

Aging Disability Issues 2016 A Guide for Hawai'i's Legislators, Organizations & Citizens



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About the Hawai'i Family Caregiver Coalition, the Hawai'i Pacific Gerontological Society, the Disability and Communication Access Board, and the Maui County Office On Aging.



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 HFCC at P.O. Box 3088, Honolulu, Hawai'i 96802, or at hawaiifamilycare-givercoalition@yahoo.com.



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. DCAB's mailing address is: 919 Ala Moana Boulevard, Room 101; Honolulu, Hawai'i 96814.



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 Hawai'i Pacific Gerontological Society online at www.hpgs.org or mail your inquiry to: P.O. Box 3714, Honolulu, Hawai'i 96812.



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.



Aging & Disability Issues 2016

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Section 1 Introduction & Overview

ging & Disability Issues 2016 is the 11th annual publication that offers an overview of legislative issues dealing with aging, disability, caregiving, and longterm care services and support 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 Hawai'i State Department of Health, and the Maui County Office on Aging (MCOA). Their support is gratefully acknowledged.

Aging & Disability Issues 2016 has 8 sections:

Section 1 offers an overview of the report, as well as an introduction of some general observations of the political and economic changes in Hawai'i in 2015.

Sections 2 through 6 describe the priority issues for the Legislature in the 2016 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 them. These five sections also discuss the specific bills that address priority issues and their status at the time this report was written.

Section 7, the conclusion, provides a brief summary, as well as a look ahead.

Section 8 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 importance of public policies in enabling them to care for their loved ones can be found throughout the report. These stories convey the emotional trials and rewards experienced in caregiving, 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 2016

Two thousand sixteen is a year to call attention to the needs of our elderly and disabled populations. At the same time, we must acknowledge that 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 Community Living has continued to channel resources into elderly and disabled services, and the Veteran's Administration has launched aggressive new support for the aging veteran population.

However, the working relationship between Democrats, including the President, and Republicans who continue to control both the House and the Senate, remains less than friendly. The Federal Older Americans Act authorization expired in 2011, and the Administration on Community Living is proceeding on a year-by-year extension. Republicans have expressed an intention to address a re-authorization, but it remains stalled in Congress.

The Executive Office on Aging continues to work with public and private agencies with 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 have generously supported innovations such as the development of Aging and Disability Resource Centers (ADRCs) by county. ADRCs have improved access to services, enabling persons to obtain appropriate services in a timelier manner, resulting in 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 housing. Other State priorities include transportation and fighting the current dengue fever outbreak. Despite the huge funding that these priorities require, the Governor is determined to preserve the safety net of services for our vulnerable populations.

In this election year, candidates at all levels of government should be asked for their commitment to the expansion of services to the rapidly aging population.

Section 2 Kupuna Care, ADRCs, Fall Prevention & Healthy Aging Partnerships

Introduction

n our rapidly aging society, a wide range of 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 services were created by federal and state agencies. Some evolved at the local level, either through private or public entities. 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:

- 1. Kupuna Care
- **2.** Aging and Disability Resource Centers (ADRC)
- 3. Fall Prevention Programs
- **4.** Healthy Aging Partnerships.

All support the major goals identified above. Funding for these programs is contained in two so-called "Omnibus Bills" (HB [House Bill] 1878 and SB [Senate Bill] 2085). These bills contain funding provisions for a number of aging-related programs, including the four described below.

1. Kupuna Care

Established in 1999, Hawai'i's Kupuna Care program provides long-term services and support to frail and vulnerable older adults who lack access to other comparable services. Kupuna Care services include personal care, chore

Respite For a Full-Time Caregiver

Germaine Kiyomoto Isara is a full-time caregiver to her 90-year-old mother Delma, who had heart surgery 10 years ago, fractured her hip in 2012, has since fallen several times at home, and continues to be prone to falls. She needs round-the-clock care, which Germaine has provided as the only child.

Project Dana volunteers provided home visits and transportation to medical appointments during the period when Delma needed a wheelchair. Currently, Project Dana volunteer Clara provides respite for Germaine twice a month so she is able to participate in the Project's caregiver support group. Germaine has greatly benefited by attending support group meetings, where she learns about various topics related to being a caregiver. She realizes that she is not alone in caregiving and that caregiving can be emotionally stressful at times.

Delma looks forward to visits with Clara while Germaine is at the support group.



Germaine Isara with her mother Delma

They enjoy talking about "small kid time," food, and Japanese culture, and watch television shows. Visits with Clara provide Delma with laughter and compassionate caring while Germaine takes a breather from her caregiving responsibilities. Clara brings out the "chatterbox in my mother," says a very grateful Germaine.

services, attendant care, case management, housekeeping, assisted transportation, home-delivered meals, and day care programs. 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 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 nonprofit 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 Kupuna Care has remained at \$4.85 million since 2002, while the older adult population in Hawai'i has increased sig-

nificantly. The Ige Administration has included Kupuna Care in its 2016 budget with an increase of \$4,145,696 as a supplemental budget request. However, the Kupuna Caucus and senior advocacy groups have requested an additional \$5.1 million, and that this amount be added to the EOA's base budget so that all funds are available on July 1. If appropriated, the additional funding from **Senate Bill 2085** and **House Bill 1878** would enable Hawai'i to serve, at minimum, an additional 800 older adults in need of long-term services and support.

