of caring for her husband.

Since Lenora did not know where to find help, she followed the recommendations of her former coworkers and friends to call the Maui County Office on Aging (MCOA) and Aging and Disability Resource Center (ADRC) to seek assistance. After completing the assessment process, the Ferreriras have been authorized to receive home delivered meals, personal care, and in-home respite from MCOA. Since Lenora was providing the majority of the caregiving by herself, she explains that the services have been "so helpful...and even though providing a bath to James may sound like a simple task,

evidence-based prevention and disease self-management strategies to empower older adults to stay healthy, active, and socially engaged. It is a joint effort by the EOA, County Offices on Aging, non-profit senior services providers, and the University of Hawai'i. The HAP offers two different but related components: Chronic Disease Self-Management Program (locally known as Better Choices Better Life—Ke Ola Pono) and Enhance Fitness. Developed and tested



it is such a relief to not have to assist with that task as often." Even with the services the Ferreriras receive, Lenora often feels overwhelmed with the stress of caregiving.

With the home and community based services authorized by MCOA and the help of her son, Lenora has been able to return to work part-time at Costco in Kahului. In addition to the supplemental income, Lenora says that she really enjoys the opportunity to work part-time because it allows her some time to socialize. She feels the socialization is very important to her overall well-being and even provides respite from her caregiving duties. The Ferreriras greatly appreciate the services they receive, but they are also concerned about all of the other working caregivers in the community and the everyday struggles that all caregivers face. Both Lenora and James are hopeful that there will someday be enough funding to provide even more services to all those in need.

by Stanford University, Better Choices Better Life is a 6-week evidence-based program where individuals with chronic medical conditions learn how to better manage their health to improve their quality-of-life. It helps people learn skills to manage their health problems and interact with their healthcare providers. Participants learn such things as how to deal with chronic pain, action planning, relaxation techniques, and exercises to do at home. A diabetes-spe-

cific program—Living Well with Diabetes—is also available. Enhance Fitness is a 16-week exercise program that improves cardiovascular fitness, strength, flexibility, and balance. In addition, the program helps build relationships among participating seniors and creates a friendly exercise environment. It has been scientifically tested and shown to improve health and reduce care costs among regular participants.

Evaluation research conducted by the University of Hawai'i Center on Aging shows that these programs reduced hospital stays, emergency room use, and falls among the frail elderly while increasing physical functioning, thus resulting in substantial reductions in healthcare costs. Furthermore, national studies conclude that the annual total health costs of these participants was \$642 compared to non-participants at \$1,175. Those who attend the Enhance Fitness class once a week show a health care costs savings of 6%. Those who attend more than once a week show a cost savings of 21%.

However, the State didn't fund the Healthy Aging Partnership in either FY16 or FY17. Currently, these programs are supported by carry over funds, which are depleting rapidly. Unless the counties find other funding, these programs simply will vanish. In the 2017 Legislative Session, the Kūpuna Caucus and senior advocacy groups requested an appropriation of \$550,000 for the Healthy Aging Partnership program through **Senate Bill 531** and **House Bill 615** for FY18/FY19. If appropriated, the Healthy Aging Partnership program will be able to serve 220 participants through 22 Chronic Disease Self-Management Program workshops (\$92,400) and 575 participants through classes for Enhance Fitness (\$344,600).



This will also help EOA to reach the first goal identified in the Hawai'i State Plan on Aging: "strives to maximize opportunities for older adults to age well, remain active, and enjoy life in their communities."

4. Long-Term Care Ombudsman Program

Senate Bill 530 and **House Bill 610** appropriates \$150,000 to the Office of the Long-Term Care Ombudsman to support the Long-Term Care Ombudsman Program on O'ahu and to provide funds for contracted services in Hawai'i, Kaua'i, and Maui counties.

Begun in 1972 as a demonstration program, the Long-Term Care Ombudsman Program today exists in all states, the District of Columbia, Puerto Rico, and Guam under the authorization of the Older Americans Act. Each state has an Office of the State Long-Term Care Ombudsman, headed by a full-time state ombudsman. The statewide programs are federally funded under Titles III and VII of the Older Americans Act and other federal, state, and local sources.