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

ADRCs are an integral component of health and long-term care reform, and essential in the development of effectively managed person-centered service systems. Hawai'i's ADRC initiative is administered by the Executive Office on Aging (EOA) and implemented by each of the county Area Agencies on Aging. Improving access to long-term services and support, Hawai'i's ADRC initiative is designed to ensure that individuals and their families receive the right services when needed and in the right setting. Through two broad strategies, 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.

Since 2006, Hawai'i has been planning and implementing ADRCs in each county. Through support from federal grants and the Hawai'i State Legislature, the continued development of the statewide ADRC system has been strengthened. The Ige administration has identified Hawai'i's ADRC system as a priority for 2016. If appropriated, SB 2085 and HB 1878 would allocate \$1.7 million for the continued development of the ADRC system in addition to the \$1.4 million already included within the EOA's base budget. With additional funding, the EOA and the county Area Agencies on Aging will be able to:

- **1.** Measure the effectiveness of service delivery in order to ensure the best use of public funds;
- 2. Increase capacity to target effective levels of support to those most functionally and financially in need;
- **3.** Provide comprehensive and individualized service planning to help consumers access the most relevant and useful services and support; and,
- 4. Manage resources and monitor program quality through centralized data collection, evaluation, and identification of unmet needs

3. Fall Prevention Programs

Falls are among the leading causes of hospitalization and severe injury among the elderly. This often preventable occurrence can seriously affect the quality-of-life for elderly individuals and also impacts healthcare costs for

the community at large. The impact of falls and legislative initiatives to deal with the problem are described in Part III, Section 5 of **SB 2085**:

"The legislature finds that every year in Hawai'i, on average 85 seniors die, 1,960 are hospitalized, and 8,700 are treated in emergency departments as a result of falls. Falls among the elderly also result in almost \$120,000,000 in hospital and physician charges. In recognition of this critical public health issue, Act 153, Session Laws of Hawai'i 2014, established a fall prevention and early detection services coordinator position within the Department of Health's emergency medical services and injury prevention system branch. This position enables the Department of Health to support a coordinated statewide approach to prevent and reduce the impact of falls among older adults. Act 153 funded a new position for a fall prevention and early detection coordinator for fiscal year 2014 to 2015.... Falls among the elderly are a significant public health issue. Yet, currently, there are insufficient resources to develop a coordinated statewide approach to reduce and promptly detect falls among the elderly...."

Hawai'i has a Falls Prevention Consortium which has implemented a number of programs in the past, including: securing/developing a form of tai chi, which can be done in a seated position, and supporting the training of instructors statewide; working with pharmacies, OTs, PTs, and organizations to provide balance screening and medication reviews to prevent falls from occurring; developing a video, public service announcements, and coordinating programming via television and radio to provide public awareness on fall prevention. The \$32,000 being requested in the above bills will allow for the further development of fall prevention interventions statewide.

4. Healthy Aging Partnerships

The Healthy Aging Partnership program has two different but related components: Better Choices Better Health – Ke Ola Pono; and Enhance Fitness. Better Choices Better Health, known nationwide as the Chronic Disease Self-Management Program, is an evidence-based program where individuals with chronic

Project Dana: Caring for the Caregiver

By Sabina F. Swift

My husband was diagnosed with Alzheimer's disease (AD) in March 2008. His mother and an older brother both died with AD. Per suggestions by our friends Barbara and Barry Brennan who are both familiar with Project DANA, I became involved with the DANA's Caring for the Caregiver Support Group (CGSG) in December 2013.

The CGSG is extremely well organized and coordinated. Participants are men and women of different ethnicities and range from new caregivers like me to graduates whose loved ones passed away and continue to share their experiences. The unique combination of providing needed knowledge from known, experienced specialists/ speakers (education session), and an openfor-all talk story (rap session) with well-selected relevant topics on providing care to



Sabina Swift and her husband

sick loved ones and care of the caregiver in a classroom venue, is extraordinary. Outings and field trips to fun places like museums followed by lunch allow participants to mingle, have time to chat at length with other participants, and fully relax.

James Pietsch, JD, from the UH Law School's Elder Law Program spoke on legal concerns affecting older persons and their families and the challenges caregivers face in helping parents or a spouse at home and in the community. Recently, Dr. Michael Cheang shared his experiences in caring for his mother, which was complicated by sibling differences and cultural miscommunication. Many other topics, such as long-term care insurance, caregiver nutrition, and end-of-life issues, were taken up with handouts of presentations and a list of resources.

There is one significant takeaway value that stays with me: the friendships forged in the group. I don't feel so alone, neglected, or forgotten. My fellow caregivers are just a phone call or an email message away. I have become a more knowledgeable and confident caregiver, and even happier. CGSG has been one of the best things that crossed my caregiving journey. Thank you, Project DANA!

medical conditions learn how to better manage their health to improve their quality-of-life. A six week workshop developed and tested by Stamford University, Better Choices Better Health does not replace prescribed medical treatment, but does help people learn skills to manage their health problems and interact with their healthcare providers. These workshops are offered at sites throughout the State. Participants learn such things as how to deal with chronic pain, action planning, relaxation techniques, and exercises for home use. A diabetes-specific program is also available.

Better Choices Better Health is being studied by researchers from the University of Hawai'i. Preliminary outcome data show that, after six months, participants had a decreased number of visits to physician offices and emergency rooms; were exercising more and had greater strength; and reported fewer symptoms, such as pain, fatigue, and shortness of breath.

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. Moreover, it has been scientifically tested and has been shown to improve health and reduce care costs among regular participants. These classes are currently offered in the County of Kaua'i and in Maui County, and in churches, senior centers, and neighborhood centers.

Preliminary studies by the Univer-

sity of Hawai'i indicate that, by the conclusion of the Enhance Fitness program, participants report fewer falls; an increased number of days of physical activity per week; improvement in measures of physical function; and high levels of satisfaction with the program.

Funding for these programs has expired, and the Omnibus Aging Bills include an appropriation of \$485,000 for the Healthy Aging Partnership Program.



Section 3 Alzheimer's Disease & Related Dementias

lzheimer's disease and related dementias (ADRD) have become a major cause of death in the older population. These 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 designed to greatly improve the way individuals with ADRD and their families will live in and be served by their communities. It includes five recommendations, or 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 local healthcare professionals and the public informed about 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 the state, 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 & 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 dementia screening, and will have access to referral resources.

Happy Birthday, Mom!

By Felicia Marquez-Wong

My mom turns 95 tomorrow. Changes happen as expected in life, yet the dementia diagnosis sits in our space like an elephant in the room. There is no denying it and everyone has an opinion about it. Some moments are heart-wrenching and heartwarming at the same time.

Knowing how dementia makes you forget how to smile, it became my daily goal to smile and laugh with her. Happy Birthday, Nanay!



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

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

Goal 4: Enhance Public Awareness & 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 will be 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 international plans. The fear and stigma associated with dementia are compounded by a lack of knowledge and public education about the disease, its stages, treatments, how to support caregivers, and where to get services. Consequently, ADRD 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 currently 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 ADRD 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 for achieving each goal, key milestones, and the timelines for achieving them.³ **Senate Bill 2085** (Part V) and **House Bill 1878** (Part V) propose an appropriation for the Alzheimer's Disease and Related Dementia Services Coordinator Position.

References

¹Executive 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.

²Ibid.

³Ibid.

Section 4 Family Caregiving Issues

Introduction

aregiving is a challenging issue for families of frail or disabled persons and for society. According to an AARP report based on a 2013 survey, on any given day in Hawai'i, there are 154,000 family caregivers for persons age 18 and over who provide 162 million hours of unpaid care annually. This unpaid care would have had a yearly cost of \$2 billion if provided by paid caregivers and healthcare personnel. Without the efforts of family caregivers, it is inconceivable that providing care would be affordable to the State or to the families themselves. For example, the average annual cost in Hawai'i in 2015 for homemaker services was \$54,912; for a licensed health aide, \$56,016; and for adult day healthcare, \$17,225 (Genworth.com). Thus, unpaid family caregivers play a critical—and often unappreciated—role in the care of the most vulnerable members of our population.

These caregivers face many obstacles. One is the fact that there are fewer family members available to provide care than in previous years. Families themselves are smaller, and many of Hawai'i's children leave home for school or jobs on the mainland and do not return. Thus, caregiving responsibilities fall on a smaller number of persons. This, combined with the fact that over half of all family caregivers are employed full-time, creates serious demands on caregiver time and energy. Additionally, most caregivers are middle-aged women, many of who also have children at home, and thus additional responsibilities. These realities, plus

Godsend for a Granddaughter

About four years ago, Lydia Alfonsi moved from Upcountry Maui to Kihei to care for her grandmother, Margaret Higgins, who has worsening dementia and persistent health concerns from a stroke that occurred in December 2012. After contacting the Maui County Office on Aging (MCOA), it was apparent that home-delivered meals and in-home respite care would be most beneficial to both Margaret and Lydia. Since receiving services from MCOA, Lydia states, "The home-delivered meals have been a godsend and wonderful...it has been most helpful and allows me to spend more time caring for my grandma." In addition to the home-delivered meals, Lydia also says that the in-home respite care has been a great relief from the stress of caregiving. Lydia states, "The respite care has been helpful in giving me time for myself to regroup and take charge again." Since they have been receiving services from MCOA, Lydia has had more energy to join in activities that she and her grandma are both interested, which includes Picnic for Poki at the Historic Kaahumanu Church in Wailuku where they both especially enjoy listening



Lydia Alfonsi and Margaret Higgins

to traditional Hawaiian music. While Lydia and Margaret are very grateful of the services they receive, Lydia is especially concerned about other Kupuna that may not have the support that is needed to prevent placement in an institution. Lydia is most hopeful that more funds will be allocated for Kupuna Care services in the future, as she believes that she would not be able to provide the same level of care to her grandmother without the services that she receives from MCOA.

difficulties in obtaining professional assistance when needed, are significant sources of caregiver stress.