Nationally, thousands of local ombudsman staff and volunteers work in hundreds of communities throughout the country as part of the statewide ombudsman programs, assisting residents and their families and providing a voice for those unable to speak for themselves.

The State of Hawai'i currently does not have a functioning program with only one full-time long-term care ombuds-

man servicing more than 12,000 individuals residing in 28 facilities, over 500 adult resident care homes, and in senior foster-care homes. Hawai'i has one of the highest proportions of small care homes

"Enhancing the Long-Term Care Ombudsman Program is essential to provide quality care and service to Hawai'i's citizens."

per capita in the United States and is an island state spread across seven islands, which adds a major challenge to an already difficult situation. Hawai'i does have a Long-Term Care Ombudsman Volunteer Program; however, some inquiries from the public to become a volunteer go unanswered for months due to understaffing and not being able to contact interested volunteers in a timely fashion.

Enhancing the Long-Term Care Ombudsman Program is essential to provide quality care and service to Hawai'i's citizens. This can be accomplished by:

1. Ensuring the maximum allowable and available amount of federal and state funds are advocated for, are included in the base budget, and are received annually; and
2. Adding either part-time or full-time ombudsman positions for each island (Kaua'i, Maui, and Hawai'i), which would allow for more appropriate staffing ratios to serve the population.

Alzheimer's Disease Related & Dementias

ALZHEIMER'S DISEASE and related dementias (ADRD) have become a major cause of death in the older population. Alzheimer's disease and other dementia patients frequently require extensive care in the home or in an institutional setting. The Hawai'i Executive Office on Aging published *Hawaii 2025: State Plan on Alzheimer's Disease and Related Dementias* to address this critical issue which may ultimately affect as many as half of the 85 and over population.

The *State Plan* is a blueprint created to greatly improve the way individuals with ADRD and their families will live in and be served by their communities. It includes five goals:¹

Goal 1: Prevent and Effectively Treat Alzheimer's Disease

By 2025, Hawai'i will seek to expand and support local research efforts, as well as keep Hawai'i healthcare professionals and the public informed on the most current dementia research, both nationally and worldwide. Hawai'i's diverse cultural and ethnic environment can be a laboratory for studies unique to Hawai'i, which could contribute to the growing worldwide body of research. Efforts will be made to examine the role culture plays in the perception and care of persons with ADRD.

Goal 2: Enhance Care Quality and Efficiency

By 2025, primary healthcare providers will be fully engaged in dementia diagnosis and treatment supported by a clear understanding and availability of care options. Every primary care physician will be trained in memory and de-



mentia screening, and will have access to referral resources.

Goal 3: Expand Supports for People with Alzheimer's Disease and Their Families

Quality, professional healthcare for people with dementia should be balanced with the community supports necessary to help caregivers and families coping with the disease. Upon diagnosis, there should be easy and affordable access to a multitude of services and trainings, including respite, legal, and financial counseling; advance care planning; and safety measures.

Goal 4: Enhance Public Awareness and Engagement

By 2025, the public will be well-educated about brain health and dementia, risk factors, recognition of early signs of dementia, and behavioral issues—and are able to maintain good health practices and appropriately access resources when necessary. Public awareness of ADRD is one of the most recommended goals of all state, national, and world plans. The fear and stigma associated with dementia are compounded by a lack of knowledge and public education about the disease, its stages, the treatments, how to support caregivers, and where to get services. Consequently, the disease and how to communicate with someone living with dementia are misunderstood by many. Awareness and education should start with young people in schools and universities.

Goal 5: Improve Data to Track Progress

By 2025, Hawai'i will have identified measurable indicators to track its progress in reaching its goals and objectives, and have in place a system for collecting the data and monitoring the implementation of its action plan. There is a general lack of data specific to dementia in Hawai'i. Recent sources include the 2011 Behavioral Risk Factors Surveillance Survey cognitive module, the Alzheimer's Association's 2013 Facts and Figures, the Hawai'i Dementia Caregiver Survey, and a key informant survey conducted by the Alzheimer's Disease and Related Dementias Task Force. There may be isolated data collection in Hawai'i research studies or in hospitals and health plans, but the data is not unified. Any effort to seek out better data will involve a collaboration of all stakeholders.²

A coordinator is needed to develop an implementation work plan specifying the tasks required to achieve each goal, key milestones, and the timelines for achieving them.³ Senate Bill 532 and House Bill 611 propose an appropriation for the Alzheimer's Disease and Related Dementia Services Coordinator Position.