Caregiving issues thus include:

- Coping with the stresses and time demands of caregiving;
- Learning the skills needed to perform critical medical and nursing tasks at home;
- Risks to family finances, health, and well-being when trying to balance job demands and the care of loved ones;
- Finding appropriate professional resources to assist in caretaking when needed; and
- Paying for expensive in-home and/or institutional care.

This section of the report will focus on two aspects of caregiving:

- Helping caregivers obtain needed training and skills to assist their loved ones after discharge from a hospital; and
- **2.** Providing financial support for employed caregivers who must take time off from their jobs to care for a family member at home.

Others sections will focus on the types of services needed by caregivers and the broader issue of paying for long-term care.

Caregiver Recognition, Support & Training

Hawai'i's population is aging rapidly, and many older people have chronic health conditions that require a hospital stay. Following discharge, most care of such patients is provided by family members. Traditionally, family caregiv-

Passionate About Caregiving

By Monica Morakis, Community Living Program Coach, Maui County Office on Aging

Manny Jr. has been taking care of his dad for many years and still remains passionate and eager to learn new things to help his dad and other caregivers.

There was something different about his dad in 2013 when Manny Jr. noticed a decline in memory. Since then, Manny Sr. has been diagnosed with Alzheimer's disease and has lost his ability to communicate with words. However, Manny Jr. is able to ask his dad the right questions and watch his facial expressions to figure out what is needed. He takes care of his dad 24/7, as Manny Sr. is also struggling with kidney failure in addition to the dementia.

In late 2014 and early 2015, Manny Sr. was hospitalized several times for urinary difficulties affecting his kidney function. Manny Jr. wanted to help him avoid dialysis, so he learned about the benefits of a renal diet. The diet, which includes watching what he gives his dad to eat and keeping him well-hydrated, has been highly effective. Manny Sr.'s kidney function went from 19 percent to a current function of 27 percent.

Manny Jr. is also passionate about helping others find services, especially the Community Living Program (CLP). Since January 2015, the family has been working with the CLP coach to create a spending plan for their dad's care. Through CLP, which is administered by the Maui County Office on Aging (MCOA) and Executive Office on Aging (EOA), Manny Jr. can be paid for part of his



Manny Jr. and his dad

hours of care for his dad and receive limited financial assistance for medication co-pays. Manny Jr. advocates for his dad on frequent doctor visits, supports other caregivers with his knowledge of services, and takes classes for caregivers whenever he can on Moloka'i.

Manny Jr. acknowledges that he gets frustrated sometimes when facing the daily challenges (e.g., inventive ways to get his dad to take all of his medicine), but he is driven to learn and care for Manny Sr. in the best way possible. He remembers how his dad took care of him as a young child when he was in pain and confused about his diabetes condition at the young age of 3. Manny Sr. would stay home from work and lovingly take care of his son, which is something Manny Jr. will never forget.

Manny Jr. likes it when his dad smiles, especially when watching old movies with Frank Sinatra songs. He loves it when he can make his dad laugh by singing songs they remember from the past "real loud."

ers have assisted with bathing, dressing, eating, household tasks, and other activities of daily living. However, it is now common for caregivers to perform complex medical and nursing tasks that formerly were provided in hospitals and long-term care facilities. At the 2014 legislative session, a bill was introduced to recognize the role of caregivers and provide the training necessary to assist loved ones following hospital discharge. This bill did not pass. Instead, the Legislature passed a Resolution to

create a Working Group to study the issues raised by the 2014 legislation, and to report back to the Legislature on its findings. The Working Group agreed on the number of questions, but did not support legislation requiring hospitals to provide the training described above.

Nonetheless, bills supporting this concept, commonly referred to as the CARE Act, were introduced at the 2015 legislative session. These bills contain three basic elements:

- If requested by a patient, the name of a family caregiver is recorded when a family member is admitted to a hospital;
- **2.** The caregiver is notified when the person is to be discharged to another facility or back home; and
- **3.** The hospital must provide an explanation and a demonstration of the medical and nursing tasks that the family will need to perform at home for the discharged family member.

These bills did not pass during the session. However, it should be noted that 18 other states have passed essentially similar legislation since 2014, and 20 other states were considering such legislation.

Between the 2015 and 2016 legislative sessions, a CARE Act Coalition was organized under the leadership of AARP Hawai'i. The Coalition included advocacy groups, labor unions, aging service providers, and others. It developed a revised version of the 2015 Act, which became a part of the Kupuna Caucus legislative package. The 2016 version had stronger language protecting hospitals from liability for caregiver errors after discharge, and gave hospitals greater flexibility in creating their own policies for engaging caregivers in the discharge process.

At the time of writing, two bills on discharge planning (**House Bill 2252** and **Senate Bill 2397**) are alive, and appear to have strong community and legislative support.

Paid Family Leave for Working Caregivers

At some time, nearly every worker needs time away from the job to recover from a serious illness or care for a new child or sick family member. Yet, the majority of American workers cannot take the time they need without risking their jobs or financial security. Only 12% of private-sector workers in the United States have access to paid family leave (PFL) through their employers, and only 40% can take personal medical leave through a temporary disability program. Low-wage and minority workers are even less likely to have access to paid leave. Just 5% have paid family leave, and 16% can access



temporary disability insurance through their employers.

The federal Family Medical Leave Act (FMLA) allows up to 12 weeks of unpaid leave with job protection for employees of companies with 50 or more employees. However, FMLA covers only 60% of the national workforce. Hawai'i has its own Hawai'i Family Leave Act, which only applies to companies with 100 or more employees and allows for job protection of up to four weeks per year. However, only 16% of Hawai'i's workforce is protected by our HFLA law.

The only partially paid leave program available in Hawai'i is Temporary Disability Insurance, or TDI. All employers are required to provide TDI for their employees. Employers may ask their workers to contribute up to half the premium cost, so long as that amount does not exceed a half of one percent of the employees' wages. Also, under Hawai'i family leave law, public and private sector workers who earn sick leave are en-

titled to use up to 10 days for the care of a newborn or to assist an ill or disabled family member.

Clearly, Hawai'i lacks a comprehensive policy of partial wage replacement to allow any worker to take substantial amounts of time off to care for a family member without fear of losing his or her job.

Paid leave is not a new issue in Hawai'i, where studies were conducted and bills were introduced since 2008. At the 2015 legislative session, four bills were introduced to provide 12 weeks of paid family leave, and two additional bills were offered with provisions for shorter leave periods. The four bills offered a comprehensive leave package. They created a family leave insurance program that requires employees-not employers—to contribute to a trust fund to be used for family leave benefits in order to care for designated persons. Partial wage replacement for up to 12 weeks of leave would be available to all employed persons in the State. Employee contributions would be in accordance with contribution rates to the TDI fund in most of the above bills.

A number of paid family leave bills (either carried over from 2015 or newly introduced) were available for legislative review at the beginning of the 2016 session. However, at the time of this writing, only SB 2961 had survived initial screening by Senate committees. Its provisions are essentially similar to those of the 2015 legislation. As in past years, this legislative effort is supported by a coalition of women's groups, mother/child organizations, community non-profits, senior advocates, and others. PFL legislation is also a priority issue for two legislative groups, the Keiki Caucus and the Kupuna Caucus. Objections to the bill have been raised by both the State Department of Budget and Finance and the State Department of Labor and Industrial Relations, as well as several business organizations. The fate of this bill remains to be seen.

Section 5 Long-Term Care Services, Support & Related Legislative Proposals

Proposed Limited Public Insurance for Long-Term Care Services & Support

ur families and our communities are facing seemingly challenges insurmountable in finding the resources to address the growing care needs of our aging population. In Hawai'i, those over 65 are projected to increase to more than 1 in 5 (22%) by the year 2030. Among persons reaching age 65, about 70% are expected to require some form of long-term care in the future.¹ The increasing longevity of our population into older age groups will result in the need for care that exceeds existing resources. The most rapid expansion will be among those 85 and over, which is projected to grow by 65% over the next 20 years.² More than half of those 85 and older suffer disabling chronic conditions that require assistance with at least some activities.

Traditionally, family members have provided care for their own members, and indeed, they continue to provide about 80% of all care for our frail elder and disabled population. Nevertheless, the capacity of families to provide care is facing limits. An increasing number of frail persons lack family members available to care, and many families are able to offer care only if long-term support and services are provided to supplement their informal care.¹

However, these home and communi-

ty-based services are beyond the financial means of most families to pay out-ofpocket. For example, the average annual cost in Hawai'i in 2012 for homemaker service was \$53,768, a licensed health aid was \$57,200, and an assisted living facility was \$50,400, whereas nursing homes exceeded \$120,000 per year.3 State revenues and Title III funds from the Federal Administration on Aging provide significant help to a limited number of persons through the state-funded Kupuna Care program and similar programs. However, the general revenue of the State falls far short of being able to meet all the needs of our vulnerable population and will become even more inadequate as that population grows.