1. Executive Office on Aging, Department of Health, State of Hawaii, Executive Summary, *Hawaii 2025: Hawaii State Plan on Alzheimer's Disease and Related Dementias*, December, 2013.

2. Ibid.

3. Ibid.



Aid to Caregivers

Introduction

IN RECENT YEARS, all developed countries have recognized that their populations are aging rapidly in a way never before seen. In particular, the growth of the oldest old 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 serving as unpaid caregivers, who provide approximately 80 percent of all care of 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 State 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 which 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 needing assistance due to serious health problems. Second, bills which would cover the cost of a limited number of home and community-based services to provide respite for caregivers for several hours per day. The bills which authorize this type of relief would create a Kūpuna Caregivers Program. Both will be discussed in the following sections of this report.

Juggling Caregiving, Work & Family

Born on Hawai‘i Island in 1933 and raised on the Island of Lana‘i, Victor Ranis, Sr., served his country as a paratrooper for the U.S. Army in the 1950s. After the military, Mr. Ranis returned to Lana‘i, where he worked as a construction worker and raised his family. Toward the end of his career, he also worked abroad but returned to Lana‘i in 2001 to enjoy his retirement.

In October 2015, Mr. Ranis was hospitalized and later discharged to his residence at Hale Kūpuna O Lanai, low income housing for seniors. Since he is unable to live independently on his own due to dementia and memory loss; his daughter, Lisa Kaniho, moved in with him to be his full-time live-in caregiver. In order to care for her father full-time, she has been unable to live in her home with her husband since October 2015. While Lisa says that it “has been very difficult to be away from her husband and family...she is where she needs to be to keep her father safe, healthy, and out of an institution.” Due to the struggles of caregiving, Lisa was having great difficulty juggling the responsibilities of work and caregiving. Since caregiving had to be the priority and she was unable to privately pay for the care her father requires, she was forced to leave her job.

Faced with the potential of losing her home since she lost her job, Lisa was also experiencing caregiver burnout. In April 2016, Lisa sought assistance from the Maui County Office on Aging (MCOA). Since Victor is a veteran, MCOA’s Community Living Program (CLP) coach helped Lisa and her father to obtain assistance with the Veteran Directed Home and Community Based Services program (VD-HCBS).

Paid Family Leave

The United States is the only industrialized country that does not mandate paid family leave (PFL) for the care of newborn children, persons with disabilities, and frail elders. Workers who need to take time off to care for family mem-



The VD-HCBS program provides veterans the opportunity to self-direct their long-term supports and services and continue to live independently at home. Eligible veterans manage their own flexible budgets, decide for themselves what combination of goods and services best meet their needs, and hire and supervise their own workers. Through their CLP Coach, MCOA provides facilitated assessment and care/service planning, arranges fiscal management services, and provides ongoing options counseling and support to Mr. Ranis, Lisa, and the rest of his family.

With the help of MCOA and the VD-HCBS program, Lisa has been able to obtain a new full-time position where she is able to work overnight shifts, help maintain her family’s mortgage, and care for her father, who is being allowed to continue to age in place. The Ranis family thanks MCOA, the Veterans Administration, and federal and state legislators for providing these crucial home and community-based services to their family and to others facing similar situations.

bers face significant economic hardship, especially in states like Hawai‘i with its high cost of living. Here, typically both husbands and wives are employed in order to make ends meet. Many households also consist of unmarried women who work full-time while at-

tempting to meet the needs of parents or grandparents. Those who take unpaid leave experience reduced income, and in some cases, job insecurity, a loss of opportunities for promotion, early retirement, and reduced Social Security or other retirement benefits. Employers may experience job disruption and loss of productivity. As the number of frail and disabled elders grows, more working family members will have to take on caregiving responsibilities. By 2020, it is estimated that 40 percent of Hawai'i's labor force will be caring for older parents, grandparents, or other elder family members.