Persons who are genuinely impoverished can qualify for Medicaid-financed services. However, this is a welfare program, with 50% of the cost borne by the State and the remainder by the Federal government. The financial burden on State revenue is already highly problematic and any increased reliance on Medicaid is not viable. Both Federal and State policies are emphasizing the importance of aging in place, assisting families with home and community-based services, and reducing the use of more expensive institutional/residential care settings.

The unsustainability of our current modes of financing long-term services and support has become more obvious as the frail population and care needs increase. In 2008, the Hawai'i State Legislature appointed a Long-Term Care Commission to take a long-term and comprehensive approach to addressing this growing challenge (Act 224). In a statewide survey, the Commission found that the majority of adults had engaged in little planning, had no idea about their future risk for needing services, and had inaccurate knowledge. For example, they believed their health insurance or Medicare would pay for long-term care services. Furthermore, they did not believe they could afford to purchase private long-term care insurance or pay out-of-pocket for even a few months of care. While they resisted the idea that a tax should be levied for longterm care, a large majority believed that the government should pay for their care. These results confirmed the findings of research sponsored by AARP.4

In January 2012, the Commission reported its recommendations to the State Legislature.⁵ First, they recommended that a broad-based public awareness campaign should be mounted to:

- **1.** Increase attention to long-term care planning by adult residents;
- **2.** Communicate the high risk of needing long-term care by older adults;
- **3.** Correct the many misconceptions they had about who paid and did not pay for services; and
- **4.** Increase awareness of the options that might be available for providing and financing their care.

Second, after careful examination of various options, the Commission concluded that the only feasible approach to making long-term services and support accessible and affordable was to adopt a social insurance approach. As with Social Security and Medicare, individuals would be required to make modest payments throughout their adult lives so that an insurance fund could finance their care at the time they required it. Because everyone is required to participate and pay into the fund over many years, the payments would be affordable to everyone. The proposed program would increase the General Excise Tax by a ½ percent.

The Legislature appropriated funds

Daughter's Full-Time Caregiving Challenges

Prior to a stroke in 2014, Diane Henke was living independently and enjoying her retirement at her condominium in Kihei. Due to dementia and neurological damage from the stroke, Diane was placed in Hale Makua for rehabilitation. Her daughter, Kristen Silva, did not want to see her mother living in an institution full-time, so she made arrangements for her and her son to move in with Diane so she could become her full-time caregiver. Kristen must now juggle full-time caregiving for her mom, raise her son, and continue to work full-time. At the age of 42, Kristen is concerned that a majority of her adult life will be spent caring for her mother.

Suffering from caregiver burnout, Kristen was in desperate need of assistance. From the advice of a friend, she was directed to the Maui County Office on Aging (MCOA). Before contacting MCOA, Kristen was paying privately for respite care so she could continue to work, but the cost became a financial burden for her and her mom. Due to their situation, Diane and Kristen have been able to receive a caregiver respite scholarship from MCOA for Maui Adult



Day Care Center. Kristen states, "Maui Adult Day Care Center has been a lifesaver and the only relief that enables me any time to myself." In addition to the caregiver respite, Diane greatly enjoys interacting with others, seeing new faces, and participating in fun activities like bingo at the Maui Adult Day Care Center. While the scholarship to the Maui Adult Day Care Center has been very helpful, budget cuts and an increase in

demand for services have required MCOA to limit attendance at daycare to two times per month; Kristen and her sister must pay out-of-pocket for the remainder so Kristen can continue to work. She says, "We are very thankful for the assistance that we are receiving from MCOA, but I hope that the Legislature will increase the budget in the future to assist kupuna and caregivers in similar situations even further."

to the Hawai'i Executive Office on Aging to undertake an actuarial analysis and feasibility study. Dr. Lawrence Nitz subcontracted the actuarial study to a highly respected Washington, DC agency, with the task of assessing the viability of the specific program parameters using conservative estimates, such that the program would remain solvent for 75 years into the future. Dr. Nitz submitted the feasibility report based on the actuarial study in December 2014.

The proposed insurance program would provide a basic level of benefits to most of the population, *i.e.*, those above the Medicaid poverty criterion. Benefits would be paid to persons who qualified by being vested through having filed Hawai'i tax returns for 10 years and who needed assistance with at least two activities of daily living or who had significant dementia. The program is envisioned as a public-private

partnership, where individuals would receive a modest benefit (\$70 per day) for 365 days. Individuals could purchase private long-term care insurance as a supplement to cover additional costs. The state would continue to operate the Kupuna Care program and other public services, which individuals might qualify for once their insurance benefit was exhausted. However, even a modest public insurance would have a major impact in financing care by paying for such services as in-home personal care, homemaker services, and adult day care, preserving family savings, and reducing or postponing enrollment in Medicaid.

Senate Bill 2478 SD 1 and **House Bill 1885** request the creation of the limited public insurance program for long-term services and support. **SB 2478** passed the Senate Consumer Protection and Health Committee and is currently before the Senate Ways and Means Com-

mittee. **HB 1885** was referred directly to the House Finance Committee, but has so far not received a hearing.

Although passage of a major program involving a tax increase is unlikely in an election year, many legislators understand the merits of this proposal and the urgency of addressing the financing of services. At a minimum, the hearings in the current session provide an opportunity for considered discussion of the proposal, and if need be, it will be reintroduced next year.

The Community Awareness of Long-Term Services and Support Campaign will continue over the coming year to increase attention to the need for planning by families and for considering the options for financing care. The case will also be made to consider the limited public insurance program for long-term care as an option that will create an insurance fund to pay for services for the broad population be-

yond continued reliance on Medicaid and the general revenues of the State. Hawai'i could prove to be a national leader by realistically and creatively addressing the long-term care challenges that our aging population will pose in the future.

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Ensuring Safety and Quality within Long-Term Care

The 2016 legislative session contains four bills that focus on ensuring safety and quality within long-term care (SB 2384, HB 2005 HD 2, HB 1884 HD 1, HB 859 HD SD 1.)

Adult residential care homes and community care foster family homes are a critical part of the long-term care continuum in Hawai'i. There are approximately 1,130 community foster family care homes (2,824 beds) and 500 adult residential care homes (2,729 beds), which account for 46% of Hawai'i's 12,000 long-term care beds. The rest of the long-term care beds are from 49 nursing facilities (4,304 beds or 36%) and 13 assisted living facilities (2,249 beds or 18%). Community residential care homes are more affordableabout a third to a half of the cost of staying in a nursing home. However, the safety and care quality of these care homes and foster homes must be improved to protect vulnerable seniors under their care. The bills addressing safety and quality focus on four main areas:

- 1. Mandating unannounced inspections;
- **2.** Increasing staffing to ensure the timely posting of inspection reports on the Department of Health website;
- Providing additional staffing for the Long-Term Care Ombudsman Program; and
- **4.** Requiring licensing fees to be paid by facilities to cover inspection costs.

SB 2384 requires the Department of Health to conduct unannounced visits and re-licensing inspections for statelicensed care facilities (and medical marijuana dispensaries). The need for unannounced visits and re-licensing inspections is paramount in order to maximize the effectiveness of the inspections for care homes. The unannounced visits would be consistent with other re-licensing inspections of healthcare facilities under the regulatory responsibility of the Office of Health Care Assurance. They are an important safeguard for the public and ensures that facilities are providing a high standard of quality on a day-to-day basis.

HB 2005 HD 2 initially set out to strike a compromise between the

interests of the industry that provides long-term care for the elderly in community-based settings and the consumer advocate looking out for thousands of Hawai'i residents who live in these community-based settings. This bill would have required the Department of Health to conduct

unannounced visits of the various types of community-based healthcare settings it oversees instead of giving the operators a heads up that they are coming. It would also require care home operators to pay (for the first time) licensing and certification fees, which could have created a new revenue stream to enhance the department's oversight and make inspection reports accessible to the public online in a timely manner. The intent of this bill was to help Hawaiʻi caregivers financially while boosting consumer protection and potentially opening up more space in family-like settings for elderly people who require nursing home-level care.

HB 1884 HD 1 appropriates funds to establish three neighbor island positions

for the Long Term Care Ombudsman program. According to the Older American Act, the LTC Ombudsman Office's responsibility is to advocate for residents in long-term care facilities, as well as in community-based care homes, assisted living facilities, and community care foster family homes. The Ombudsman Office should ensure that residents have regular and timely access to its services, and that any complaints will be responded to in a timely manner. The Older Americans Act also requires the Ombudsman Office to provide technical support for resident and family councils in long-term care settings.

Currently, about 12,340 residents live in these settings, with 25% on Kaua'i, Maui, and Hawai'i Islands combined. With the recent reorganization of the Executive Office on Aging, the LTC Ombudsman Office is down to only one staff member. The Office used to have a volunteer coordinator and over 180 volunteers who were trained and certified over the past 15 years; however, the availability of volunteers fluctuated and the turnover rate was high. As of now, the total number of active volunteers is eight and there is no ombudsman volunteer on Kaua'i.

The minimum staffing ratio as recommended by the Institute for Medicine in its 1995 report was one full-time ombudsman staff member to 2,000 long-term care residents. Although the number of residents on each of the neighbor island counties is less

than 2,000, having one ombudsman staff member in each county would be necessary to ensure timely and accessible services. Hawai'i expects the number of long-term care residents to continue to grow rapidly in the next 20 years.