What do our family leave laws currently look like? The Federal and Medical Leave Act of 1993 (FMLA) allows 12 weeks of



unpaid leave to employees who have worked at least 12 months at a business employing 50 or more employees. The Hawai'i Family Leave Law allows 4 weeks of unpaid leave to employees who have worked at least 6 consecutive months at a business that employs 100 or more persons within the state. The only paid leave in Hawai'i is partial wage replacement through the TDI system. However, this is not available to new fathers or to family members caring for ill or elderly family members.

In the past several years, legislative and community support for PFL has increased, and in 2016, a comprehensive bill providing 12 weeks of paid leave for all workers was introduced and supported by a coalition of advocates, community organizations, and key legislators. Although the legislation did not pass, community interest increased, as well as calls for Hawai'i data needed to

A Senior Caring for a Super Senior

By Pat Hubbard

On the day she was diagnosed, I felt as if I were in a huge black hole—the future journey uncertain and indeed, very frightening. I'm entering my 16th year as the only child and caregiver for my 95-1/2 year old mother Mabel Lee, who was diagnosed with Alzheimer's disease. Up until two months ago, I've been helping her to live independently in Kaimuki from where I live 17 miles away in Aiea. My main goal has always been to have her "live her life" and keep her from needing to go into a care home for as long as possible.

Thank goodness a friend encouraged me to join Project Dana! A few years into caregiving I thought of quitting because the time and energy were so overwhelming with so much on the to-do list. But I realized the meetings each month kept me afloat, treading water in an unpredictable ocean. The immeasurable value through excellent resource speakers and connecting to other caregivers in so many other situations simply are heaven sent time after time.

In daily life you can be with close friends or even family members, but you can feel so

understand the implications of a state PFL program. During the year, the Center on the Family at the University of Hawai'i and the Hawai'i State Commission on the Status of Women received grants to develop policy papers; prepare public information materials; and conduct economic analyses, feasibility studies, focus groups, and public polling to determine public awareness with regard to paid family leave.

Against this background, it is interesting to note that 13 bills dealing with paid family or medical leave were introduced during the 2017 Session. These included comprehensive programs covering all Hawai'i workers, a well as those covering state employees; victims of sexual or domestic violence; independent con-



Mabel Lee and Patricia Hubbard

alone. Just sitting among other caregivers at our Project Dana meetings gives many of us a sense of "Sigh...they understand, it's not just me, it's normal..." We teach each other and support one another.

I've been a member for over 10 years. Starting at the helm with Rose Nakamura's dedication and with the gentle leadership of Maria Morales, we are not only educated in caring for our loved ones in the present, but also have the treasure of knowledge and experiences that benefit us caregivers, as so many of us are seniors as well!

For the sake of Hawai'i's "aging in place" seniors, I hope there'll be more of Project Dana.

tractors; service workers; and maternity and paternity leave. As of this writing, four bills are still under consideration: **House Bill 4**, **House Bill 213**, **House Bill 678**, and **Senate Bill 425**. **House Bill 4** requires employers to provide a minimum amount of paid sick leave for family caregiving; **House Bill 213** per-





mits family leave to care for a sibling, or upon the death of a family member; **House Bill 678** allows family leave in the case of domestic or sexual violence; and **Senate Bill 425** requires employers with 50 or more employees to provide sick leave for service workers under specified conditions.

Kūpuna Caregivers Program

Every 8 seconds, someone in the country turns 65 years old. 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 often 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 their work hours to care for an aging family member. In 2017, our legislators are considering creation of a program to help caregivers provide care for our kūpuna. The Kūpuna Caregivers Program is found in **House Bill 607** and **Senate Bill 534**.

Purpose: These bills will help working caregivers pay for home health care workers, extra help preparing meals,

Juggling Caregiving, Work & Family

FOR AROUND the past 7 years, Peter Cockett has provided and continues to provide care for his mother Elizabeth Cockett in their family homestead on Moloka'i. Over the past few years, Mrs. Cockett has experienced a constant decline with her memory. While she has "better days and not so good days" with her dementia, the balance of being a caregiver and working full-time can be very demanding and taxing at times for Peter. Faced with caregiver burnout, Mr. Cockett reached out to the Maui County Office on Aging (MCOA) on Moloka'i to seek home and community based services.



Photo by Travis Tancayo

L-R: Kenui Cockett, Elizabeth Cockett, and Peter Cockett attend the fire engine blessing on Moloka'i in January 2017. Elizabeth's late husband, Capt. Christopher Cockett, moved from Maui to Moloka'i to open the Kaunakakai Fire Station.

Since Elizabeth has been authorized home delivered meals, personal care, homemaker, and transportation services from MCOA, Peter explains that all of the services "have been very helpful and have made a great difference in both of our lives." The services have been even more beneficial since they allow Peter to continue to work full-time at First Finance Company of Moloka'i.

transportation when a family caregiver is not available, or other designated services. This program will help make long-term care for our kūpuna more affordable and provide the helping hand caregivers so desperately need.



According to Peter, the home and community-based services have truly helped him maintain his employment and also provide his mom "the extra help when she needs it." In particular, the home delivered meals have been a blessing because Elizabeth is able to eat a hot, nutritious meal at lunch. Even though the services have been very helpful, Peter also explains that it is a very heavy concern for him to be at work while his mom is at home because her dementia worries him.

While the Cocketts are very grateful and appreciative of the services they receive, Peter also wishes that MCOA could receive more funding to authorize even more services for his mother and for other families in similar situations. Due to her finances, Elizabeth falls in a bracket where she does not have enough money to private hire for additional services, but she is also over the threshold to receive assistance from Medicaid. Peter believes that this is a "donut hole" in the system, and he and his mother remain hopeful that funding will increase in the future to meet the growing demand of home and community based services for their family and others sharing similar circumstances.

Qualifications and Program Administration: Beneficiaries of this program must meet the same qualifications as recipients of Kūpuna Care. In addition, they must be employed full-time in Hawai'i. The program will be administered by the Executive Office on Ag-

ing and delivered by the Aging and Disability Resource Centers (ADRCs) of the county Area Agencies on Aging (AAAs).

Estimated Need and Future Costs: Data from the Hawai'i long-term care actuarial model (Actuarial Research Corporation, 2016) indicates that there could be 2,000 new clients in 2018, 2,566 in 2019, 3,572 in 2020, and 4,016 in 2021 for the proposed program. Informal estimates of the number of working individuals between age 50 and 70 suggests that about 3% 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 about 4,600 clients. The \$600,000 cost figure given above for the period July 2017 to June 2018 is for development of the program, contracting with

county AAAs, and qualifying beneficiaries for services beginning in July 2018. During the next year, July 2018 to June 2019, service would begin, with a projected 900 persons served. The total cost would be \$6 million.

Finding Support at Project Dana

By Jacqueline Toma

I recently became a caregiver for my 91-year-old mom, Nora Toma. I moved back to Honolulu in September 2015 after living in Seattle for 37 years. My father passed away in 2013 and my mom was living alone. She had always been very active and independent despite having rheumatoid arthritis since her 40s.

My mom was diagnosed with congestive heart failure and began to decline in the summer of 2015. My younger brother, Paul, who lives in Makiki, was coming over after work and weekends to check on her. It was becoming stressful for him since he worked full-time and had joint custody of two teenagers.

After I arrived, my mom was hospitalized twice in three months for fluid in her lungs. She was fairly functional at that time—she could bathe herself, go to the bathroom, and take her medication. She mainly needed a companion.

My mom was getting rides to her doctor's appointments through Project Dana. The volunteers would pick her up, take mom



Nora and Jacqueline Toma

to her appointment, and wait for her at the doctor's office until she was done, then take her home. She was so grateful for their patience and kindness. I asked Theo Matsumoto, the lead volunteer, if she knew of any caregiver support groups since this was new for me. Theo told me Project Dana had a caregiver support group that met three times a month and offered to take me since I didn't drive much.

The caregivers at the support group were friendly and welcoming to me. The first meeting of the month is devoted to presenters who provide information on timely topics: Medicare, Social Security, Meals on Wheels, services for the blind, long-term care, senior housing options, estate planning, dementia, and hiring caregivers. The second meeting is a rap session on topics

such as stress management, dealing with feelings, creative outlets, spiritual resources, and family mediation. Members get to share their experiences, their feelings, and resources. The third meeting is for an outing.