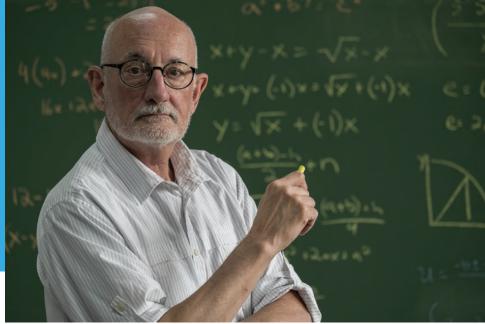
HB 859 HD SD 1 proposes inspection reports from state-licensed care facilities be posted on the Department of Health's website reporting violations committed by each facility. The bill further proposes that the Department of Health 1) maintain a forum on its website where all state-licensed care facilities may post vacancy information to facilitate placement of individuals; and 2) convene a working group to discuss and give feedback on the implementation and maintenance of the forum.

Section 6 The University of Hawai'i Center on Aging

ver the past 30 years, the University of Hawai'i Center on Aging (COA) has provided education, research, and community services to benefit older persons living in Hawai'i. However, due to retrenchment at UH, its capacity has been limited for a number of years. Currently, it has a part-time administrator and a half-time acting director. The certificate programs in Gerontology have been on hold for several years due to lack of staff. COA continues to have an active research program, using temporary positions on contract and

grants to perform important evaluation research for a number of Executive Office on Aging programs and for other aging-related agencies and programs.

Several bills have THE FA O KA 'AINA been introduced to the 2016 legislative session requesting funding for two positions at the Center on Aging. One position is for an associate professor who would be responsible for teaching gerontology courses and reestablishing the certificate programs at UH-Mānoa. The second position is for an assistant specialist position who would be responsible for developing continuing education courses to update and upgrade the skills of the current paraprofessional and professional eldercare workforce. The assistant specialist would also work with other university campuses throughout the State to offer courses for family caregivers, as well as create courses that promote active aging among older persons in the State.



The Policy Advisory Board for Elder Affairs and the Hawai'i Family Caregiver Coalition have always supported COA as essential to home- and community-based services. COA is in the process of rebuilding, and these two requested positions would significantly impact its capacity. The new positions would especially be used to address COA's educational mission. The State

faces a shortage of eldercare workers, and many persons entering these jobs

have no formal training in gerontology.
The demise of the Kupuna Education Center at Kapi'olani Community College this past year has negatively impacted the situation further.
UH is key to addressing the shortage and in assur-

ing adequate training to deliver quality care.

The Center on Aging is approaching the Legislature in a stronger position this year. The university has authorized a search currently in progress for a permanent director and will finance the position from the UH-Mānoa general budget. This summer, the UH-Mānoa chancellor formally appointed Noreen Mokuau, Dean of the School of Social Work, and Kathryn Braun, Director of the Public Health Program, as co-chairs to oversee COA's \$2 million endowment at the UH Foundation. The income from

the endowment will be used to fund new COA initiatives. COA also was awarded a three-year Federal grant to undertake a new program to serve persons with Alzheimer's disease and related dementias, including training programs for staff and family caregivers.

Current Status

House Bill 493 is the quickest route to approval. **HB 493** was introduced in the 2015 legislative session and was passed by the House Higher Education Committee, and passed the House Finance Committee as HB 493 HD 1. The bill was carried over to the 2016 session and referred to the Senate. The wording was updated to be consistent with the current request for two permanent positions, one an associate professor and the other an assistant specialist. HB 493 HD 1 SD 1 passed the Senate Committee on Higher Education and the Arts and the Senate Committee on Human Services on February 16. The bill is awaiting consideration by the Senate Ways and Means Committee, and if passed, will be sent to the Governor for his approval.

HB 1883 is a new bill introduced in the 2016 session. The bill contains the same request for an appropriation for two positions at COA and is identical to **HB 493 HD 1 SD1**. The bill passed the House Higher Education Committee as **HB 1883 HD 1** on February 2 and has been referred to the House Finance Committee.

Section 7 Conclusion

ections 2 through 6 of this publication illustrate the kinds of issues that legislators face each 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 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 op-

position to legislation deemed harmful to the kupuna or persons with disabilities. Successful advocacy involves three key elements:

- **1.** Personal contact with key legislators and legislative staff to educate them about important issues;
- **2.** A substantial number of convincing written testimonies and personal appearances at committee hearings to show wide support for bills being heard; and
- Increasingly, solid scientific evidence and reliable data clearly demonstrating the need for services and program effectiveness.

Hawai'i now is in the midst of the baby boom "Silver Tsunami," with its many thousands of additional elders and unprecedented numbers of the very old. 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 progressively think 5 to 10 years ahead, as well as 10 to 20 or more years ahead. Three challenges that must be considered and addressed are:

- 1. How do we create efficient service networks that will meet the needs of all our island populations, especially in rural areas that are often 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 massive future needs?

How well Hawai'i will be able to meet these challenges remains to be seen.



Section 8 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@hawaiiantel.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 Hawaiʻi

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 Address: Hawai'i Family Caregiver Coalition; 2630 O'ahu Avenue, Honolulu, HI 96822

Email: garysimon@hawaii.rr.com

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 HAWAI'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. Christy Nishita, Interim 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 Kupuna: 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

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Website: http://www.publicpolicycenter.

hawaii.edu/