I have gotten a lot of emotional support from the group. Before, I was dumping all my frustration with my mom on Paul, who had his own concerns. I now talk to members who understand firsthand and provide me with feedback on what helped them in similar situations.

At our last rap session, experienced members talked about taking time out—briefly going into another room, crying in the shower, or calling someone before getting so upset and saying or doing something that they regret. This resonated with me. We also looked at ways to take care of ourselves and turn negative feelings into positive actions.

I look forward to our monthly get-togethers, which provide a respite for me. My mom has gotten weaker and needs help with going to the bathroom, bathing, preparing meals, and dressing. She began in-home hospice at the end of last December. The Project Dana Caregiver Support Group helped me become a more compassionate and effective caregiver, so I now cherish caring for her.

University of Hawai'i Center on Aging



OVER THE PAST 30 YEARS, the University of Hawai'i Center on Aging has provided education, research and community service to benefit older persons living in Hawai'i. Due to retrenchment at the University, however, its capacity has been limited for a number of years. In recent years, the Center on Aging has continued a research program using temporary positions on contracts and grants, including evaluation research for a number of Executive Office on Aging programs and other aging-related agencies and programs.

However, in the past decade, the Center on Aging has been unable to fulfill its mission in addressing the critical educational and workforce shortages in the field of eldercare, as well as in addressing the other important educational needs of family caregivers and the well elder population. The certificate programs in gerontology had to be placed on hold when it lost funding for instructional staff. Prior to the retrenchment, these programs, both undergraduate and graduate, were successful in providing a stream of students entering careers in gerontology, and many of the current administrators and practitioners in eldercare programs and facilities were products of these programs.

At the present time, Hawai'i is experiencing a multi-faceted crisis in the

eldercare workforce. There is a critical shortage of persons entering the eldercare workforce, as well as related problems, such as a lack of qualified persons with gerontological education. This results in highly variable levels of quality in eldercare; inadequate educational and career opportunities for persons in the eldercare field; and fragmentation and lack of articulation among existing educational programs, as well as inadequate access to training for family caregivers.

Bills have been introduced in the 2017 legislative session which would revitalize the role of the Center on Aging in providing gerontology education programs and in coordinating efforts statewide across institutions to provide access to education and training for students and professionals in the eldercare field. **House Bill 609** and **Senate Bill 529** request an appropriation to the Center on Aging for two faculty posi-

tions needed to accomplish these goals:

One position would be for a full-time associate professor in the Center on Aging at \$92,000. The associate professor would re-establish the undergraduate and graduate interdisciplinary certificate programs in gerontology which have been suspended for a number of years. This person would teach courses as well as coordinate curriculum with faculty across disciplines.

The second position would be to fund a full-time associate specialist position in the Center of Aging at \$92,000. The associate specialist would undertake comprehensive workforce development and continuing education programs for professionals and paraprofessionals employed in eldercare, and family caregiver education and training courses, as well as active aging and wellness courses to reach the wider community. This person will work with institutions across the State to assure that





high quality training and education are available statewide. This program would employ a range of media, including online courses and 'Ōlelo TV broadcasts to serve educational needs statewide.

The request for this appropriation comes at a time when the Center on Aging is poised to revitalize its role in taking on the serious challenges of our rapidly aging of our population. In recent years, the UH-Mānoa Chancellor's Office has supported a number of steps in this renewal.

In January 2017, Dr. Peggy Perkinson arrived as the new director of the Center on Aging after many years without a permanent director. The university administration provided the funds for the Center of Aging to fill this position. Dr. Perkinson is a highly successful gerontologist and has served in some of the most prestigious institutions and programs in the field. She has broad experience in gerontological education and research, and years as a practitioner. Dr. Perkinson has also been instrumental in developing programs in other institutions.

"The University of Hawai'i Center on Aging is poised to undertake a major role in addressing the eldercare workforce issues across the State of Hawai'i."

The Center on Aging also received a generous \$2 million bequest to establish an endowment fund for the Center on Aging at the UH Foundation. The income from the endowment is now available to support new initiatives and grants for the educational and research mission of the Center on Aging.

Despite the retrenchment, the Center on Aging continues to have experienced and competent persons working on grants who have a solid record of accomplishments. For example, the Center on Aging currently has a three-year federal grant to undertake a new program to serve persons with Alzheimer's and related dementia, including training programs for staff and family caregivers who care for them.

In summary, the University of Hawai'i Center on Aging is poised to undertake a major role in addressing the eldercare workforce issues across the State of Hawai'i. The recent hire of an experienced full-time director is a major step. However, at present, there are no other permanent staff members. The requested appropriation for two full-time staff for the Center on Aging is essential in order to undertake the challenges and to achieve the Center's mission of serving the State of Hawai'i.

Current Status: House Bill 609 passed House Human Services Committee and **House Bill 509 D1** passed the House Higher Education Committee. The bill was referred to the House Finance Committee but was not scheduled for a hearing. Thus, the bill is dead for this session.

Senate Bill 529 was passed following a joint hearing by both the Senate Human Services Committee and the Senate Higher Education Committee. The bill was referred to the Senate Ways and Means Committee. However it was not scheduled for a hearing and is dead for this session.

Saving for Retirement

Making Retirement Saving Simple Saves Workers & the State Money

HAWAI'I'S WORKERS lack retirement savings. Most people are just not saving enough so that they can enjoy a retirement filled with real possibilities. That means they will have to keep working or they will have to depend on Social Security to provide most of their retirement income—Social Security alone is not enough to live comfortably in high-cost Hawai'i.

Gone are most of private sector pension plans that made it simple to retire with a comfortable source of income. They've been replaced by 401Ks for people fortunate enough to have a retirement plan at work, but about half of Hawai'i's workers—roughly 216,000 people who mostly work for small businesses—do not have retirement savings through their job.

Studies show that when a person has no employer payroll-based retirement savings plan, there is only a 4.25 percent participation in retirement savings ac-



counts. But when the employer offers retirement savings, the participation rate jumps to 71 percent.

The National Institute on Retirement Security reports that the average working household in the U.S. has virtually no retirement savings. When all households are included—not just those with retirement accounts—the median retirement account balance is \$2,500 for all working-age households and \$14,500

for near-retirement households.

AARP Hawai'i believes the Legislature can help make it easier for people to save for retirement. **House Concurrent Resolution 38** and **Senate Concurrent Resolution 16** will create a work group to study and recommend strategies to help people who do not have a retirement plan at work. Eight states have already passed legislation that offers workers access to retirement savings plans. Hawai'i is among two dozen other states considering similar steps.

Creating simple ways for people to save money for retirement will also save the State money in reduced Medicaid payments. A study by Segal Consulting estimates Hawai'i would save \$21.1 million in the first 10 years from retirement savings assuming a modest 1 percent reduction in spending for workers currently age 64. The potential for savings increases exponentially after that.

An AARP survey of registered voters last year found 49 percent feel they are behind in saving for retirement and 79 percent are concerned as taxpayers that those who are not able to save for retirement will end up on public assistance. Providing an easy way to save for retirement would reduce that retirement insecurity.





Conclusion

The Legislative Process

Sections 2 through 6 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 they 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 the kūpuna or persons with disabilities.

Advocacy

Successful advocacy involves three key elements:

1. Personal face-to-face contact or personal phone contact with key leg-

islators and their legislative staff to educate them about important issues;

2. A substantial number of convincing and compelling written testimonies and personal appearances at committee hearings to show broad support for bills being heard; and
3. Increasingly, solid scientific evidence and reliable data clearly demonstrating a need for services and program effectiveness.

Hawai'i is now in the midst of the baby boom "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 2035.¹

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 three challenges:

1. How do we create comprehensive, coordinated, efficient, and wide service networks that will meet the needs of all our island populations, especially in rural areas that are often inadequately and poorly served?
2. How will we recruit, educate, and retain the necessary professional and paraprofessional workforce, as well as provide appropriate training for family caregivers?
3. Given the limitations of government's 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?

How well Hawai'i will be able to rise to these challenges for the well-being and independence of our aged and our disabled remains to be seen.

1. Hawaii State Plan on Aging, 2011 – 2015.

Information, Education & Research Resources

Public & Nonprofit Agencies

Hawai'i Aging and Disability Resource Center

A one-stop source for information, assistance, and access to services and care for older adults, people with disabilities, and family caregivers.
Website: www.hawaiiadrc.org
Phone: (808) 643-2372
TTY Line: (808) 643-0889

Executive Office on Aging

Terri Byers, Director
Phone: (808) 586-0100
Fax: (808) 586-0185
Email: Terri.Byers@doh.hawaii.gov
Website: <http://hawaii.gov/health/eoa/>

Kaua'i Agency on Elderly Affairs

Kealoha Takahashi,
County Executive on Aging
Phone: (808) 241-4470
Fax: (808) 241-5113
Email: elderlyaffairs@kauai.gov
Website: www.kauai.gov/OCA/Elderly

Maui County Office on Aging

Deborah Stone-Walls,
County Executive on Aging
Phone numbers
Main Office: (808) 270-7774
Lahaina: (808) 661-2387
Hana: (808) 248-8833
Moloka'i: (808) 553-5241
Lana'i: (808) 565-7114
Fax: (808) 270-7935
Email: aging@mauicounty.gov
Website: www.mauicounty.gov/departments/Housing/aging.htm

Hawai'i County Office of Aging

Kimo Alameda,
County Executive on Aging



Hilo: (808) 961-8600
Kona: (808) 323-4390
Fax: (808) 961-8603
Email: hcoa@hawaiiintel.net
Website: www.hcoahawaii.org

Elderly Affairs Division, City and County of Honolulu

Nalani Aki, County Executive on Aging
Phone: (808) 768-7705
Fax: (808) 768-7720
Email: naki@honolulu.gov
Website: www.elderlyaffairs.com

AARP Hawai'i

Barbara Kim Stanton, State Director
Phone: (808) 545-6001
Fax: (808) 536-2288
Email: bstanton@aarp.org
Website: www.aarp.org/states/hi

Disability and Communication Access Board

Francine Wai, Executive Director
919 Ala Moana Blvd., Room 101,
Honolulu, HI 96814
Phone: (808) 586-8121
Email: Francine.wai@doh.hawaii.gov
Website: <http://www.state.hi.us/health/dcab/home/index.htm>

Hawai'i Family Caregiver Coalition

Gary Simon, President
2630 O'ahu Avenue
Honolulu, HI 96822
Phone: (808) 547-8140
Email: gsimon@stfrancishawaii.org

St. Francis Healthcare System

2226 Liliha Street, #227
Honolulu, HI 96817
Email: info@stfrancishawaii.org

Website: stfrancishawaii.org
Phone: (808) 547-6500.

Hawai'i Pacific Gerontological Society

Percy Ihara, President
P.O. Box 3714, Honolulu, HI 96812
Email: hpgs.hawaii@gmail.com
Website: www.hpgs.org

Educational & Research Institutions

THE UNIVERSITY OF HAWAII'I AT MĀNOA

Center on the Family

Dr. Maryanne Berry, Director
Phone: (808) 956-4132
Fax: (808) 956-4147
Email: gfong@hawaii.edu
Website: www.uhfamily.hawaii.edu

Center on Aging

Dr. Margaret "Peggy" Perkinson, Director
University of Hawai'i at Mānoa
Honolulu, HI 96822
Phone: (808) 956-5001
Fax: (808) 956-9582
Email: uhcoa@hawaii.edu
Website: www.hawaii.edu/aging

University of Hawai'i Elder Law Program

Professor James H. Pietsch, Director
Phone: (808) 956-6544
Website: www.hawaii.edu/uhelp

Ha Kūpuna : National Resource Center for Native Hawaiian Elders

Drs. Kathryn Braun, Colette Browne,
and Noreen Mokuau,
Co-Principal Investigators
Phone: (808) 956-6243
Fax: (808) 956-5964
Email: hakupuna@hawaii.edu
Website: <http://manoa.hawaii.edu/hakupuna/index.html>

Public Policy Center

Dr. Susan Chandler, Director
Phone: (808) 956-4237
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Email: chandler@hawaii.edu
Website: <http://www.publicpolicycenter.hawaii.edu/>





Aging & Disability Issues 2017
A Guide for Hawai'i's Legislators, Organizations & Citizens